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**PALLIATIVE CARE NEEDS OF PATIENTS WITH  
ADVANCED CANCER AND THEIR INFORMAL  
CAREGIVERS IN CHINA**

**WANG TAO**

**PhD**

**THE HONG KONG POLYTECHNIC UNIVERSITY**

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**School of Nursing**

**Palliative Care Needs of Patients with Advanced Cancer  
and Their Informal Caregivers in China**

**WANG TAO**

**A thesis submitted in partial fulfilment of the requirements  
for  
the degree of Doctor of Philosophy**

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WANG TAO

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## **Abstract**

### **Background**

Cancer is one of the leading causes of death in China, and a majority of the patients are already at an advanced stage at the time of diagnosis. Despite the advances of cancer treatment, cancer patients, particularly those at an advanced stage, and their informal caregivers still suffer from a wide range of undesirable distress. There has been a significant demand for palliative care to relieve cancer patients' distress and improve their quality of life. However, the development of palliative care in China is still at an initial stage. There is much room for improvement; hence, more rigorous studies are needed to provide more high-quality evidence and to persuade policymakers of the benefits of palliative care. Palliative care needs assessment is the first step that should be addressed given that appropriate and ongoing needs assessment within this context could support the development of evidence-based and tailored intervention protocols and the establishment of culturally tailored palliative care services.

### **Aim and objectives**

The overall intention of this project was to provide preliminary evidence to researchers and policymakers in relation to developing tailored palliative care interventions and services to better meet the palliative care needs of Chinese patients with advanced cancer and the needs of their informal caregivers. This doctoral research project proceeded in two phases. Phase One aimed to quantify the palliative care needs of Chinese patients with advanced cancer and the needs of their informal caregivers, with the following objectives: (1) to identify the prevalence of unmet palliative care needs of advanced cancer patients; (2) to determine the unique contribution of each hypothesized predictor to the palliative care needs of patients; (3) to identify the prevalence of unmet needs of informal caregivers of patients; (4) to determine the unique contribution of each hypothesized predictor to the needs of informal caregivers; (5) to determine the relationship between the palliative care needs of patients and the needs of their informal caregivers; and (6) to identify the common and prominent unmet needs of both the patients and their informal caregivers. Phase Two aimed to explore more details of the

common and prominent unmet needs that were identified in the survey in Phase One, with two additional objectives: (7) to further clarify and elaborate the identified unmet needs of both patients and their informal caregivers; and (8) to further explore the perceptions and experiences of patients and their informal caregivers in relation to the identified unmet needs.

## **Methods**

This doctoral research project employed a multimethod research design, namely, a quantitatively driven study followed by a qualitative descriptive study. A cross-sectional study was conducted first as the driven method to quantify the palliative care needs of patients and the needs of their informal caregivers, the predictors of their needs, and the relationship between the needs of patients and the needs of their informal caregivers. The selection of the design and outcome variables of the cross-sectional study was performed based on a conceptual framework of palliative care needs. A total of 419 patients and 419 caregivers (in dyads) from two hospitals in Sichuan completed the questionnaires. For the patients, the dependent variable was palliative care needs, which was measured by the Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv), and the independent variables were demographic and clinical characteristics, anxiety, depression, physical distress, social support, coping strategies, and quality of life, which were measured by the Baseline Data Assessment Form, the Hospital Anxiety and Depression Scale (HADS), the Edmonton Symptom Assessment Scale (ESAS), the Medical Outcomes Study-Social Support Survey (MOS-SSS), the Brief Coping Orientation to Problems Experienced (Brief-COPE) inventory, and the European Organisation for Research and Treatment of Cancer (EORTC) Quality-of-Life Questionnaire Core 15-Palliative Care (QLQ-C15-PAL) scale, respectively. For the informal caregivers, the dependent variable (needs of informal caregivers) was measured by the Comprehensive Needs Assessment Tool for Cancer Caregivers (CNAT-C), and the relevant independent variables, including demographic and clinical characteristics, anxiety, depression, social support, coping strategies, and quality of life, were assessed by the Baseline Data Assessment Form, the HADS, the MOS-SSS, the Brief-COPE, and the Caregiver Quality of

Life Index-Cancer (CQOLC), respectively. Semi-structured interviews were subsequently conducted after the completion of the cross-sectional study to further elaborate and explore the perceptions and experiences of the patients and their informal caregivers in relation to their identified unmet needs, which involved 17 patients and 15 informal caregivers. Descriptive analysis was used to describe the characteristics of the needs of patients and their caregivers. Stepwise regression analysis was adopted to identify the influencing factors of the needs of patients and caregivers. Pearson's correlation coefficient was employed to explore the general linear relationships between the needs of patients and caregivers. Content analysis was used to analyse the qualitative data.

## **Results**

The cross-sectional study recruited 428 patient-informal caregiver dyads and 419 dyads (419 patients and 419 caregivers) completed the questionnaires. The top five palliative care needs of the patients were related to financial ('extra expenditures because of the disease', 88.3%; 'loss of income because of the disease', 85.2%), information ('insufficient information', 82.3%), physical ('pain', 69.7%), and psychological ('fear of physical suffering', 64.9%) domains. Regarding the informal caregivers, the commonly reported needs were related to the domains of healthcare staff ('nurses to promptly attend to patient discomfort and pain', 95.0%), information ('information about tests and treatment', 92.1%), and hospital facilities and services ('a designated hospital staff member who would be able to provide counselling for any concerns, and guidance with the course of the treatment, from the point of diagnosis to the period after discharge', 90.5%). Information needs was a common and prominent unmet need of both the patients and their informal caregivers. Significant positive correlations between the palliative care needs of patients and the needs of informal caregivers were identified across a majority of the needs domains.

The results of the multiple stepwise regression analysis indicated that the patients' and informal caregivers' care needs were influenced by not only the factors related to themselves but also the factors related to their partners. The physical (symptom distress) and psychological



factors (anxiety and depression, coping, and quality of life) were found to be more significant than the demographic and clinical factors in predicting the care needs of patients and informal caregivers. The presence of anxiety and depression, the use of coping strategies (particularly, less use of problem-focused coping), and caregivers' poorer quality of life (QoL) were three common and significant predictors of higher levels of need for both patients and informal caregivers. The patients' symptom distress was identified as another negative factor of their palliative care needs.

Seventeen patients and 15 informal caregivers with unmet information needs participated in the follow-up qualitative interviews. Four categories were extracted from the interview data of both the patients and the informal caregivers, which were types of unmet information needs, reasons for information needs being unmet, preferences for the provision of information, and the meaning and role of information. Each category had two to four sub-categories. The sub-categories for the patients and informal caregivers were similar but not totally the same.

## **Conclusion**

The findings from the cross-sectional study and the semi-structured interviews contributed to a comprehensive and in-depth understanding of the palliative care needs of patients with advanced cancer and the needs of their informal caregivers within the Chinese context, which will provide evidence to researchers and policymakers in terms of developing tailored palliative care interventions and services. Patients' and informal caregivers' needs cannot be addressed optimally only by increasing the amount of external help and resources; there is also a need for healthcare professionals to incorporate regular and dynamic assessment of the presence and intensity of physical and psychological distress, as well as the use of certain coping strategies, into conventional clinical practice to determine the target group for more specific interventions to address their needs and concerns. Some specific components can be included in intervention programmes to relieve patients' physical and psychological distress and to improve their coping and problem-solving skills. Informal caregivers' well-being should be regarded as important as that of patients. The care needs of patients and informal

caregivers can be better fulfilled via family-based healthcare services and interventions. More emphasis should be placed on unmet information needs, and how to develop and provide tailored and appropriate information provision regarding the type and amount of information to patients and their informal caregivers should be considered in clinical practice.

## Publications Arising from PhD Training

1. Wang, T., Molassiotis, A., Chung, B. P. M., & Tan, J. Y. (2018). Current research status of palliative care in Mainland China. *Journal of Palliative Care*, 33(4), 215-241. [Chapter 3 of this thesis.]
2. Wang, T., Molassiotis, A., Chung, B. P. M., & Tan, J. Y. (2018). Unmet care needs of advanced cancer patients and their informal caregivers: A systematic review. *BMC Palliative Care*, 17(1), 96. [Chapter 4 of this thesis.]
3. Wang, T., Molassiotis, A., Chung, B. P. M., & Tan, J. Y. (2019). Psychometric assessment of the Chinese version of the Problems and Needs in Palliative Care questionnaire-short version in advanced cancer patients. *BMC Palliative Care*, 18(1), 68. [Chapter 6 of this thesis.]
4. Wang, T., Molassiotis, A., Tan, J. Y., Chung, B. P. M., & Huang, H. Q. (2020). Prevalence and correlates of unmet palliative care needs in dyads of Chinese patients with advanced cancer and their informal caregivers: a cross-sectional survey. *Supportive Care in Cancer*, 1-16. [Chapter 7 of this thesis]
5. Molassiotis, A., Wang, T., Hoang, H. T. X., Tan, J. Y., Yamamoto-Mitani, N., Cheng, K. F., ... & Suen, L. K. (2020). Doctoral nursing education in east and Southeast Asia: characteristics of the programs and students' experiences of and satisfaction with their studies. *BMC Medical Education*, 20, 1-12.

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## **List of Abbreviations**

<b>3LNQ</b>	3-Levels-of-Needs Questionnaire
<b>ADL</b>	Activities of daily living
<b>ASCO</b>	American Society of Clinical Oncology
<b>Brief-COPE</b>	Brief Coping Orientation to Problems Experienced scale
<b>CAHPC</b>	China International Exchange and Promotive Association for Medical and Health Care and Chinese Association for Humanistic and Palliative Care
<b>CBM</b>	Chinese Biomedical Literature Database
<b>CENTRAL</b>	Cochrane Central Register of Controlled Trials
<b>CFI</b>	Comparative Fit Index
<b>COPD</b>	Chronic Obstructive Pulmonary Disease
<b>CINAHL</b>	Cumulative Index to Nursing and Allied Health Literature
<b>CNAT-C</b>	Comprehensive Needs Assessment Tool for Cancer Caregivers
<b>CNKI</b>	China National Knowledge Infrastructure
<b>CNQ</b>	Cancer Needs Questionnaire
<b>CQOLC</b>	Caregiver Quality of Life Index-Cancer
<b>CVI</b>	Content validity index
<b>EORTC QLQ-C30</b>	EORTC Quality-of-Life Questionnaire-Core 30
<b>EORTC QLQ-C15-PAL</b>	EORTC Quality-of-Life Questionnaire Core 15-Palliative Care
<b>ESAS</b>	Edmonton Symptom Assessment Scale
<b>FACT-G</b>	Functional Assessment of Cancer Therapy-General
<b>HADS</b>	Hospital Anxiety and Depression Scale
<b>KPS</b>	Karnofsky performance status
<b>MDASI-C</b>	MD Anderson Symptom Inventory-Chinese version
<b>MMAT</b>	Mixed Methods Appraisal Tool

<b>MOS-SSS</b>	Medical Outcomes Study-Social Support Survey
<b>MQOL</b>	McGill Quality of Life questionnaire
<b>NA-ACP</b>	Needs Assessment of Advanced Cancer Patients
<b>NAT: PD-C</b>	Needs Assessment Tool: Progressive Disease-Cancer
<b>NCCN</b>	National Comprehensive Cancer Network
<b>NICE</b>	National Institute for Clinical Excellence
<b>PNAP</b>	Patient Needs Assessment in Palliative Care
<b>PNPC-sv</b>	Problems and Needs in Palliative Care-short version, PNPC-sv
<b>POS</b>	Palliative Care Outcome Scale
<b>QoL</b>	Quality-of- life
<b>RCTs</b>	Randomized controlled trials
<b>RMR</b>	Root mean square residual
<b>RMSEA</b>	Root-mean-square error of approximation
<b>SCNF</b>	Supportive Care Needs Framework for Cancer Care
<b>SCNS</b>	Supportive Care Needs Survey
<b>SCNS-P&amp;C</b>	Supportive Care Needs Survey-Partners and Caregivers
<b>SD</b>	Standard deviation
<b>SRQR</b>	Standards for Reporting Qualitative Research
<b>TCM</b>	Traditional Chinese Medicine
<b>TLI</b>	Tucker-Lewis Index
<b>TNM</b>	Tumor, Node, Metastasis classification

## **Chapter One: Introduction**

## **1.1 Introduction**

This chapter will present a general introduction of this doctoral research project, including the background and study procedures, the operational definitions of terms in this project, and the organization of the thesis.

## **1.2 Background and procedures of the study**

The worldwide ageing population and increasing incidences of chronic diseases such as cancer not only add a heavy burden to the healthcare system but also undesirable experiences for patients and their informal caregivers. China, as the most populous country in the world, faces the same healthcare-related problems. Around 4.3 million new cases of cancer were diagnosed and 2.9 million new cancer deaths occurred in China in 2018 (Bray, Ferlay, Soerjomataram, Siegel, Torre, & Jemal, 2018). Cancer has become one of the leading causes of death in China (Feng, Zong, Cao, & Xu, 2019). Long-term illness experiences and excessive treatments cause patients to suffer from a wide range of problems (Gysels, Higginson, Rajasekaran, Davies, & Harding, 2004), which usually change across the stages of illness, and patients at an advanced stage usually experience different symptoms from those at early stages (Waller et al., 2012a). Informal caregivers are closest to the patients and they are usually responsible for taking care of their loved ones (Chen, Chen, & Chu, 2015a). During the caregiving process, there is an ‘imbalance of care demands relative to caregivers’ personal time, social roles, physical and emotional states, financial resources and formal care resources’ (Given, Given, Azzouz, Kozachik, & Stommel, 2001, p. 5), which may cause many problems and increase caregivers’ needs and caregiving burden. The long-term caregiving process therefore is physically and psychologically challenging, particularly when patients are already at an advanced stage (Cui, Song, Zhou, Meng, & Zhao, 2014a). Informal caregivers are usually the ‘fellow sufferers’ of patients (Proot et al., 2004). Unsolved problems and the unmet needs of informal caregivers not only decrease their own quality of life (Hodgkinson et al., 2007; Park et al., 2010) but also create negative impacts on patients’ health outcomes (Hodgkinson et al., 2007). On this occasion, high-quality and ‘patient-and-family-centred’ care is needed to address both the

patients and their informal caregivers' various care problems and needs to improve their quality of life.

Palliative care is an approach that aims at 'improving the quality of life of patients with life-threatening illness and their families through means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual' aspects (World Health Organization, 2002). Plenty of evidence that palliative care offers benefits to patients with life-limiting diseases and their families has been identified (Luckett et al., 2014; Smith, Brick, O'Hara, & Normand, 2014), such as relieving pain (Higginson et al., 2003), improving quality of life (Peters & Sellick, 2006; Rabow et al., 2013; Temel et al., 2010; Zimmermann et al., 2014), decreasing unwanted hospital admissions (Chen et al., 2015a), prolonging median survival time (Rabow et al., 2013; Temel et al., 2010), improving family coping (HealthTeamWorks, 2011), and promoting the optimization of medical resources and decreasing burden on the healthcare system (Rabow et al., 2013).

However, palliative care is still a new specialty in Mainland China. Although hundreds of hospice units have been established, the distribution has been uneven, with a majority of these units concentrated in major cities (Li et al., 2011; The Economist Intelligence Unit, 2015). In many other regions, palliative care is either totally non-existent or still at the initial stage (Li et al., 2011). Approximately 90% of advanced cancer patients cannot benefit from palliative care due to the lack of adequate palliative care services (Li et al., 2011). According to the 2015 Quality of Death Index (The Economist Intelligence Unit, 2015), China was ranked 71st out of 80 countries. The availability, affordability, and quality of palliative care in China are still suboptimal and there is still much room for improvement.

Research can play an important role in the development of palliative care services in Mainland China, as strong research evidence is usually one of the important facilitators for policymaking and practice (Ritter, 2009). More rigorous studies within the Chinese cultural context are needed to provide more high-quality evidence to improve palliative care practices and persuade policymakers of its benefits. In order to understand the entire picture of the current



research status of palliative care in Mainland China and to identify the crucial research direction, the doctoral researcher therefore conducted a comprehensive review (Wang, Molassiotis, Chung, & Tan, 2018a). In this review, several knowledge gaps were identified. The quality and availability of palliative care in Mainland China are suboptimal, and standardized and comprehensive palliative care education and training programmes are lacking. Palliative care needs assessment is commonly ignored in practice and research, and early palliative care referral checklists and procedures and culturally tailored palliative care intervention protocols are scant. Although several potential knowledge gaps to be addressed in future research were identified, palliative care needs assessment is the first step that should be addressed because appropriate and ongoing care needs assessment can support the construction of comprehensive palliative care education and training programmes, the identification of prognostic factors for timely referral, the development of evidence-based palliative care intervention protocols, and the establishment of culturally tailored palliative care services.

Studies regarding palliative care needs assessment have been scanty in Mainland China; however, a large number of relevant studies have been performed in other countries over the past decades, particularly in developed countries. To have a better understanding of palliative care needs assessment, to identify possible limitations in current studies, and to draw implications for further research on this issue in China, the doctoral researcher therefore conducted another systematic review regarding the unmet care needs of advanced cancer patients and informal caregivers (Wang, Molassiotis, Chung, & Tan, 2018b). The findings showed that both advanced cancer patients and their informal caregivers had a wide range of context-bound unmet needs. The majority of the included studies investigated the unmet needs of either patients or caregivers using a cross-sectional study design only, and significant heterogeneity was identified across studies regarding differences in study contexts, assessment methods, instruments used for outcome assessment, needs classification, and reporting methods. Due to the context-specific feature of palliative care needs, data from other contexts cannot be directly used to develop healthcare services or interventions (Moghaddam, Coxon,

Nabarro, Hardy, & Cox, 2016). Therefore, it is necessary to assess and interpret the unmet needs of advanced cancer patients and their informal caregivers comprehensively within a given context using a multimethod research design. A qualitative study design is an appropriate approach because it can explore participants' in-depth experiences and subjective feelings that cannot be measured by quantitative methods; additionally, the scope can be much broader than of quantitative methods (Britten et al., 2002; Grypdonck, 2006). Moreover, unmet needs assessment on the basis of viewing advanced cancer patients and informal caregivers as a 'whole unit' is generally suboptimal, and more rigorous studies that comply with this concept are needed. The doctoral research project was therefore designed to address these research gaps.

The overall aim of this doctoral research project was to explore the palliative care needs of advanced cancer patients and the needs of their informal caregivers through a quantitatively driven study followed by a qualitative study by viewing advanced cancer patients and informal caregivers as a 'whole unit'. A cross-sectional study was conducted first to quantify the palliative care needs of advanced cancer patients, the needs of their informal caregivers, and the associated variables (predictors) of their needs and the relationships between the needs of patients and their informal caregivers. Following the completion of the cross-sectional survey, a descriptive qualitative study was designed and conducted to further explore information needs, which was identified as a common and prominent unmet need for both advanced cancer patients and their informal caregivers in the cross-sectional survey. The descriptive qualitative study was built on the results of the quantitative survey, which aimed to further elaborate and clarify both advanced cancer patients' and their informal caregivers' information needs and to explore their perceptions and experiences regarding information needs through semi-structured interviews. In addition, as the palliative care needs assessment instrument (Problems and Needs in Palliative Care questionnaire-short version, PNPC-sv) had not been translated for and validated among Chinese advanced cancer patients before the commencement of the doctoral research project, a preparatory study on the psychometric assessment of the PNPC-sv was also performed and included in this doctoral research project.

The findings of this research project provided implications for the development of tailored and evidence-based interventions for both advanced cancer patients and their informal caregivers, as well as the improvement of current palliative care services in Mainland China.

### **1.3 Operational definitions of terms**

To have a better understanding and interpretation of this research project, the following operational definitions were used.

#### **(1) Advanced cancer**

Advanced cancer in this project refers to patients with solid tumours who were histologically or cytologically confirmed as no longer amenable to cure and had either extensive local, regional, or distant metastasis. According to the Tumor, Node, Metastasis (TNM) classification of malignant neoplasm, patients with stage III and stage IV cancer are classified as having an advanced stage of cancer (Au et al., 2013; Cancer Council, 2016; Cancer Research UK, 2016; Lam et al., 2014)

#### **(2) Palliative care**

The definition of palliative care is a somewhat inconsistent and complex concept. In this study, we adopted the World Health Organization's (WHO) (2002) proposed definition (as stated in page 3), which emphasizes the importance of healthcare professionals being able to identify patients and families' unmet palliative care needs and developing tailored services based on their needs. In this research project, the unmet palliative care needs of both patients and families are to be assessed, and the 'families' that are mentioned in the definition refers to the people who matter to the patients and those who are taking care of the patients (informal caregivers). In order to minimize the heterogeneity of the participants, we focused on cancer patients at the advanced stage and their informal caregivers.

#### **(3) Informal caregiver**

'Caregiver is used to denote a family caregiver, rather than a professional caregiver' (Papastavrou, Charalambous, & Tsangari, 2009, p. 128). In the present study, caregivers are

non-professional and unpaid caregivers who are nominated by the patient, including a spouse, daughter/son, daughter-in-law/son-in-law, friend, or relative of the patient.

#### **(4) Care needs**

Care needs are defined as ‘the requirement of some action or resource in care that is necessary, desirable, or useful to attain optimal well-being’ (as cited in Sanson-Fisher et al., 2000, p. 227). According to Bradshaw’s (1972) taxonomy of needs, human needs is sociological context and individual’s needs should be considered from their own perspective. In this project, the needs of patients and their informal caregivers were assessed within Chinese context from their own perspectives.

#### **(5) Unmet needs assessment**

Unmet needs assessment is designed to identify how well and how much the needs of advanced cancer patients and their informal caregivers have been satisfied or not (Harrison, Young, Price, Butow, & Solomon, 2009).

### **1.4 Organization of the thesis**

This doctoral thesis presents the palliative care needs of advanced cancer patients and their informal caregivers through nine chapters. This chapter (Chapter One) presented a brief introduction of the whole doctoral research project. The second chapter consists of a narrative literature review of palliative care. Chapter Three will detail the current research status of palliative care in Mainland China and will present the identified research directions through a comprehensive literature review. In Chapter Four, the specific research gaps will be identified through a systematic review. The fifth chapter will display the details of the research methodology, including the research aim and objectives, research questions and hypotheses, and research design for different phases of the research project. Details about the preparatory work on the psychometric assessment of the PNPC-sv will be presented in Chapter Six. The study results, including the results of the quantitative survey and the qualitative interviews, will be shown in Chapter Seven and Chapter Eight, respectively. Chapter Nine will present the discussion and conclusion of the whole doctoral research project.

## **Chapter Two: A Literature Review of Palliative Care**

## **2.1 Introduction**

This chapter will present a narrative literature review and details on palliative care. Seven sections are included in this chapter. This section (Section 2.1) is a general introduction of this chapter. Section 2.2 will present the increasing need for palliative care worldwide and in Mainland China. The following two sections (Section 2.3 and Section 2.4) will generally review the definitions and the benefits of palliative care, respectively. The overall development of palliative care worldwide and in Mainland China will be described in Section 2.5 and Section 2.6, respectively. A summary of this chapter will be given in Section 2.7.

## **2.2 An increasing need for palliative care**

### **2.2.1 Aging population**

According to projections by the United Nations (UN) (2009), the population of those aged 60 years and above is expected to total 2 billion worldwide by 2050, which will represent 22% of the total population, and approximately 120 million will live in China (World Health Organization, 2015). The aging population has become a big concern for China (Banister, Bloom, & Rosenberg, 2012), and the percentage of older people is expected to exceed 30% of the total population by 2050 (World Health Organization, 2015). Older people reaching the end of life are more likely to live with multiple debilitating diseases. In China, half of the elderly suffer from one or more chronic diseases (National-Health-and-Family-Planning-Commission-of-P.R.C, 2015), which decreases their quality of life and indicates a strong demand for comprehensive healthcare services, including palliative care (World Health Organization, 2011). Annual healthcare costs rise significantly in the final year of life (Payne, Laporte, Deber, & Coyte, 2007), which accounts for approximately 10% of lifetime healthcare costs (Polder, Barendregt, & van Oers, 2006). The aging population therefore contributes considerably to increasing national healthcare costs (Alemayehu & Warner, 2004; Rice & Fineman, 2004; Spillman & Lubitz, 2000).

### **2.2.2 Chronic diseases**

A chronic disease is a result of a combination of genetic, physiological, environmental, and behavioural factors (World Health Organization, 2017). Cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes are the four main types of chronic diseases (World Health Organization, 2014). People, regardless of age and region, are all vulnerable to these risk factors, but these conditions are more likely associated with older people (World Health Organization, 2017). Due to the aging population, chronic diseases are not only a national health issue but also an international health issue, and they increase the global health burden (Geneau et al., 2010). Chronic diseases were responsible for 38 million (68%) of the world's 56 million deaths in 2012 (Porche, 2011). China, as the biggest developing country, faces an increasing incidence of chronic diseases, particularly cardiovascular disease and cancer. Every year, there are around 2.6 million new cases of cancer, and four out of five are already at an advanced stage (Li et al., 2011). By 2012, death from cancer in China has accounted for 23% of the total deaths (World Health Organization, 2014).

### **2.2.3 Cancer**

As a chronic disease, cancer is a major cause of morbidity and mortality worldwide. According to a GLOBOCAN statistic (Bray, et al., 2018), approximately 18.1 million people were diagnosed as new cases of cancer and 9.6 million died of cancer throughout the world in 2018. The WHO estimates that more than 15 million people will be diagnosed with cancer and 10 million will die of cancer per year by 2020 (World Health Organization, 2003). The top five cancer types are lung cancer (11.60%), breast cancer (11.6%), colorectum cancer (10.2%), prostate cancer (7.1%), and stomach cancer (5.7%) (Bray, et al., 2018), and those five types of cancer contribute to nearly half of the global cancer burden. When it comes to cancer-related deaths, lung cancer ranks first with a percentage of 18.4% of all deaths from cancer, followed by colorectum cancer (9.2%), stomach cancer (8.2%), liver cancer (8.2%), and breast cancer (6.6%) (Bray, et al., 2018). The incidence of cancer is closely associated with age. In the age group of 0 to 14 years old, the cancer rate is about 10 per 100,000 and the corresponding rate

increases to 150 per 100,000 in the age group of 40 to 44 years old, reaching more than 500 per 100,000 in the age group of 60 to 64 years old (Stewart & Wild, 2014). The incidence of cancer has strong regional distribution characteristics and is associated with regional economic levels. More than 60% of the world's cancer patients live in Africa, Asia, and Central and South America, and their cancer deaths account for about 70% of the overall deaths in the world (Bray, et al., 2018), among which more than 50% of the incidence burden occurs in Asia and around half of the burden is in China (Bray, et al., 2018).

China, a middle-to-high income country, has an intermediate incidence rate of cancer (Stewart & Wild, 2014). According to the statistics of National Central Cancer Registry of China (NCCRC) (Chen et al., 2018), the crude incidence rate of cancer was about 278.07 per 100,000. The top five cancer types in China were lung cancer ( $57.13/10^5$ ), breast cancer ( $41.82/10^5$ ), stomach cancer ( $30.00/10^5$ ), colorectum cancer ( $27.08/10^5$ ), and liver cancer ( $26.67/10^5$ ). Most of the cancer cases were diagnosed at a medium or advanced stage, which resulted in unsatisfactory efficacy of treatment and brought many undesirable experiences to patients and their families (Stewart & Wild, 2014). Cancer has become one of the leading causes of death in China (Feng, et al., 2019). Lung cancer ( $45.80/10^5$ ), liver cancer ( $23.31/10^5$ ), stomach cancer ( $21.48/10^5$ ), esophagus cancer ( $14.11/10^5$ ), and breast cancer ( $9.9/10^5$ ) were the leading types of cancer that caused deaths in China (Chen et al., 2018).

With advances in cancer treatments, the illness trajectory and prognosis of cancer have changed, and patients diagnosed with advanced cancer can now live for a relatively long period (Kim, Schulz, & Carver, 2007; Thorne, Oliffe, Oglov, & Gelmon, 2013). However, lengthy cancer experiences and anticancer treatments cause patients to suffer from a wide range of problems, including physical, psychological, social, emotional, spiritual, and practical issues (Gysels et al., 2004). Cancer-related symptoms and patients' experiences during cancer treatment vary across different cancer stages (Waller et al., 2012a). Cancer patients at an advanced stage usually encounter more difficulties in optimizing their well-being compared with those at an early-stage, which subsequently contributes to a poor quality of life and an



increasing demand for care needs (Sanson-Fisher et al., 2000; Waller et al., 2012a). Such ‘chronic and uncertain’ conditions pose a challenge not only to healthcare services but also to patients’ informal caregivers (Moghaddam et al., 2016).

Informal caregivers are closest to the patients and they are usually responsible for taking care of their loved ones for a long period (Chen et al., 2015a). The long-term caregiving process is physically and psychologically challenging, particularly when taking care of patients at an advanced stage (Cui et al., 2014a). Many informal caregivers, including those who do not regard caregiving as a burden, suffer from a wide range of problems, such as sleep disturbance, anxiety, depression, and practical and financial difficulties (Grunfeld et al., 2004; Lambert et al., 2012). Informal caregivers are therefore usually regarded as ‘fellow sufferers’ alongside patients (Proot et al., 2004). The unmet needs of patients can increase the level of caregiver burden (Sharpe, Butow, Smith, McConnell, & Clarke, 2005). In turn, caregivers’ problems are closely linked with patients’ well-being (Milbury, Badr, Fossella, Pisters, & Carmack, 2013).

Unsolved problems and the unmet needs of caregivers not only decrease their own quality of life but also affect the patients’ health outcomes negatively (Hodgkinson et al., 2007). Informal caregivers and patients with advanced cancer are considered a ‘whole unit’ in fighting cancer (Lambert et al., 2012). In this situation, high-quality and ‘patient-and-family-centred’ care is needed to address the healthcare problems of both patients and their informal caregivers, including symptom and side effects management, emotional, psychosocial, and spiritual support, and quality of life improvement. All these aspects of support are typically categorized under the umbrella term ‘palliative care’ (World Health Organization, 2002).

### **2.3 Definitions of palliative care**

In addition to the commonly adopted WHO definition (World Health Organization, 2002) of palliative care, some other definitions recommended by other organizations will be presented in the following to help us have a better understanding of palliative care.

#### **National Institute for Clinical Excellence (NICE)**

“The active holistic care of patients with advanced progressive illness, management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.” (National Institute for Clinical Excellence, Guidance on cancer services improving supportive and palliative care for adults with cancer, 2004)

#### **National Comprehensive Cancer Network (NCCN)**

“Palliative care is a special kind of patient and family-centered health care that focuses upon effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and cultures.” (National Comprehensive Cancer Network , 2016)

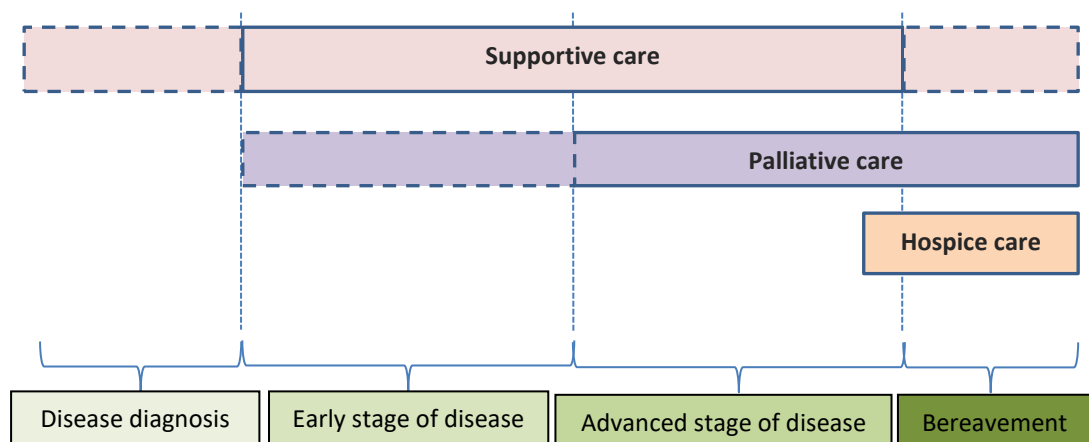
#### **American Society of Clinical Oncology (ASCO)**

“Palliative care is focused on the relief of suffering, in all of its dimensions, throughout the course of a patient’s illness. Palliative management focuses on the care of patients with advanced illness or a significant symptom burden by emphasizing honest communication about prognosis and treatment options, setting of medically appropriate goals, and symptom management.” (Smith et al., 2012, p. 881)

Given all the definitions mentioned above, palliative care therefore is a somewhat inconsistent and complex concept. Some have pointed out that palliative care should focus on patients with advanced progressive illness, whereas others have stated that palliative care should be used once the patients’ needs are not being addressed, regardless of the stages of their life-limiting diseases (Waller, Girgis, Currow, & Lecathelinais, 2008). Nevertheless, almost all the

definitions emphasize that both patients and those individuals who matter to them should be included in palliative care services.

Many other similar terms such as ‘supportive care’ and ‘hospice care’ are also commonly used in the clinical setting and in research. To distinguish those similar terms, Hui et al. (2013) conducted a systematic review of 46 articles and subsequently developed a conceptual framework to promote the understanding of ‘supportive care’, ‘palliative care’, and ‘hospice care’ (see **Figure 2.1**). The framework showed that the stage of the disease was a key distinguishing factor among ‘supportive care’, ‘palliative care’, and ‘hospice care’. For palliative care, although its service scope has gradually extended to the early stage of a disease, the target population of palliative care is still patients who are living with advanced life-limiting illness, particularly in regions with limited healthcare resources (Hui et al., 2013). The proposed service scope is consistent with the WHO definition of palliative care. Considering all the palliative care definitions above and the proposed service scope of palliative care, palliative care is needs-based (multidisciplinary) and ‘patient-and-family-centred’ care for any life-limiting illness at any stage, but the target population is patients at an advanced stage. In this research project, to minimize the heterogeneity of the participants, the focus was on cancer patients at an advanced stage and their informal caregivers. Cancer patients at any other early stages should be explored in future.



**Figure 2.1** A conceptual framework for ‘supportive care’, ‘palliative care’, and ‘hospice care’ adapted from Hui et al. (2013)

## 2.4 Benefits of palliative care

Plenty of evidence has demonstrated that palliative care offers benefits to patients with life-limiting diseases and their families (Luckett et al., 2014; Smith et al., 2014). Improving the quality of life of patients and families is the primary goal of palliative care (Cohen, Boston, Mount, & Porterfield, 2001), and many empirical studies have indicated that early palliative care with needs-assessment-based services can effectively relieve the distressing symptoms of patients with life-limiting diseases (Higginson et al., 2003), improve their quality of life (Peters & Sellick, 2006; Rabow et al., 2013; Temel et al., 2010; Zimmermann et al., 2014), and reduce invasive treatments at the end of life (Temel et al., 2010). For patient autonomy, integrating advance care planning into palliative care can decrease unwanted hospital admissions (Chen et al., 2015b). For many common end-stage diseases, patients who receive early palliative care have a relatively longer median survival compared with those who receive standard treatments/care (Rabow et al., 2013; Temel et al., 2010). Moreover, early palliative care can also improve family coping and adjustment after the death of a patient (HealthTeamWorks, 2011). In addition, the implementation of palliative care can help adjust over-treatment, promote the optimization of medical resources, and decrease the burden on the healthcare system (Rabow et al., 2013). According to a comprehensive literature review on the cost-effectiveness of palliative care interventions, palliative care, particularly home-based palliative care, was most frequently found to be less costly than usual medical care, which has been verified by many studies (Smith et al., 2014).

## **2.5 Development of palliative care: The global level**

Palliative care began in the United Kingdom (UK) in the 1960s in response to the unmet needs of patients with progressive and incurable illnesses and the needs of their families (Bennahum, 2003). Subsequently, palliative care has spread rapidly all over the world and has promoted the development of care models in both developed and developing countries (Crane, 2010). Many palliative care guidelines have been recommended by different organizations in several countries, particularly in developed countries, based on their own national conditions and cultural contexts (Wang et al., 2018a). A number of palliative care studies have been conducted,

and needs-based provisions and service models and systems of palliative care have been established and developed (Girgis et al., 2006; National Institute for Health and Care Excellence, 2004; Richardson, Medina, Brown, & Sitzia, 2007). Different models of palliative care services have been developed and implemented across European countries (Centeno et al., 2007). In addition to the UK, countries such as Germany, Austria, Poland, and Italy all have a well-developed and extensive network of hospices (Centeno et al., 2007).

According to the latest comparative analysis of palliative care development in 2011 (Lynch, Connor, & Clark, 2013), 58% of the world's 234 countries (n=136/234) had at least one palliative care service; however, a small number of countries (20 countries) were categorized as 'hospice-palliative care services are at a stage of advanced integration into mainstream service provision' (Lynch et al., 2013 ). Mainland China was categorized as a 'country where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision' (Lynch et al., 2013, p. 1097), and the ratio of services to population (1:8.5 million) was the highest among all the countries within this category (Lynch et al., 2013). For quality of palliative care, the UK ranked first in the 2015 Quality of Death Index among 80 countries (The Economist Intelligence Unit, 2015), followed by Australia and New Zealand. The availability and quality of palliative care has developed rapidly worldwide, with mainly wealthy countries clustered at the top. Some common characteristics exist among countries/regions with high death quality, such as "effective and efficiently national palliative care policy frameworks", "sufficient public financial support on healthcare services", "sufficient training resources for general and specialized healthcare professionals", "wide access to opioid analgesics", and "strong public awareness of palliative care" (Liu & Guo, 2017, p. 13).

## **2.6 Palliative care in Mainland China**

### **2.6.1 General development of palliative care**

Palliative care is a new specialty in Mainland China (Crane, 2010). The first institute for end-of-life care was established at Tianjin Medical University in 1988 (Li et al., 2011). In 1998,

the concept of end-of-life care was first introduced in a chapter of the Chinese textbook *Community Nursing* (Lin, 1998). Another textbook, *Palliative Medicine*, was published afterwards (Li, 2005). Despite these earlier works, palliative care was still not an independent discipline in medical universities until now.

Since 1998, 32 hospice units have been established throughout China by the Li Ka Shing Foundation (2017), and these hospice units mainly provide free services such as pain management for dying people, particularly for indigent advanced cancer patients. In 2004, the international Collaborating Centre for Palliative Cancer Care was established in the West China University of Medical Sciences (Liu, Xu, & Yuan, 2008). Following this development in palliative care, more than 200 palliative care units and hospice care units in urban areas have been established to date (Li et al., 2011).

In addition, two academic societies related to palliative care have been established in Mainland China, which are the Committee for Rehabilitation and Palliative Care for Cancer in the Chinese Society of Clinical Oncology and the Chinese Association for Life Care (Sun & Gu, 1999). In 2015, the China International Exchange and Promotive Association for Medical and Health Care and Chinese Association for Humanistic and Palliative Care (CAHPC) was established (Liu & Guo, 2017), which provided a new platform for facilitating the advance of palliative care and medical humanities in China. In 2016, the government notice 'Enhancement on Standardized Cancer Diagnosis and Treatment' was released by the National Health and Family Planning Commission (Liu & Guo, 2017), and it emphasized the optimization of cancer treatment and care, palliative treatment, and the importance of addressing patients' needs.

However, China is a huge and heavily populated country with severe income inequality, which has resulted in an uneven development and distribution of palliative care and hospice units, with a majority of these resources concentrated in major cities such as Beijing, Shanghai, and Guangzhou (Li et al., 2011; The Economist Intelligence Unit, 2015). In many other regions, palliative care is either totally non-existent or still at the initial stage (Zou, O'Connor, Peters, & Jiejun, 2013), and no formal palliative care service has been incorporated in the government-

supported mainstream healthcare system (Li et al., 2011). Funding for the promotion of palliative care services mainly comes from charitable donations and philanthropic activities such as the Li Ka Shing Foundation (Zou et al., 2013). Guidelines and standards on palliative care services are still scant. Healthcare resources for palliative care are mostly allocated in tertiary hospitals, while community-based and home-based palliative care services are still limited. Approximately 90% of patients with advanced cancer cannot access palliative care due to the lack of palliative care services (Li et al., 2011). According to the 2015 Quality of Death Index (The Economist Intelligence Unit, 2015), China ranked 71st out of 80 countries, which indicates that the availability, affordability, and quality of palliative care for Chinese patients are still suboptimal, and there is considerable room for further enhancement.

### **2.6.2 Importance of research for palliative care development**

The lack of national policy support and guidelines is one of the main barriers to progress in the development of palliative care services in Mainland China (Liu & Guo, 2017). Research has played an important role in the development of palliative care services in Mainland China and being able to draw on research evidence is one of the important facilitators for policymaking and practice (Ritter, 2009). Regarding palliative care research, there has been a limited number of registered trials so far in Mainland China. More rigorous studies within the Chinese cultural context are needed to provide more high-quality evidence to improve palliative care services and persuade policymakers of its benefits. For the overall research status of palliative care in Mainland China, it remains unclear and no systematic review has been conducted thus far. Only three narrative reviews (Li et al., 2011; Liu & Guo, 2017; Zou et al., 2013) have been carried out, and these have mainly focused on the status of current palliative care practices and existing barriers/challenges to the development of palliative care in Mainland China. The current research status of palliative care in Mainland China therefore should be explored to identify specific research directions for further research and practice of palliative care in Mainland China.

### **2.7 Summary of this chapter**

This chapter provided a narrative literature review of palliative care, which is needs-based (multidisciplinary) and ‘patient-and-family-centred’ care for life-limiting illness. Due to the aging population and high incidence of chronic diseases, there is an increasing need for palliative care worldwide. China, as the most populous country, is currently facing an aging population and an increasing incidence of chronic diseases like cancer. In the past decades, many palliative care guidelines and needs-based palliative care service models and systems have been developed and established in many countries based on their own national conditions and cultural contexts, particularly in several developed countries. However, palliative care is regarded as a new specialty in Mainland China. Although hundreds of palliative care units and hospice care units have been established to date, the distribution is uneven, with the majority of these units in major cities. In many other rural areas, palliative care is totally non-existent or at the initial stage. Due to the lack of palliative care services, the majority of advanced cancer patients have not received the benefits of palliative care.

Given the differences in cultural contexts, palliative care service models and systems in other countries cannot be directly applied in China, and culturally tailored palliative care services are needed. Research evidence is generally regarded as one of the important facilitators for practice and policymaking. In this situation, highly rigorous studies within the Chinese cultural context are needed to provide high-quality evidence of the need to improve palliative care practices and to persuade policymakers of the benefits of palliative care. Over the past decades, many studies have been conducted (as those included and analysed in Chapter 3), but the overall research status of palliative care in Mainland China remains unclear, and no systematic review has been conducted thus far. The following chapter will present a comprehensive review conducted systematically by the doctoral researcher, which intended to obtain an overview of the current research status of palliative care in Mainland China and to draw potential research directions for this doctoral research project, as well as implications for further research and practice.



## **Chapter Three: Systematic Review I: Identification of Research Directions**

### **3.1 Introduction**

The overview of current research status of palliative care in Mainland China is presented in this chapter through a comprehensive review which was conducted systematically by the doctoral researcher. This review was conducted based on a review guide that developed by extracting key and commonly emphasized information from existing international palliative care guidelines and definitions. The identified research status and the limitations retrieved from the current studies served as potential research directions in this doctoral research project. This chapter consists of four sections. The first section (Section 3.1) shows a general introduction of this chapter; Section 3.2 will present the whole systematic review, including the study objectives, study methods, review findings, discussion of the study results, and summary of the identified evidence. The identified research gaps and implications for this doctoral research project will be displayed in Section 3.3. Section 3.4 will be a summary of this chapter. It should be noted that this systematic review has already been published in an international peer-reviewed journal (Wang et al., 2018a). In order to fit the structure and organization of this doctoral thesis, the major contents and text citations styles and reference list of this review have been slightly modified based on the published one. Permission for using the article in this doctoral thesis has been granted by the publisher (Tao Wang, Alex Molassiotis, Betty Pui Man Chung, and Jing-Yu Tan, Current research status of palliative care in Mainland China, *Journal of Palliative Care*. 2018, 33(4), 215-241. DOI: 10.1177/0825859718773949. with permission of SAGE under the Green Open Access: SAGE's Archiving and Sharing Policy.).

### **3.2 Systematic review: Current research status of palliative care in Mainland China**

#### **3.2.1 Study objectives**

This study aimed to obtain an overview of the current research status of palliative care in Mainland China and identify research directions for this doctoral research project and future studies by characterizing palliative care studies conducted among patients with life-limiting illness in Mainland China and published in a peer-reviewed journal before November 2016.

### **3.2.2 Methods**

A review guide with 7 categories was developed by extracting key and commonly emphasized information from existing international palliative care definitions (Center to Advance Palliative Care, 2015; National Comprehensive Cancer Network, 2016; National Institute for Clinical Excellence [Improving supportive and palliative care for adults with cancer], 2004; Smith et al., 2012; World Health Organization, 2002; Zagonel et al., 2009) and guidelines (A National Framework and Preferred Practices for Palliative and Hospice Care Quality, 2012; Clinical Guideline in Palliative Care, 2012; Clinical Practice Guidelines for Quality Palliative Care, 2013; Evidence-based Guideline: Palliative Care for Patients with Incurable Cancer, 2015; National Comprehensive Cancer Network, 2016; Health Care Guideline: Palliative Care for Adults, 2013) through content analysis (Graneheim & Lundman, 2004; Robinson, Gott, & Ingleton, 2014) to guide the review toward a highly systematic and structured approach (see **Table 3.1** for an example of the process of data extraction and synthesis). The seven categories were ‘palliative care education and training,’ ‘palliative care screening and timely identification,’ ‘palliative care needs assessment and implementation,’ ‘advanced decision-making,’ ‘caring for patients at the end of life,’ ‘death and bereavement care,’ and ‘psychological support for palliative care providers’ (see **Table 3.2** for details). The seven categories of the review guide serve as evidence and outline on the manner in which relevant studies are identified and categorized in this study.

#### **3.2.2.1 Eligibility criteria of the included studies**

The inclusion criteria for the current review were as follows: (1) original research articles with a clearly described study design; (2) any study design type, including quantitative, qualitative, and mixed-methods approaches; (3) any study topic that fell within one of the extracted categories of the review guide; (4) studies were conducted in Mainland China, and the participants were Chinese adults; and (5) articles written in Chinese if published in peer-reviewed core Chinese journals as categorized by the Chinese Science Citation Database, Institute of Scientific and Technical Information of China, and General Core Journals of China,

and articles written in English if published in international peer-reviewed journals. The exclusion criteria were as follows: (1) reviews, conference articles, and empirical studies without any data analysis; (2) articles without any description of the study design; and (3) the participants were Chinese, but the studies were conducted in regions other than Mainland China, such as Hong Kong, Taiwan, and Macau given that the health-care systems in these regions differ from that in Mainland China.

**Table 3.1** Examples of meaning contents, condensed meaning contents, and categories

Meaning Contents	Condensed Meaning Contents	Category
<p><b>Guideline 1</b> (NCCN, 2016): ‘Educational programs should be provided to all health care professionals and trainees so they can develop effective palliative care knowledge, skills and attitudes’ (p. MS-8). ‘Clear, consistent, and empathetic communication with the patient and family about the natural history of the cancer and its prognosis is at the core of effective palliative care’ (p. MS-9). ‘Training in communication has been shown to improve clinician communication skills’ (p. MS-9). ‘Effective training in palliative care can also positively impact provider, patient and caregiver quality of life’ (p. MS-8).</p> <p><b>Guideline 2</b> (Palliative care for adults, 2013): ‘Provide education to clinicians, patients and families regarding the elements and appropriateness of palliative care’ (p. 12). ‘Prior to implementation, is important to consider current organizational infrastructure that address the following: System and process design, and...’ (p. 52).</p> <p><b>Guideline 3</b> (Evidence-based Guideline: Palliative care for patients with incurable cancer, 2015): One of the principles for palliative care providers who care for patients with incurable cancer is ‘Be prepared to get more continuing education’ (p. 26). For the qualifications of palliative care professionals, ‘acquired by training courses and/ or further education’ (p. 75).</p> <p><b>Guideline 6</b> (A National Framework and Preferred Practices for Palliative and Hospice Care Quality, 2012): ‘Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care’ (p. VII). ‘Provide adequate training and clinical support to assure that professional staff are confident in their ability to provide palliative care for patients’ (p. VII). ‘Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise’ (p. VII).</p>	<p>Palliative care education and training should be provided to healthcare staffs (or patients and/or families) as it can produce positive effects on providers, patients and caregiver</p> <p>Palliative care education and training should be provided prior to its implementation</p> <p>Palliative care education and training is one of the necessities of qualified professionals Palliative care education and training should be provided to make the professionals qualified</p>	<p>Palliative care education and training</p>

**Table 3.2** Seven collected categories and interpretations

Categories	Sub-categories	Interpretations
<b>Category 1:</b> PC education and training		PC education and training programme for professionals (or patients and/or families) is one of the most crucial components of PC. This programme makes professionals qualified and facilitates positive effects on providers, patients, and caregivers
<b>Category 2:</b> PC screening and timely identification		Whenever and wherever a patient is diagnosed with a life-limiting conditions, health-care professionals should have the consciousness to screen and identify whether the patient will benefit from PC regardless of the stage of the disease based on certain criteria and/or checklists
<b>Category 3:</b> PC needs assessment and implementation	Assessment and management of physical symptoms	- PC needs assessment is an important precondition for developing tailored PC interventions. Methods including standardized and validated scales and communication or discussion among patients, families, and professionals can be used for PC needs assessment
	Assessment and management of psychosocial distress	- On the basis of the results of PC needs assessment, if/when appropriate, multidisciplinary providers may consider adopting PC interventions, including pharmacologic and/or non-pharmacologic ones to address undesirable symptoms, which include physical symptoms (e.g., pain, dyspnea, nausea and vomiting, insomnia, fatigue, and constipation), psychosocial distress (anxiety, depression, financial burden, and social relationship), educational and information needs (diagnosis- and prognosis-related information), and cultural and spiritual needs
	Assessment of educational and information needs	
	Assessment and management of cultural and spiritual needs	- Dynamic reassessment should be performed to identify if the palliative intervention/plan meets patients' and families' needs. Reassessment should be ongoing throughout the total PC process
	PC quality reassessment	
<b>Category 4:</b> Advanced decision-making such as advance directives		Advanced decision-making should be initiated among patients and their families when patients have the ability to make decisions. The decision-making should consider patients' preferences and wishes, and decisions should be recorded and documented in medical records
<b>Category 5:</b> Caring for patients at the end-of-life		Treatment decisions and measures should be medically sound on the basis of patients' and families' needs, wishes, and values. Preserving patients' dignity and comfort is the foremost component
<b>Category 6:</b> Death and bereavement care		Comprehensive care can be provided for patients' families and caregivers based on their cultures and customs after patients' death. This assistance includes immediate issues and bereavement care for patients' families
<b>Category 7:</b> Psychological support for PC providers		PC providers encounter the death of patients and deal with grief, which can cause burnout, compassion fatigue, and/or moral distress. However, relevant evidence-based interventions are not included

**Note:** PC is palliative care.

### 3.2.2.2 Information sources and search strategies

Ten databases were searched by two independent researchers from the inception of their online cataloging to November 2016, which included PubMed, CENTRAL, CINAHL, EMBase, PsycINFO, Web of Science, Wan Fang Data, China National Knowledge Infrastructure (CNKI), Chongqing VIP (CQVIP), and Chinese Biomedical Literature Database (CBM). No restriction was set for the types of study design when conducting electronic database searches. Additional sources including the reference list of the included publications, were also screened by the review authors to determine whether any additional publication could be identified for possible inclusion. Relevant English and Chinese MeSH terms, key words, and free words identified from the seven extracted categories of the review guide were included in the search terms. **Table 3.3** lists the relevant search terms and one representative search strategy (PubMed) of this review.

**Table 3.3** Selected search strategies (PubMed)<sup>a</sup>

PubMed	
ID	Search Strategies
#1	Search (((((((((((((((Palliative care[MeSH Terms]) OR Palliative medicine[MeSH Terms]) OR Palliative care[Title/Abstract]) OR Palliative therap*[Title/Abstract]) OR Palliative treatment*[Title/Abstract]) OR Palliative care medicine[Title/Abstract]) OR Palliative nursing[Title/Abstract]) OR Palliative care nursing[Title/Abstract]) OR (Hospice[Title/Abstract] OR Hospice care[Title/Abstract]) OR Terminal care[Title/Abstract]) OR Terminal ill[Title/Abstract]) OR Hospice[Title/Abstract]) OR Home care service[Title/Abstract]) OR Attitude to death[Title/Abstract]) OR Endstage[Title/Abstract]) OR End-stage[Title/Abstract]) OR Hospice nursing[Title/Abstract]) OR End of life[Title/Abstract]
#2	Search (("education"[MeSH Terms]) OR "education"[Title/Abstract]) OR "training"[Title/Abstract]
#3	Search ("screening"[Title/Abstract]) OR "early palliative care"[Title/Abstract]
#4	Search (((((((((((("needs assessment"[MeSH Terms]) OR "pain"[MeSH Terms]) OR "dyspnea"[MeSH Terms]) OR "constipation"[MeSH Terms]) OR "anorexia"[MeSH Terms]) OR "cachexia"[MeSH Terms]) OR "nausea"[MeSH Terms]) OR "vomiting"[MeSH Terms]) OR "anxiety"[MeSH Terms]) OR "depression"[MeSH Terms]) OR "spirituality"[MeSH Terms]) OR "emotions"[MeSH Terms]
#5	Search (((((((((((((((("needs assessment"[Title/Abstract]) OR "assessment of healthcare needs"[Title/Abstract]) OR "care needs"[Title/Abstract]) OR "needs"[Title/Abstract]) OR "symptom assessment"[Title/Abstract]) OR "symptom management"[Title/Abstract]) OR "management"[Title/Abstract]) OR "physical suffering"[Title/Abstract]) OR "pain"[Title/Abstract]) OR "dyspnea"[Title/Abstract]) OR "breath shortness"[Title/Abstract]) OR "breathlessness"[Title/Abstract]) OR

	"constipation"[Title/Abstract]) OR "dyschezia"[Title/Abstract]) OR "insomnia"[Title/Abstract]) OR "psychological"[Title/Abstract]) OR "emotional"[Title/Abstract]) OR "spiritual"[Title/Abstract]) OR "nausea"[Title/Abstract]) OR "vomiting"[Title/Abstract]) OR "anorexias"[Title/Abstract]) OR "cachexia"[Title/Abstract]) OR "anxiety"[Title/Abstract]) OR "depression"[Title/Abstract]) OR "symptom control"[Title/Abstract]
#6	Search (((("advance care planning"[MeSH Terms]) OR "advance care planning"[Title/Abstract]) OR "advance health care planning"[Title/Abstract]) OR "advance directives"[Title/Abstract]
#7	Search ("quality palliative care"[Title/Abstract]) OR "quality"[Title/Abstract]
#8	Search (((("dying patient"[Title/Abstract]) OR "end of life"[Title/Abstract]) OR "terminal"[Title/Abstract]) OR "end stage"[Title/Abstract]
#9	Search (((("bereavement"[MeSH Terms]) OR "grief"[MeSH Terms]) OR "bereavement"[Title/Abstract]) OR "bereavement care"[Title/Abstract]) OR "grief care"[Title/Abstract]
#10	Search ((((((("psychological support"[Title/Abstract]) OR "oncologist"[Title]) OR "physician"[Title]) OR "nurse"[Title]) OR "health care professional"[Title]) OR "health care professional"[Title]) OR "health care provider"[Title]
#11	#2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10
#12	Search (((((((("China"[MeSH Terms]) OR People's Republic of China[Title/Abstract]) OR Mainland China[Title/Abstract]) OR Chinese[Title/Abstract]) OR Chinese Mainland[Title/Abstract]) OR Manchuria[Title/Abstract]) OR Mandarin[Title/Abstract]) OR Sinkiang[Title/Abstract]) OR Inner Mongolia[Title/Abstract]
#13	#1 AND #11 AND #12

#1 was the search strategy for "palliative care"; #2, #3, #4, #5, #6, #7, #8, #9 and #10 were the search strategies for the seven categories of the review guide; #12 was the search strategy for "China". PubMed was the first electronic database used for literature search, and search strategies used in other databases were adapted from PubMed.

### 3.2.2.3 Study selection and data collection

After the completion of the literature search, possible duplications were identified using reference management software. Two review authors (WT and TJY) then selected the potentially eligible studies by checking the title and abstract of the remaining articles independently. The full-text versions of potentially eligible articles were obtained for the final assessment of their inclusion. Disagreements were solved via group discussions, and, if necessary, a third party was involved to reach a final consensus.

The characteristics of the included studies were extracted and checked independently by the two review authors through extraction forms that were piloted prior to the current review. The data extraction form includes information regarding first author, year of publication, country/region, study sites, aims/ objectives of the study, study design, sample, and relevant research findings. Disagreements were settled via group discussions with a third party as well.



### **3.2.2.4 Quality assessment of the included studies and data analysis**

A quality appraisal of the included studies is commonly recommended for a systematic review, particularly when the scope of sampling is narrow and when the study design is similar (Robinson et al., 2014). The current review included studies with quantitative, qualitative, or mixed-methods approaches, which makes the quality evaluation difficult (Whittemore & Knafl, 2005). More importantly, the review aimed to explore what has been done in terms of palliative care research in Mainland China without any emphasis on study quality. Therefore, no quality appraisal of the included studies was performed.

Approaches to data synthesis should be determined by the review questions and the heterogeneity of the included studies (Ryan, 2013). If the included studies exhibit significant heterogeneity, then quantitative data synthesis is generally not recommended, and descriptive analysis can be adopted instead (Ryan, 2013). For the current review, studies were identified on the basis of any of the seven categories, and the heterogeneity of these studies was high with different research objectives, research designs, interventions, and outcome assessments, and thus, descriptive analysis was adopted for the review.

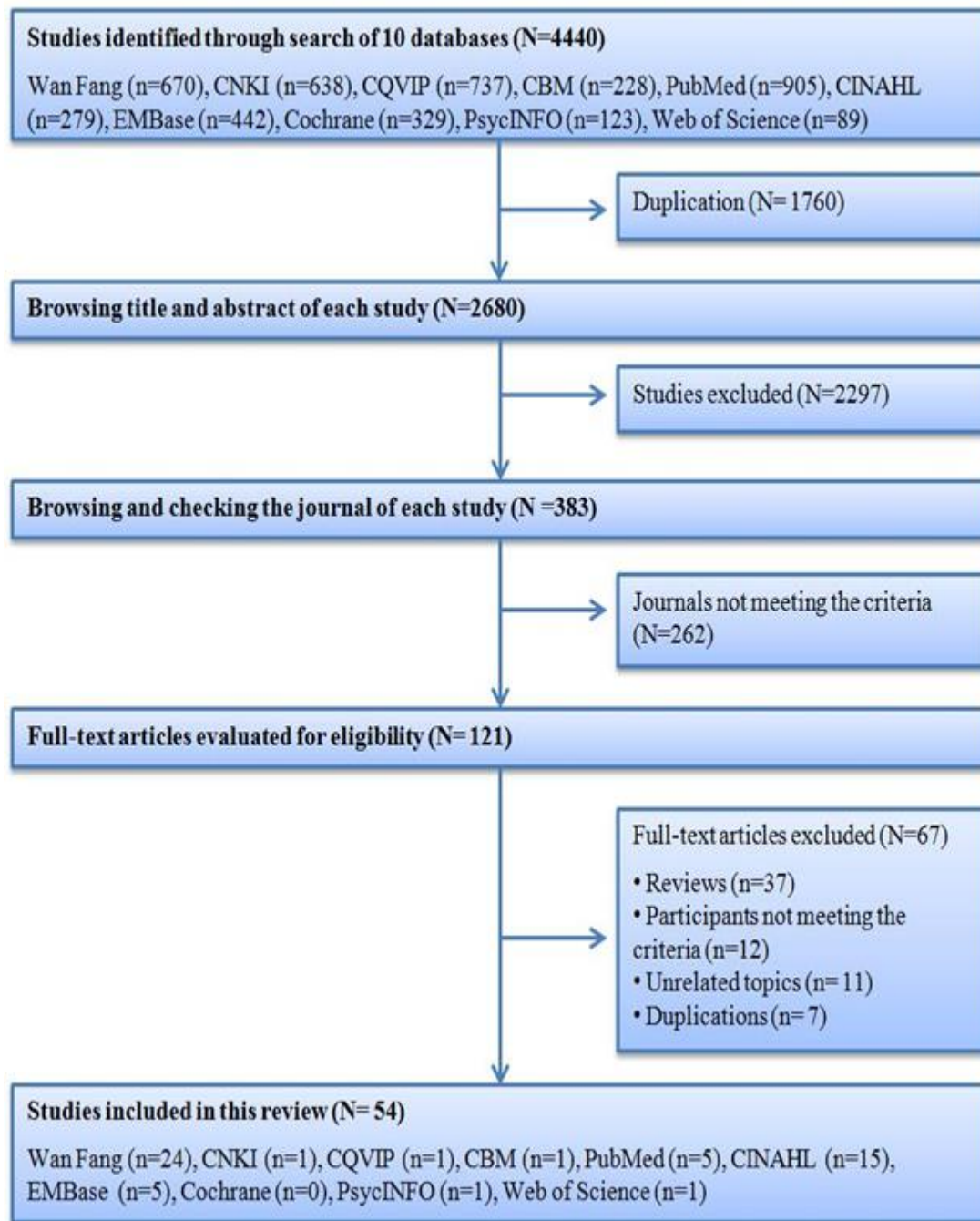
### **3.2.3 Results**

#### **3.2.3.1 Characteristics of the included studies**

A total of 4440 studies conducted in Mainland China were identified by searching the 10 electronic databases, and 54 relevant studies (detailed characteristics of the included studies are shown in **Table 3.4** to **Table 3.8**) were eventually included in the review (see **Figure 3.1** for the selection process).

The 54 studies, including 27 in English and 27 in Chinese, were published between 2005 and 2016. Twenty-one studies were conducted in Shanghai, a major and developed city in Mainland China. The majority (33/54) of the studies recruited patients with cancer, of which 28 (28/33) included patients with advanced cancer. Ten studies focused on health-care professionals, and 9 focused on the families/informal caregivers of patients with cancer. Only a few studies recruited patients with other chronic conditions, for instance chronic obstructive

pulmonary disease (COPD) (Liu, Cui, Huang, & Lu, 2016), HIV (Sheng, Qiu, He, Juniper, & Zhang, 2010), and renal failure (Lv, Xue, & Tan, 2014). Of the studies within each category, three focused on ‘palliative care education and training’ (category 1) (Liu, Xu, & Yuan, 2008; Liu & Yuan, 2009a, 2009b), five were related to ‘palliative care screening and timely identification’ (category 2) (Gu, Cheng, Chen, Liu, & Zhang, 2016a; Gu, Cheng, Chen, Liu, & Zhang, 2016b; Huang et al., 2014; Liu et al., 2013; Zhou, Cui, Lu, Wee, & Zhao, 2009), 31 were about ‘palliative care needs assessment and implementation’ (category 3) (detailed characteristics of the included studies are shown in **Table 3.6**), 12 concentrated on ‘advanced decision-making’ (category 4) (Gu et al., 2016b; Hong, 2015; Li & Li, 2016; Li, Zhou, & Luo, 2014; Liu et al., 2015; Wang, 2012; Wang, Hu, Lu, & Gu, 2011; Wang, Hu, Lu, & Gu, 2012b; Wang et al., 2016; Wang, Lu, Hu, & Gu, 2012a; Zhang, Chen, Gu, Liu, & Cheng, 2015; Zhang, Xie, Xie & Liu, 2016c), and the remaining four investigated ‘caring for patients at the end of life’ (category 5) (Dong et al., 2016; Gu, Cheng, Cheng, Liu, & Zhang, 2015b; Zheng, Dong, Qiang, & Wang, 2013; Zheng, Guo, Dong, & Owens, 2015). No relevant study relating to the other two categories, ‘death and bereavement care’ (category 6) and ‘psychological support for palliative care providers’ (category 7), was identified.



**Figure 3.1** Study selection process

### 3.2.3.2 Category 1: Palliative care education and training

Three studies (Liu et al., 2008; Liu & Yuan, 2009a, 2009b) focused on education and training in palliative care for health-care professionals, with 1 published in English and 2 in Chinese (see **Table 3.4**). These studies were conducted by the same research team in Shanghai. Study 1 investigated (Liu et al., 2008) the palliative care training needs of nurses using a self-designed questionnaire, and the psychometric properties of this questionnaire were not

reported. The most preferable training content of nurses was ‘communication skills’, which was followed by ‘psychological care’, ‘symptom care’, ‘moral and ethical issues’, ‘terminal care’, and ‘overview of palliative care’. (Liu et al., 2008) Study 2 considered (Liu & Yuan, 2009a) the ‘level’ of the hospital (ie, primary, secondary, and tertiary levels) and explored the common and individual palliative care training needs of nurses in hospitals of different levels using the same questionnaire as in Study 1. Nurses in primary- and secondary-level hospitals had great needs in terms of defining palliative care and basic care, whereas nurses in tertiary-level hospitals had great needs in terms of ethical and moral issues within the palliative care context. A third study (Liu & Yuan, 2009b) formed a 6-module training programme for nurses through a 2-round Delphi survey with 36 professional experts, which included experienced nursing researchers, nursing teachers, clinical nurses, and oncology physicians. The training programme developed by the Delphi panel consisted of 69 items within the 6-module training programme, included content such as ‘palliative care overview’, ‘symptom care’, ‘psychological care’, ‘communication and exchange’, ‘ethics and laws’, and ‘terminal care’. (Liu & Yuan, 2009b)

### **3.2.3.3 Category 2: Palliative care screening and timely identification**

Five articles (Gu et al., 2016a, 2016b; Huang et al., 2014; Liu et al., 2013; Zhou et al., 2009) published in English were included in the ‘palliative care screening and timely identification’ category, 3 of which were retrospective study designs (see **Table 3.5**). Three of the studies (Huang et al., 2014; Liu et al., 2013; Zhou et al., 2009) focused on exploring the prognostic factors for life expectancy (1 and 3 months) (Huang et al., 2014; Zhou et al., 2009), with the common factors identified being performance status (Karnofsky performance status [KPS]), dyspnea, lack of appetite, and edema. The other 2 studies used the time interval from admission to palliative care unit to patient death to identify whether patients with advanced cancer were referred in a timely manner, with the median time intervals being 21 and 16 days (Gu et al., 2016a, 2016b), respectively.

**Table 3.4** Characteristics of the included studies on palliative care education and training (Category 1, N=3) <sup>a</sup>

Author, Setting, and Year	Aims/Objectives	Methods	Relevant Findings
<p><b>S1<sup>b</sup></b>: Liu, et al., 2008 An oncology hospital in Shanghai (in Chinese)</p>	<p>To explore the needs for PC training contents and the relevant influential factors in oncology nurses</p>	<p>Cross-sectional study Convenience sampling Sample size: 148 Valid respondents: 131 (91.3%) Questionnaire: a self-designed questionnaire (93 items) without specifying the psychometric properties</p>	<p><b>Important sequence of PC training contents based on nurses' needs:</b> communication skills, psychological care, symptom care, moral and ethics, terminal nursing, and overview on palliative care <b>Influential factors:</b> (1) The length of service of the nurse was positively related to psychological care, communication skills, and moral and ethics professional. (2) The professional title of the nurse was positively related to communication skills.</p>
<p><b>S2:</b> Liu, &amp; Yuan, 2009a Shanghai (in Chinese)</p>	<p>To analyze the common and individual PC training needs among nurses in different hospital levels</p>	<p>Cross-sectional study Stratified sampling, including 15 hospitals (8 hospitals for the primary level, 4 hospitals for the secondary level, and 3 hospitals for the tertiary level) Sample size: 405 Valid respondents: 340 (83.9%) Questionnaires: the same self-designed questionnaire of S1 <sup>31</sup></p>	<p><b>Important and common training contents:</b> 24 common training contents for different hospital levels <b>Individual training contents:</b> (1) Primary-level hospital: the concept of PC, basic care, and bereavement support (2) Secondary-level hospital: the overview of PC, basic care, and pain management (3) Tertiary-level hospital: radiotherapy and chemotherapy care and ethical and moral problems in PC</p>
<p><b>S3:</b> Liu, &amp; Yuan, 2009b Shanghai (in English)</p>	<p>To construct the PC-related training contents for clinical nurses</p>	<p>Development of the initial questionnaire (the same as S1 <sup>31</sup> and S2 <sup>32</sup>): Literature review + experts' comments + group discussion Expert panel: 50 experts were invited on the basis of specific criteria, and 36 experts gave their responses. Two-round Delphi studies were conducted: Round 1: emailed the questionnaire (36 experts) Round 2: stamped the questionnaire (36 experts)</p>	<p><b>A six-module training programme with 69 training items was constructed</b> (pp. 453-454): (1) 'overview of the palliative care'-8 items (2) 'symptom care'—24 items (3) 'psychological care'—15 items (4) 'communication and exchange'—13 items (5) 'ethics and laws'—5 items (6) 'terminal care'—4 items</p>

**Notes:** Abbreviations PC, palliative care. <sup>b</sup> S: study. <sup>a</sup> All three studies were performed by the same research group.

**Table 3.5** Characteristics of the included studies on palliative care screening and timely identification (Category 2, N=5)

Author, Year, Setting, and Language	Aims/Objectives	Study Design	Participants	Measurements	Outcomes
<b>S1<sup>a</sup>:</b> Gu et al., 2016a A cancer center, Shanghai (in English)	To investigate the PC referral time of patients with advanced cancer	Retrospective study, data in 2007–2013	759 patients with advanced cancer	<b>Time interval:</b> from PCU enrollment to the death of patients (LOS) and longer long LOS indicated early referral	<b>The median LOS (days) was 21 days.</b> <b>The LOS presented an increasing trend</b> in the recent years (2007–2013) although the statistic difference insignificant ( $p = 0.157$ ).
<b>S2:</b> Zhou et al., 2009 A hospice center, Shanghai (in English)	To explore a prognostic scale for predicting life expectancy in patients with advanced cancer	Retrospective study, data in 2003–2007	1,019 patients with advanced cancer: Training set <sup>b</sup> : 814 Testing set <sup>c</sup> : 205	Symptoms/signs Performance status: Karnofsky Performance Status (KPS) Quality of life (QOL): a Chinese version QOL scale Survival time	<b>10 prognostic factors:</b> loss of weight, nausea, difficulty swallowing, edema, cachexia, breathlessness, dehydration, gender, low KPS, and QOL <b>The cutoff point of 3-month survival was 28:</b> >28 means that survival time is more likely less than 3 months. <b>The accuracy rate: &gt;65.4% (testing set)</b>
<b>S3:</b> Huang, et al., 2014 Two cancer centers, Wuhan (in English)	To develop a prognostic scale of survival in Chinese patients with terminal cancer	Prospective study	309 patients with terminal cancer: Training set: 181 - Testing set: 128	Symptoms/signs Performance status: KPS Laboratory variables: white blood cell and platelet counts, lymphocyte percentage, urea, and calcium	<b>8 prognostic factors:</b> low KPS, dyspnea, cognitive impairment, leukocytosis, loss of appetite, edema, and increased urea and alanine transaminase concentrations <b>The cutoff point of one-month survival was 4;</b> scores more than 4 indicated a high risk of survival for less than one month.
<b>S4:</b> Liu et al., 2013 A hospital, Xuzhou (in English)	To investigate the independent risk factors for the survival of patients with end-stage cancer	Cross-sectional study	163 patients with end-stage cancer	Performance status: KPS Prevalence and severity of common symptoms: Edmonton Symptom Assessment Scale (ESAS)	<b>Five independent risk factors:</b> low KPS, fatigue, lack of appetite, dyspnea, and age (RR = 0.797, 1.581, 1.122, 1.123, and 1.022)
<b>S5:</b> Gu et al., 2016b A PCU, Shanghai (in English)	To investigate the associated factors of decision-making in patients with terminal cancer <sup>d</sup>	Retrospective study, data in 2007–2013	436 patients with advanced cancer	Time interval: from PCU enrollment to the death of patients (LOS) and long LOS indicated early referral	<b>The LOS was 16 days (range: 1–179 days).</b> Associated factors were present in Table 7 (Category 4)

**Notes:** Abbreviations: PC: palliative care. PCU: palliative care unit; LOS: length of stay; <sup>a</sup>S: study. <sup>b</sup>The ‘training set’ means the group of patients for developing the scale; <sup>c</sup>The ‘testing set’ means the group of patients for validation study; <sup>d</sup> This study was included in Category 2 (because the data of LOS was mentioned) and Category 4.

### 3.2.3.4 Category 3: Palliative care needs assessment and implementation

**Palliative care needs assessment.** Twelve studies (Cui et al., 2014a, 2014b; Deng, Lin, & Law, 2015a; Gu, Shi, & Yuan, 2015a; Hong, Song, Liu, Wang, & Wang, 2014; Hu et al., 2015; Liu, 2008; Liu, Cui, Huang, & Lu, 2016; Sheng et al., 2010; Wang, Shen, & Xu, 2011; Yan, 2013; Zhang et al., 2016a) explored palliative care needs assessments, with eight published (Cui et al., 2014a, 2014b; Deng et al., 2015a; Hong et al., 2014; Hu et al., 2015; Sheng et al., 2010; Wang et al., 2011; Zhang et al., 2016a) in English and four published (Gu et al., 2015a; Liu, 2008; Liu et al., 2016; Yan, 2013) in Chinese (see **Table 3.6**). Three cross-cultural validation studies (Hu et al., 2015; Yan, 2013; Zhang, et al., 2016a) aimed at introducing new instruments for conducting needs assessments to Mainland China, including the McGill Quality of Life Questionnaire (MQOL) (Hu et al., 2015), EORTC Quality-of-Life Questionnaire-Core 15-Palliative Care (QL-C15-PAL) Scale (Zhang et al., 2016a), and Palliative Care Outcome Scale (POS) (Yan, 2013).

Six studies (Cui et al., 2014a, 2014b; Gu et al., 2015a; Liu, 2008; Liu et al., 2016; Wang et al., 2011) adopted a cross-sectional design to assess palliative care needs. Three of the studies (Cui et al., 2014b; Gu et al., 2015a; Wang et al., 2011) assessed the palliative care needs of patients with advanced cancer, one study (Cui et al., 2014b) evaluated the needs of the informal caregivers of patients with advanced cancer, one study (Liu, 2008) evaluated the palliative care needs of patients with advanced cancer and their informal caregivers, and one study (Liu et al., 2016) focused on patients with COPD. The majority of these studies explored palliative care needs more from the perspectives of patients with advanced cancer than from the perspectives of informal caregivers or health-care professionals. The sample sizes of the 6 studies ranged from 108 to 649. The adopted scales were Functional Assessment of Cancer Therapy—General (FACT-G) (Wang et al., 2011), MD Anderson Symptom Inventory (MDASI-C) (Wang et al., 2011), MQOL (Cui et al., 2014a), POS (Liu et al., 2016), KPS (Cui, et al., 2014a; Liu et al., 2016), Hospital Anxiety and Depression Scale (HADS) (Liu et al., 2016) and self-designed questionnaires with (Cui et al., 2014b; Liu, 2008) or without (Gu et al., 2015a) testing their psychometric properties. The commonly identified palliative care

needs of patients with cancer were physical symptoms, including fatigue (Cui et al., 2014a; Liu, 2008; Wang et al., 2011), pain (Cui et al., 2014a; Liu, 2008), and dyspnea (Cui et al., 2014a); education and information needs related to their disease (Liu, 2008); and psychosocial needs and family support (Gu et al., 2015a; Liu, 2008). The identified needs of informal caregivers were illness-related information (Cui et al., 2014b; Liu, 2008), symptom management for the patients (Cui et al., 2014b), and psychological and technical support from health-care professionals (Cui et al., 2014b; Liu, 2008).

The other three studies (Deng et al., 2015a; Hong et al., 2014; Sheng et al., 2010) adopted qualitative study designs to explore palliative care needs. One study (Hong et al., 2014) assessed the needs of patients with cancer through a focus group discussion, identifying five needs, including ‘informational needs’, ‘emotional and psychological needs’, ‘technical support needs’, ‘social resource mobilization’, and ‘palliative care in certain stage’. One study (Sheng et al., 2010) focused on patients with end-of-life HIV and through a focus group discussion identified three palliative care needs, including ‘be accepted by others’, ‘mental health care and support from professionals’, and ‘more material support from the government’. Another study (Deng et al., 2015a) explored the spiritual needs of hospice patients (mainly patients with advanced cancer) and identified two particular needs, including ‘having a nice day without pain’ and ‘wishes of family health and happiness’.

**Palliative care implementation.** Nineteen studies (Chen et al., 2014; Chen, Ju, Lu, & Shi, 2008; Deng, Deng, Liu, Xie, & Wu, 2015b; He, Wang, & Liu, 2005; Huang & Wang, 2016; Lai, Zhou, & Qu, 2013; Li, 2013; Lv et al., 2014; Peng, Wang, Wei, Lu, & Zhan, 2005; Wang, 2009; Xiao, Kwong, Pang, & Mok, 2012, 2013; Yang, 2012; Yang, Liu, & Huang, 2016; Yao, et al., 2016; Zhang, Fan, Wu, & Lin, 2016b; Zhang, Zhu, Liu, Hui, & Mu, 2015a; Zhang, Qiu, Zhou, Liu, 2013; Zhu Sun, & Zhang, 2016) focused on palliative care implementation, five (Chen et al., 2014; Deng et al., 2015b; Lv et al., 2014; Xiao et al., 2012, 2013) of which were published in English and the others (Chen et al., 2008; He et al., 2005; Huang & Wang, 2016; Lai et al., 2013; Li, 2013; Peng et al., 2005; Wang, 2009; Yang, 2012; Yang et al., 2016; Yao, et al., 2016; Zhang et al., 2016b; Zhang et al., 2015a; Zhang, et al., 2013; Zhu et al., 2016) in



Chinese (see **Table 3.6**). Seven studies (He et al., 2005; Li, 2013; Peng et al., 2005; Xiao et al., 2013; Yang, 2012; Yang et al., 2016; Zhang et al., 2015a) were randomized controlled trials (RCTs), six were single-group pre–post studies (Chen et al., 2008; Deng et al., 2015b; Lai et al., 2013; Wang, 2009; Yao, et al., 2016; Zhang et al., 2016b), four were controlled clinical trials (Chen et al., 2014; Huang & Wang, 2016; Zhang, et al., 2013; Zhu et al., 2016), and the other two were a case study (Lv et al., 2014) and a qualitative study (Xiao et al., 2012). The majority of the included studies (17 studies) focused on patients with cancer and their family members, and only 2 studies focused on patients with other terminal diseases [ie, renal failure (Lv et al., 2014) and mixed terminal diseases (Zhu et al., 2016)]. In terms of the disciplines involved in the palliative care intervention, the providers of palliative care in 17 of the 19 studies were registered nurses without any multidisciplinary team support.

The design of the included studies revealed certain methodological issues. Regarding the development of the palliative care intervention protocol, only 8 studies (Chen et al., 2014; Chen et al., 2008; Deng et al., 2015b; He et al., 2005; Lai et al., 2013; Li, 2013; Zhang, et al., 2013; Zhu, et al., 2016) developed their intervention protocols based on the needs of patients, and no study dynamically adjusted the protocol based on ongoing needs reassessment during the study period. None of the studies adopted sample size calculation. The intervention duration varied from 2 weeks to 6 months, and 6 studies (Huang & Wang, 2016; Peng et al., 2005; Yang et al., 2016; Zhang et al., 2016b; Zhang et al., 2015a; Zhu et al., 2016) even failed to report the duration of the intervention. In terms of the 7 RCTs, some other methodological flaws existed, such as the absence of randomization methods, allocation concealment, and blinding designs (see details in the third column of **Table 3.6**). The commonly adopted palliative care intervention components in the included studies were symptom management, psychological support, health education, social support, spiritual support, individual care, and life review programmes.

Eleven studies adopted quality of life as one of their outcome measures, and the commonly used questionnaires were MQOL, quality-of-life instrument for patients with cancer, EORTC Quality-of-Life Questionnaire-Core 30 (EORTC QLQ-C30), and self-designed questionnaires

with or without testing their psychometric properties. Six studies (Huang & Wang, 2016; Lv et al., 2014; Yang et al., 2016; Yao, et al., 2016; Zhang et al., 2015a; Zhang, et al., 2013) measured anxiety and/or depression using the Self-Rating Anxiety Scale, Self-rating Depression Scale, and HADS. Two studies (Li, 2013; Zhu et al., 2016) measured the satisfaction of patients and/or their family members regarding their needs and the nursing services. Only 2 studies were identified in terms of the palliative care for symptom management, with one study (Chen et al., 2014) on pain and the other (Wang, 2009) on dyspnea. All of the studies support the proposition that palliative care improves the patients' and their families' quality of life and relieves their anxiety and depression.

**Table 3.6** Characteristics of the included studies on palliative care needs assessment and implementation (Category 3, N=31)

6-1 Palliative Care Needs Assessment (n=12)					
Author, Year Setting, and Language	Aims/Objectives	Study Design	Participants	Measurements	Outcomes
<b>S1<sup>a</sup></b> : Wang et al., 2011 Five community health-service centers, Shanghai (in English)	To evaluate the symptoms and the quality of life of patients with advanced cancer	Cross-sectional study	201 patients with advanced cancer, convenience sampling	Functional Assessment of Cancer Therapy—General (FACT-G) MD Anderson Symptom Inventory (MDASI-C)	The mean QOL score was $62.2 \pm 16.8$ . <b>The most severe and prevalent symptom</b> was fatigue (88.6%) and then followed by difficulty in remembering (78.1%), dry mouth (73.6%), distress (73.1%), and shortness of breath (69.7%). <b>Correlation:</b> symptoms (MDASI-C) negatively correlated with the QOL (FACT-G), and psychological symptoms were the most correlated factor (correlation coefficient = $-0.645$ ).
<b>S2</b> : Hu et al., 2015 Two hospitals, Wuhan (in English)	To validate the McGill Quality of Life Questionnaire (MQOL) in patients with cancer in a PC setting	Validation study	126 patients with cancer	The McGill Quality of Life Questionnaire (MQOL)	<b>Constructive validity:</b> consistent with the original model through confirmed factor analysis <b>Internal consistency reliability:</b> Cronbach's $\alpha = 0.582-0.917$ <b>Test-retest reliability:</b> 0.509–0.859 <b>Face validity:</b> satisfied
<b>S3</b> : Cui, et al., 2014b 13 hospitals, Shanghai (in English)	To investigate the QOL of patients with advanced cancer	Cross-sectional study	531 patients with advanced cancer by convenience sampling	The McGill Quality of Life Questionnaire (MQOL) Karnofsky Performance Status (KPS)	96.0% reported one most troublesome symptom, and 55.9% reported 3 most troublesome symptoms. <b>Top five symptoms:</b> pain (39.4%), loss of appetite (25.6%), fatigue (23.9%), weakness (20.0%), and dyspnea (19.2%) <b>Correlation:</b> KPS correlated with QOL (MQOL)
<b>S4</b> : Hong et al., 2014 Two hospitals, Anhui (in English)	To explore the needs of cancer patients in terms of nursing professional social support and the factors that hinder needs assessment and fulfillment	Qualitative study: focus group interview	32 health-care professionals by purposive sampling	NA (not applicable)	<b>Five nursing professional support needs</b> (pp. 1052–1054) <sup>42</sup> : (1) Information needs, such as disease information guidance and diet guidance (2) Emotional and psychological needs, such as “psychological support, esteem support, and improving coping strategies” (3) Technical support needs, such as “proficient nursing skill, disease observation, and symptom management” (4) Mobilization of the social resource such as “establishment and utilization of social resource; help returning to society” (5) Palliative care during certain stages, such as death education <b>Four potential reasons:</b> (1) Patients lack the awareness of searching for support. (2) Professionals lack training for providing support.

					(3) Professionals' shortage and heavy workload (4) Lack of appropriate assessment tools
<b>S5:</b> Zhang, et al., 2016a A hospital, Tianjing (in English)	To validate the EORTC Quality-of-life Questionnaire Core 15 Palliative (QOL-C15-PAL) in patients with advanced cancer in a PC setting	Validation study	243 patients with advanced cancer	EORTC QOL-C15-PAL and EORTC QOL-C30 Eastern Cooperative Oncology Group Performance Status (ECOG-PS)	<b>Internal consistency reliability:</b> Cronbach's $\alpha$ ranged from 0.70 to 0.80. EORTC QOL-C15-PAL sub-scale scores can explain 84.8%–90.3% of the original EORTC QOL-C30 score distribution ( $R^2$ ranged from 0.848 to 0.903) <b>Acceptability:</b> missing rate of each item: 0%–2.1%.
<b>S6:</b> Cui et al., 2014b 15 hospitals, Shanghai (in English)	To explore the needs of family caregivers of patients with advanced cancer	Cross-sectional study	649 family caregivers by convenience sampling	A self- developed validated questionnaire, with overall Cronbach's $\alpha = 0.902$	<b>Top 3 needs</b> (p.567) <sup>44</sup> : “knowledge about the disease and treatment,” “symptoms control for patients,” and “support from health-care professionals” <b>The least need</b> (p.567) <sup>44</sup> : “support on funeral”
<b>S7:</b> Sheng et al., 2010 3 villages, Henan (in English)	To learn about PC specific needs of the end-of-life patients with HIV	Qualitative study: focus group	7 end-of-life patients with HIV by purposive sampling	NA	<b>Three aspects of needs:</b> (1) Be accepted without discrimination, especially by professionals (2) Hopes of getting mental care and support from doctors and nurses (3) Additional material support from the government
<b>S8:</b> Deng et al., 2015a 21 hospice centers (in English)	To investigate the expectations and spiritual needs of Chinese hospice patients using the life review method	2–3 times in-depth interview (a life review <sup>e</sup> ) per patient	107 patients with advanced cancer	NA	76.72% reported one expectation. <b>Three expectations/spiritual needs</b> (p.728) <sup>46</sup> : (1) Have a nice day without suffering from pain (2) Wish family health and happiness (3) Fulfill their dreams such as witnessing future family events, and company of their families, etc.
<b>S9:</b> Yan, 2013 8 hospitals, Shanghai (Thesis, in Chinese)	To validated the Palliative care Outcome Scale (POS) and to explore the quality of PC for patients with advanced cancer	A validation and cross-sectional study	300 patients with advanced cancer by convenience sampling	EORTC QOL-C30 POS	<b>Internal consistency reliability:</b> Cronbach's $\alpha > 0.734$ , and correlation coefficient between POS and QOL-C30: 0.574 <b>Total POS score:</b> $16.55 \pm 6.47$ (0–40) <b>Total QOL score:</b> $37.71 \pm 19.75$
<b>S10:</b> Gu et al., 2015a A community hospice care unit, Shanghai (in Chinese)	To investigate the health-care needs of patients with terminal cancer	Cross-sectional survey	134 inpatients with terminal cancer by convenience sampling	Self-designed questionnaire without specifying the psychometric properties	91.8% of the participants were daily life dependent, and 64.2% suffered from pain. <b>Top 3 needs:</b> psychological support (47%), family support and company (51.5%), daily living (31.3%)

<b>S11:</b> Liu et al., 2016 A hospital, Guangxi (in Chinese)	To explore the PC needs and the relevant factors in COPD patients	Cross-sectional survey	108 COPD patients by convenience sampling	POS Modified Borg Scale KPS Hospital Anxiety and Depression scale (HAD)	<b>POS score:</b> 14.10 ± 5.40 (0–40) <b>Dyspnea score:</b> 4.50 ± 1.82 (0–10) <b>KPS score:</b> 60.56 ± 15.46 (0–100) <b>HAD score:</b> 8.36 ± 4.35 and 16.39 ± 7.32 (0–21)
<b>S12:</b> Liu, 2008 A hospital in Shanghai (thesis, in Chinese) <sup>b</sup>	To investigate PC needs of patients with advanced cancer and their caregivers	Cross-sectional survey	115 patients with advanced cancer and 113 caregivers	Self-designed questionnaire with acceptable content validity (no details)	<b>Needs for patients:</b> <b>(1) Psychological needs:</b> families' understanding and support (96.5%), encouragement and support from others (91.3%), and communication needs (87.9%) <b>(2) Physical needs:</b> treatment and rehabilitation information (80.9%) and symptoms control (fatigue: 76.3%, pain: 72.2%, constipation: 62.6%, and nausea and vomiting: 61.7%) <b>(3) Social needs:</b> peer support (54.8%) <b>Needs for caregivers:</b> <b>(1) Psychological needs:</b> communication with patients and professionals (76.1%), expressing undesirable experiences (58.5%) <b>(2) Social needs:</b> treatment information (81.4%) and financial support (67.3%) <b>(3) Education needs:</b> medicine (80.5%), diet (77.0%), and basic caring skills (66.4%)

**Notes:** S<sup>a</sup>: study; b: this study has 3 parts: (1) investigated the utilization status of community health-care services; 2) investigated patients and caregivers' PC needs; and 3) constructed a home-based PC service framework, and only the data of the second part were used in this review. c: All 107 patients completed a life review with 2–3 times in-depth interviews. PC: palliative care. QOL: quality of life.

### 6-2 Palliative Care Implementation (n=19)

Author, Year, Setting, and Language	Aims/Objectives	Study Design	Participants	Intervention	Measurements/Outcomes
<b>S1<sup>a</sup>:</b> Deng et al., 2015b 32 hospice centers (in English)	To evaluate the effects of hospice care on the QOL of patients with advanced cancer	Multicenter, pre–post study	640 patients with advanced cancer	<b>Practitioners:</b> multidisciplinary team (physicians, nurses, and hospice social workers) <b>Intervention (n = 640):</b> home hospice services, including needs evaluation and individual care (physical examination, psychosocial, and spiritual care) <b>Duration:</b> weekly and 3 weeks	<b>Measures</b> <b>QOL:</b> McGill Quality of Life Questionnaire-Hong Kong Chinese (MQOL–HK) <b>Effects: 4 domains</b> (physical, psychological, existential, and support) of <b>QOL (+)</b>

<p><b>S2:</b> Chen et al., 2014 Unclear (in English)</p>	<p>To explore the effects of pain management in patients with cancer who received Clinical Pharmacist-Led Guidance Teams (CPGTs)</p>	<p>Multicenter, controlled clinical trial (CCT)</p>	<p>542 patients with cancer</p>	<p><b>Practitioners:</b> multidisciplinary team (pharmacists, oncologists, oncology nurses, and administrators) <b>Intervention group (n = 269):</b> (1) Establishment and training of team practitioners (2) Pain management: evaluation, therapy selection, monitoring the process of management, providing education, and follow-up (two times per month) <b>Control group (n = 269):</b> only usual pain management <b>Duration:</b> 6-month intervention and 6-month follow-up</p>	<p><b>Measures</b> <b>Pain:</b> Numeric or visual rating scales <b>Side effects</b> <b>QOL:</b> Quality of life scale for cancer patients <b>Effects:</b> <b>Pain:</b> bone pain (+) body pain (+), visceral pain (+) nerve pain (+) <b>Side effects:</b> constipation (+), nausea, and vomiting (+) <b>QOL:</b> overall score (+)</p>
<p><b>S3:</b> Lv et al., 2014 A hospital, Xi'an (in English)</p>	<p>To describe the implementation of PC for peritoneal dialysis patients at end-stage renal failure</p>	<p>Case report</p>	<p>3 patients with end-stage renal failure</p>	<p><b>Case 1:</b> withdrawal of dialysis, pain control, skin care, itching alleviation, preventing increased abdominal pressure, and volume overload <b>Case 2:</b> prevention of abdominal distention and edema, relaxation, and improvement of sleep quality <b>Case 3:</b> prevention of volume overload, intermittent transfusions and clonazepam, a stay with her families <b>Duration</b> (from implementation to death): case 1: 15 days, case 2: 5 days, case 3: 2 months</p>	<p><b>Measures:</b> Comorbidities with Charlson Comorbidity Index (CCI) Nutritional status with subjective global assessment (SGA) KPS HAD <b>Effects:</b> reduced patients' distress improves the quality of life before death (descriptive data).</p>
<p><b>S4:</b> Xiao et al., 2012 A hospice, Fujian (in English)</p>	<p>To evaluate the effects of a life review programme for enhancing the psychospiritual well-being of patients with advanced cancer</p>	<p>A descriptive qualitative design</p>	<p>26 patients with advanced cancer</p>	<p><b>Intervention</b> (n = 26): <b>(1) Life review programme</b> (semi-structure interview): <b>Session 1:</b> reviewing patient's present life, beliefs in heaven and death; <b>Session 2:</b> reviewing adulthood, such as work, sex, family, hardship, relationships, and religion; <b>Session 3:</b> reviewing childhood and adolescence, including school, relationships, fear, grief, and religion (2) Formulation and presentation of a life review booklet to each patient <b>Duration:</b> once a week for 3 weeks</p>	<p><b>Effects:</b> (1) Accepting the unique experiences of their lives (2) Relieving negative emotions (3) Bolstering their understanding of meaning in life (4) Life review booklet was a personal legacy, and it could help their loved ones to remember them.</p>

					(5) Promoting future orientations (preparation for death, leaving words, and funeral)
<b>S5<sup>c</sup>:</b> Xiao et al., 2013 A home-based hospice, Fujian (in English)	To explore the effects of a life review programme on QOL among patients with advanced cancer	Randomized Control Trial (RCT) <b>Methodology quality:</b> MR: √ AC: × Blinding: ×	80 patients with advanced cancer	<b>Intervention group (n = 40):</b> <b>Life review programme</b> <sup>54</sup> : reviewing patients' lives and formulating and presenting the life review booklets to each patient <b>Control group (n = 40):</b> only usual home visits and telephone follow-up <b>Duration:</b> once a week for 3 weeks	<b>Measures:</b> <b>QOL:</b> (1) Self-report single-item scale (the test-retest reliability was 0.86) (2) QOL Concern in the end-of-life questionnaire (Cronbach's $\alpha = 0.6-0.77$ ) <b>Effects:</b> Overall QOL (+) and four dimensions ("support," "negative emotions," "sense of alienation," "existential distress," and "value of life") of QOL: (+)
<b>S6:</b> Huang, & Wang, 2016 A hospital, Hainan (in Chinese)	To explore the effects of special nursing intervention for the family members of patients in PC settings	CCT	101 family members of patients with advanced cancer	<b>Intervention group (n = 49):</b> (1) Health education, especially knowledge about cancer (2) Psychological management: listening and communication (3) Social support: encouraging the social workers to give help (4) Pharmacological treatment if necessary <b>Control group (n = 52):</b> usual care <b>Duration:</b> unclear	<b>Measures:</b> <b>Anxiety:</b> Self-Rating Anxiety Scale (SAS) <b>Depression:</b> Self-Rating Depression Scale (SDS) <b>QOL:</b> EORTC QLQ-C30 <b>Effects:</b> Anxiety and depression (+) Overall QOL and all dimensions ("role function," "cognitive function," "emotional function," and "social function") of QOL (+)
<b>S7:</b> Peng et al., 2005 A hospital, Shenzhen	To explore the effects of social support for patients with advanced cancer	RCT <b>Methodology quality:</b> MR: ×	100 patients with advanced cancer	<b>Intervention group (n = 50):</b> Social support (without explaining any details of the support) <b>Control group (n=50):</b> usual care	<b>Measures:</b> <b>Social support</b>

(in Chinese)	in home-based PC settings	AC: × Blinding: ×		<b>Duration:</b> unclear	<b>QOL:</b> scale of patients with cancer (without specifying the psychometric properties) <b>Effects:</b> Utilization rate of social support (+) QOL: (+)
<b>S8 :</b> Yang et al., 2016 An Oncology hospital, Hu'nan (in Chinese)	To explore the effect of spiritual care for patients with cancer in home-based PC settings	RCT <b>Methodology quality:</b> MR: × AC: × Blinding: ×	90 patients with cancer	<b>Intervention group (n = 45):</b> <b>Spiritual care:</b> 4 times psychological counseling <b>Control group (n = 45):</b> only usual home-based PC <b>Duration:</b> unclear	<b>Measures:</b> <b>Anxiety:</b> SAS <b>Depression:</b> SDS <b>Effects:</b> Anxiety and depression (+)
<b>S9:</b> Lai et al., 2013 A hospital, Shanghai (In Chinese)	To explore the effect of PC for the QOL of patients with advanced cancer	Pre-post study	86 patients with advanced cancer	<b>Intervention (n = 86):</b> basic care, pain assessment and management, psychological care, providing a comfortable environment <b>Duration:</b> 1 month	<b>Measure:</b> <b>QOL:</b> self-rating scale of life quality (SSLQ, without specifying the psychometric properties) <b>Effects:</b> Overall QOL (+)
<b>S10:</b> Li, 2013 A hospital, Qiqihaer (in Chinese)	To explore the effects of PC for the QOL of patients with advanced cancer	RCT <b>Methodology quality:</b> MR: √ AC: × Blinding: ×	86 patients with advanced cancer	<b>Intervention group (n = 43):</b> (1) Needs assessment (2) Symptoms control, including pharmaceutical and non-pharmaceutical methods (3) Psychological support (4) Death education; (5) Family support <b>Control group (n = 43):</b> usual care <b>Duration:</b> 3 weeks	<b>Measures:</b> <b>QOL:</b> EORTC QLQ-C30 <b>Self-designed Satisfaction Scale</b> (Cronbach's $\alpha = 0.836$ ) <b>with three sub-scales</b> (nursing skills, nursing service, and hospital environment) <b>Effects:</b> <b>QOL:</b> Overall QOL and all dimensions ("role function," "cognitive function," "emotional function," and "social function") of QOL (+) <b>Satisfaction:</b> Overall score and two sub-scales



					(nursing skill and nursing service): (+)
<b>S11:</b> He et al., 2005 A hospital, Wuhan (in Chinese)	To explore the effect of PC for the QOL of elderly patients with advanced cancer	RCT <b>Methodology quality:</b> MR: × AC: × Blinding: ×	54 elderly patients with advanced cancer	<b>Intervention group (n = 26):</b> (1) Assessment of pathological and physiological problems (no details) (2) Management of the physical symptoms (3) Psychological care for patients and family members <b>Control group (n = 28):</b> usual care <b>Duration:</b> 3 months	<b>Measures:</b> <b>QOL</b> questionnaire (without specifying the name and psychometric properties) <b>Self-designed symptom questionnaire:</b> emotional problems, chest pain, insomnia, and inappetence psychometric properties <b>Effects:</b> Overall QOL (+) <b>Self-designed questionnaire:</b> fatigue (+), inappetence (+), insomnia (+)
<b>S12:</b> Zhang et al., 2015a A hospital, Jilin (in Chinese)	To explore the effect of PC for the QOL of elderly patients with advanced gastric cancer	RCT <b>Methodology quality:</b> MR: × AC: × Blinding: ×	46 elderly patients with advanced gastric cancer	<b>Intervention group (n = 23):</b> 1) Pain management 2) Psychological support <b>Control group (n = 23):</b> usual care <b>Duration:</b> unclear	<b>Measures:</b> <b>Anxiety:</b> SAS <b>Depression:</b> SDS <b>Effects:</b> Anxiety and depression (+)
<b>S13:</b> Wang, 2009 A hospice unit, Nanchang (in Chinese)	To explore the effect of PC for relieving the symptom of dyspnea in patients with advanced cancer	Pre-post study	40 patients with advanced cancer	<b>Intervention:</b> medicine, health education (breathing skills and skills of relaxation), and psychological care <b>Duration:</b> 20 days and 30–60 minutes/day	<b>Measures:</b> <b>Dyspnea:</b> Dyspnea Assessment Scale without specifying the name and psychometric properties <b>QOL:</b> QOL scale (without specifying the psychometric properties), including appetite, sleep, energy, daily life, and social relationship <b>Effects:</b> <b>Dyspnea:</b> (+)

					<b>QOL:</b> appetite (+), sleep (+), energy (+), daily life (+), social relationship (+)
<b>S14:</b> Zhang et al., 2016b Unclear, Nanjing (in Chinese)	To formulate and test the effect of a handbook of PC for elderly patients with advanced cancer	Pre–post study	30 patients with advanced cancer	<b>Intervention (n = 30):</b> (1) Formulating a handbook of PC including six domains: perceptions of cancer, physical management, psychological support, social support, death education, and bereavement care (2) Giving the handbook to every patient and supervising them to reading (3) Communicating with the patients weekly and organizing family meeting monthly (4) Weekly meeting among nurses and patients <b>Duration:</b> unclear	<b>Measures:</b> <b>QOL:</b> short form 36 questionnaire (SF-36), including 8 domains: physical function, physical role, pain, general health, energy, social function, emotional role, and psychological health <b>Effects:</b> <b>QOL:</b> overall score and physical role, pain, social function, psychological health: (+)
<b>S15:</b> Zhu, et al., 2016 A hospital, Zhejiang (in Chinese)	To construct and evaluate a hospice model in patients with terminal diseases	CCT	118 patients with terminal stage	<b>Intervention group (n = 59):</b> <b>Procedure of the hospice care model:</b> needs assessment and then implementation <b>Content of the hospice care model:</b> death and hospice care education, physical care, psychological care, nutrition care, spiritual care, and bereavement care <b>Control group (n = 59):</b> usual care  <b>Duration:</b> unclear	<b>Measures:</b> <b>Patients' needs satisfaction</b> (ward environment, communication, diagnosis and progression, symptoms control, daily activities, psychological needs, guidance of nutrition, guidance of medicine, spiritual needs, and family accompany) <b>and family members' satisfaction</b> , with Cronbach's $\alpha = 0.822$ <b>Effects:</b> <b>Patients' satisfaction needs</b> (apart from ward environment and symptoms control): (+) <b>Family members' satisfaction</b> (+)
<b>S16:</b> Chen et al., 2008	To investigate the effect of individual nursing for improving	Pre–post study	89 families of patients with advanced	<b>Intervention:</b> individual nursing based on the needs assessment (not any details) <b>Duration:</b> 2 weeks	<b>Measures:</b>

A hospital, Shanghai (in Chinese)	families' emotional status		cancer by convenience sampling		<b>Emotional Questionnaire</b> without specifying the psychometric properties <b>Effects:</b> <b>Negative emotions</b> including depression, aggressive, anxiety, and confusion: (+)
<b>S17:</b> Zhang, et al., 2013 A hospital in Shenzhen (in Chinese)	To explore the effect of the PC of dyspnea in patients with lung cancer	CCT	200 patients with lung cancer	<b>Intervention group (n = 100):</b> (1) Dyspnea assessment (2) Contents of the intervention: promote the air ventilation or use fans; appropriate position, skills of breath exercise, skills of breath relaxation, and oxygen therapy <b>Control group (n=100):</b> usual care <b>Duration:</b> 2 weeks	<b>Measures:</b> <b>Anxiety:</b> SAS <b>Depression:</b> SDS <b>Effects:</b> Anxiety and depression (+)
<b>S18:</b> Yao, et al., 2016 A healthcare community, Shanghai (in Chinese)	To explore the effects of home-based PC for patients with advanced cancer patients and their families	Pre-post study	50 patients with advanced cancer and 50 families	<b>Intervention:</b> (1) Health education about cancer (2) Presenting caring skills to families, such as oral care and skin care (3) Using certain complementary therapies, such as modern era-acupuncture (4) Providing family medical services (5) Providing individual psychological support to patients and families (6) Providing social support <b>Duration:</b> 6 months	<b>Measures:</b> SAS on patients' comfort <b>Anxiety (families):</b> SAS <b>Effects:</b> Patients' comfort level (+) Family members' anxiety (+)
<b>S19:</b> Yang, 2012 A hospital, Hu'nan (thesis, in Chinese)	To investigate the effect of a systematic health education for the QOL of patients with terminal cancer in home-based PC settings	RCT <b>Methodology quality:</b> MR: × AC: × Blinding: ×	200 patients with advanced cancer	<b>Intervention group (n=90):</b> Systematic health education: (1) Giving health education based on patients' knowledge level (booklets and DVD for high level of knowledge and face-to-face education for low levels of knowledge) (2) Offering outpatient services every 7–10 days (3) Group education for families per month <b>Control group (n=110):</b> usual education <b>Duration:</b> 3 months	<b>Measures:</b> <b>QOL:</b> Chinese version QOL scale (Cronbach's $\alpha$ = 0.785) <b>Effects:</b> <b>QOL:</b> overall score and sub-scales (appetite, sleep, pain, and family support): (+)

**Notes:** Sa: study; (+): After intervention, the effect of the intervention group was significantly effective than that of the control group (two-arm study) and/or before intervention (pre-post studies) ( $p < 0.05$ ). MR: methods of randomization; AC: allocation concealment; blinding: methods of blinding for patients, care provider, or outcome assessor. ✓: low risk of bias; ×: high risk of bias; b: S4 and S5 come from the same project. PC: palliative care. QOL: quality of life.

### 3.2.3.5 Category 4: Advanced decision-making such as advance directives

Twelve studies (Gu et al., 2016b; Hong, 2015; Li & Li, 2016; Li et al., 2014; Liu et al., 2015; Wang, 2012; Wang et al., 2012b; Wang et al., 2012a; Wang et al., 2016; Wang, Y. et al., 2011; Zhang et al., 2015b; Zhang et al., 2016c) were identified as falling into the category of ‘advanced decision-making’, with five published in English (Gu et al., 2016b; Liu, et al., 2015; Wang, et al., 2016; Zhang et al., 2015b; Zhang, et al., 2016c) and seven in Chinese (Hong, 2015; Li & Li, 2016; Li et al., 2014; Wang, 2012; Wang et al., 2012b; Wang et al., 2012a; Wang, Y. et al., 2011) (see **Table 3.7**). All focused on investigating the attitudes of patients with cancer, of their families, and/or of the health-care professionals toward advanced decision-making only. More specifically, eight studies (Hong, 2015; Li & Li, 2016; Li et al., 2014; Wang, 2012; Wang et al., 2012b; Wang et al., 2012a; Wang, Y. et al., 2011; Zhang, et al., 2016c) investigated the attitudes toward advanced directives and advance care planning by patients with Cancer (Li & Li, 2016; Li et al., 2014; Wang, 2012; Zhang, et al., 2016c), their family members (informal caregivers) (Li et al., 2014; Li & Li, 2016; Wang, 2012; Wang et al., 2012a; Zhang, et al., 2016c), and health-care professionals (Hong, 2015; Li et al., 2014; Wang et al., 2012b; Wang, Y. et al., 2011). The approval rates of patients, family members, and health-care professionals varied across studies, ranging from 66.7% to 88.3% (Li et al., 2014; Wang, 2012), from 51.4% to 58.0% (Li et al., 2014; Wang, 2012), and from 85.7% to 87.2% (Li et al., 2014; Wang et al., 2012b), respectively. Inconsistent attitudes toward advanced decision-making also existed among health-care professionals (Hong, 2015; Liu et al., 2015). Six studies (Hong, 2015; Liu, et al., 2015; Wang, 2012; Wang et al., 2012b; Wang et al., 2012a; Wang, et al., 2016) explored the attitudes of patients, family members, or health-care professionals toward specific decision-making issues, such as life-sustaining treatment at end of life, and 32.1% of the family members and 41.3% of the patients (Wang, 2012) emphasized that they would choose life-sustaining treatment and ‘try their best’ to save lives. Meanwhile, many health-care professionals were unwilling to use life-sustaining treatments for patients with terminal-stage diseases (68.8%) (Wang et al., 2012b). Similar to patients in many Eastern countries, patients in Mainland China prefer that their family members make the

medical decisions for them, and this preference accounted for up to 97.25% in the study conducted by Gu et al (Gu et al., 2016b).

#### **3.2.3.6 Category 5: Caring for patients at the end of life**

Four articles (Dong et al., 2016; Gu et al., 2015b; Zheng et al., 2013; Zheng et al., 2015) published in English were included in the category of “caring for patients at the end of life,” with one quantitative and three qualitative studies (see **Table 3.8**). Three of these studies (Dong et al., 2016; Zheng et al., 2013; Zheng et al., 2015) explored the experience of health-care professionals two of nurses (Zheng et al., 2013; Zheng et al., 2015) and one of physicians and nurses (Dong et al., 2016) who cared for patients at the end of their life. The most common experiences identified among health-care professionals were ‘experiencing confusion and dilemmas due to cultural sensitivity and self-limitations’ (Dong et al., 2016; Zheng et al., 2015) and ‘experiencing both positive and negative effects on themselves’ (Dong et al., 2016; Zheng et al., 2013; Zheng et al., 2015). All three studies explored experiences of caring for end-of-life patients from the perspectives of health-care professionals. One study (Gu et al., 2015b) explored the preference for the place of death of patients with terminal cancer and their families/informal caregivers, finding that more than half of them preferred to die at home.

**Table 3.7 Characteristics of the included studies on advanced decision-making such as advance directives (Category 4)**

Author, Year, Setting, and Language	Aims/Objectives	Study Design	Participants	Relevant Findings
<p><b>S1<sup>a</sup>:</b> Gu et al., 2016b A Palliative Care Unit (PCU), Shanghai (in English)</p>	<p>To explore the characteristics of decision-making and relevant factors in patients with terminal cancer</p>	<p>Retrospective study, data in 2007–2013</p>	<p>436 patients with advanced cancer</p>	<p>A total of 97.25% patients with cancer preferred that their families make medical decisions for them, especially their spouse (45.6%) and offspring (44.3%). Only 12 patients made the decision of end-of-life by themselves. A sum of 47.3% of the patients received one or more life-sustaining treatments (LSTs), especially artificial nutrition and hydration (ANH) (40.4%) and vasopressors (49.1%), until death. The median time interval from decision-making to the death of the patients was 20.17 hours (range: 4.3–70.2) <b>Factors:</b> patients younger than 65 years old and patients who lived in urban areas were likely to receive LST at the end-of-life.</p>
<p><b>S2:</b> Zhang, et al., 2016c A Cancer Center, Guangzhou (in English)</p>	<p>To investigate the attitudes toward advance directives (ADs) in patients with cancer and their families and its predictors</p>	<p>Face-to face interview and cross-sectional study</p>	<p>424 participants (209 patients with cancer and 215 family caregivers) by convenience sampling</p>	<p>74% of the participants agreed with Ads. More than 80% of the participants agreed that the ADs should be completed when the patients were diagnosed with a life-threatening disease” (p.819) <sup>70</sup>, and less than 10% thought it should be conducted “when they were healthy” (p.819) <sup>70</sup>. 71% of the participants were in favor of the legalization of ADs. <b>Predictors of positive attitudes toward ADs</b> (p.822) <sup>70</sup>: not living with their family members, having a relative long cancer experience, agreeing with disclosure regarding their terminal conditions, having some previous information of ADs, refusing life-sustaining treatment approach, preferring hospice palliative care, and having a low family function</p>
<p><b>S3:</b> Wang, et al., 2016 A hospital, Guangdong (in English)</p>	<p>To investigate the acceptance of do-not-resuscitate (DNR) order and relevant factors</p>	<p>Retrospective study, data in 2004–2014</p>	<p>348 patients with advanced lung cancer</p>	<p>74.7% signed DNR orders by surrogates in the patients’ absence. CPR was performed on 10.3% of the patients with DNR orders. <b>Factors:</b> Patients with poor performance status and relatively long life expectancy (&gt;3 months) were likely to agree with DNR orders.</p>
<p><b>S4:</b> Liu, et al., 2015 A hospital, Luzhou (in English)</p>	<p>To explore the factors that related to end-of-life decision-making from the experience of professionals in ICU</p>	<p>Face-to face in-depth interview</p>	<p>15 professionals (8 physicians and 7 nurses) by purposive sampling</p>	<p>Professionals were unwilling to face LST decisions at the end stage of life and hold negative attitude toward CPR at that time. <b>Four factors that influence the end-of-life decision making</b> were gathered (pp.547–548) <sup>72</sup>: (1) “Negative physician–patient relationships associated with mistrust and even conflict.” (p.547); (2) Cognitive deficiencies; thinking that withdraw LST treatment means abandonment and discontinuation of comfort care to the patients. (3) Policy restrictions and absence of standards and guidelines in abandoning LST. (4) Economic status, which induced two conditions- “being forced to abandon the patient” (p.548) due to the heavy medical cost or overtreatment for rich patients.</p>

<b>S5:</b> Zhang et al., 2015b A cancer center, Shanghai (in English)	To evaluate the factors that associated with CPR selection in China	Retrospective study (case-control study), data in 2007–2012	314 end-of-life patients with cancer	<b>Factors:</b> Male patients, patients younger than 65 years old, and patients who died within one year after the diagnosis of cancer were likely to request for CPR treatment.
<b>S6:</b> Li et al., 2014 A hospital, Shaoguan (in Chinese)	To analyze the attitudes of patients with cancer, professionals, and family members to advance care planning (ACP)	Cross-sectional study with self-designed questionnaires	325 participants (210 professionals, 105 family members and 103 patients with cancer) by convenience sampling	The awareness rates of ACP in patients with cancer, professionals, and family members were 6.8%, 16.7%, and 9.5%, respectively. The agreement rates of the implementation of ACP in patients with cancer, professionals, and family members were 88.3%, 85.7%, and 51.4%, respectively. <b>Most common reason for the agreement:</b> patients considerably suffered, and ACP can help relieve distresses at the end of life. <b>Most common reason for the disagreement:</b> no legalization support, its professionals' responsibility to rescue lives, and ethical issues
<b>S7<sup>b</sup>:</b> Wang et al., 2012a An oncology hospital, Shanghai (in Chinese)	To explore the attitudes toward ADs among the family members of patients with advanced cancer	Face-to face in-depth interview	17 family members by purposive sampling	<b>Four themes about family members' attitudes toward ADs</b> were gathered: (1) Families would support if patients proposed ADs. (2) Difficult to make such a decision for patients although patients might benefit from ADs (3) Cannot make sure the positive effects of ADs due to some deficiency of ADs (4) Have some barriers for the implementation of ADs, such as weak consciousness of ADs in public <b>Attitudes toward LST at end-of-life:</b> (1) Few families would give up life-sustaining treatment. (2) Most families felt difficult to make a decision and choose life-sustaining treatments.
<b>S8:</b> Li, & Li, 2016 A hospital, Xinjiang (in Chinese)	To explore the influential factors of ADs in patients with advanced cancer and their families	Cross-sectional study with self-designed questionnaires	220 participants (100 patients with advanced cancer and 120 families) by an unclear sampling method	The agreement rate of ADs in patients was higher than that of family members. Family members' educational level, religion, and experience of bereavement were related to the agreement rate of ADs. <b>Most common reason for the agreement:</b> patients considerably suffered, and ACP can help relieve distresses; its patients' autonomous right. <b>Most common reason for the disagreement:</b> ethical issues
<b>S9:</b> Wang et al., 2011 A hospital, Shanghai (in Chinese)	To explore the attitudes of oncology professionals toward ADs for patients with advanced cancer	Face-to face in-depth interview	8 oncology professionals by purposive sampling	<b>Accepted ADs positively:</b> although ADs can help improve patients' QOL; help family members to relieve financial and ethical burden; optimize the medical resource allocation; understand medical science rationally <b>Have some barriers for the implementation of ADs:</b> traditional Chinese cultural, lack of legalization support, weak consciousness of public, and barriers from families <b>Preliminary implementation with some countermeasures:</b> communicate with families first, strengthen death education, and call for legislation and policy support
<b>S10<sup>b</sup>:</b> Wang et al., 2012b	To investigate professionals' attitudes toward	Cross-sectional study with self-	109 oncology professionals by	A total of 87.2% of the professionals hold positive attitudes toward ADs. A total of 65.1% of the professionals agreed to tell patients the truth of diagnosis and prognosis of their diseases, and 98.2% thought that informing patients the truth was a complex process.

An oncology hospital, Shanghai (in Chinese)	ADs and its relevant factors	designed questionnaires	convenience sampling	A total of 68.8% of the professionals did not agree with LST, such as CPR. <b>Factors:</b> department, education levels, and marital status
<b>S11<sup>b</sup>:</b> Wang, 2012 An oncology hospital, Shanghai (thesis, in Chinese)	To investigate the preference for ADs about LST among patients with advanced cancer and their families	Cross-sectional study with self-designed questionnaires	187 participants (75 patients and 112 families) by convenience sampling	<b>The agreement rates toward ADs</b> were 58% and 66.7% for families and patients, respectively. <b>Attitudes toward LST at end of life:</b> 32.1% of families and 41.3% of patients would select LST. <b>Factors:</b> educational level and religious belief.
<b>S12:</b> Hong, 2015 Zhejiang, (Thesis, in Chinese)	To explore professionals' attitudes toward the implementation of ACP in patients with end-stage diseases and its potential barriers	Face-to face in-depth interview	17 professionals by purposive sampling	<b>Attitudes toward informing patients of their disease conditions were inconsistent:</b> Should inform patients due to patients' right and dignity; should not directly inform patients as doing so would increase patients' psychological burden; to inform or not should depend on actual conditions. <b>Attitudes toward LST at terminal stage:</b> refuse LST based on patients and families' decisions; select LST as life is substantially important. <b>Attitudes toward the feasibility of implementing ACP:</b> it was feasible as it could help relieve patients' distresses, decrease financial burdens, and promote the optimization of medical resources; it was not feasible because it would increase medical disputes. <b>Preliminary implementation with some countermeasures:</b> calling for legislation and improving public's awareness

**Notes:** S<sup>a</sup>: study; b: S7, S10, and S11 came from the same project.



**Table 3.8 Characteristics of the included studies on caring for patients at end-of-life (Category 5)**

Author, Year, & Setting	Aims/Objectives	Study Design	Participants	Relevant Findings
<p><b>S1:</b> Zheng et al., 2015 A Cancer hospital, Tianjing (in English)</p>	<p>To explore the experience of oncology nurses for taking care of dying cancer patients</p>	<p>Face-to-face in-depth interview</p>	<p>28 nurses by purposive sampling</p>	<p><b>Five themes</b> (pp. 291-294) <sup>81</sup>: Fundamental care, spiritual support and maintenance of dignity for dying patients; Families support and family function promotion for family members; Dilemmas due to cultural sensitivity and difficult communication; Feelings of moral distress, self-limitation and negative emotions when caring for the patients; Benefits such as development of personal philosophy on death and life, and professional growth.</p>
<p><b>S2:</b> Dong et al., 2016 A Cancer hospital, Tianjing (in English)</p>	<p>To explore the experience of professionals who care for dying cancer patients</p>	<p>Face-to-face in-depth interview</p>	<p>15 physicians and 22 nurses by purposive sampling</p>	<p><b>Five themes</b> (pp. 191-194) <sup>82</sup>: Felt strong senses of obligation and crisis; Maintain patients' hope and spirit needs; Minimize patients' sufferings and improve their quality of life; Promote patients' family function and help families prepare for the death of patients Dilemmas due to cultural sensitivity, inexperienced in psychological care and professional growth versus negative influence</p>
<p><b>S3:</b> Zheng et al., 2013 A Cancer Institute and Hospital, Tianjing (in English)</p>	<p>To explore the experience of nurse for caring for catastrophic upper gastrointestinal bleeding in patients with hepatocellular carcinoma</p>	<p>Face-to-face in-depth interview</p>	<p>21 nurses by purposive sampling</p>	<p><b>Four themes</b> (pp. 410-413) <sup>83</sup>: "Feelings expressed during the process of rescuing patients: being fearful, stressful and confused; shirking from the event and death even the patients were at the terminal stage of the disease; strong sense of obligation and crisis; and sense of psychological overload and job burnout" "Feelings expressed from succeeding or failing to save the lives of patients: being proud with a high sense of accomplishment; feelings of powerless and guilty when patient bled to death; facing the reality and accepting the fact of patients' death" "Feelings expressed from family members' response to nurses' actions: doing one's best and showing sensitivity; being in doubt and perfunctory as some family members refuse to accept the death of their loved ones" Positive and negative impacts on nurses: nurses' daily life, work (especially for new nurses) and philosophy of life.</p>
<p><b>S4:</b> Gu et al., 2015b A Cancer Center, Shanghai (in English)</p>	<p>To identify the preference of death place in terminally cancer patients and their caregivers</p>	<p>Face-to-face structured interview using questionnaires</p>	<p>522 patient-caregiver dyads</p>	<p><b>Four main findings</b> (p. 837) <sup>84</sup>: 53.6% patients expressed that their preferred place of death was at home while not hospital (39.08%). 51.34% of the caregivers also preferred their loved ones could die at home. 84.10% of the patient and caregiver had a consistent preference (at home). Patients in rural areas, those lived with spouse or families and those with low educational level showed more obvious preference for dying at home.</p>

Notes: S<sup>a</sup>: study.

### **3.2.4 Discussion of the study results and implications for future research**

#### **3.2.4.1 Palliative care education and training**

Although a local palliative care training programme with 6 modules was constructed in one study, several limitations remained. First, the training programme/content was mainly constructed based on the 2-round Delphi study, whereas the results of the other 2 studies (eg, concerning the preferable training contents for nurses and the different training needs of nurses in different hospitals) were not considered. Second, although lay experts play an important role in terms of judging obscure words, ambiguous phrasing, and the validity of the relationship between initial ideas and exact expressions of meaning and wording (Tilden, Nelson, & May, 1990), no fresh nurses on the frontline were recruited to appraise the initial training items. Moreover, the feasibility and effectiveness of the programme were not evaluated by empirical studies. In addition, the content of the programme was based on the health-care context of Shanghai. The development of palliative care in Shanghai takes a relatively leading position in China (Gu et al., 2016a; Ma & Qiang, 2015), as hospice/palliative care units and services have been established and offered in many general hospitals (Gu et al., 2016b; Zhou et al., 2009) and communities there (Wang et al., 2011; Yao et al., 2016). Whether the training programme can be generalized to other places in Mainland China, particularly poor areas with limited health-care support, is unclear. The training programmes identified in this review were only formulated from the perspectives of nurses without having any training components for other health-care professionals. However, palliative care providers are not limited to nurses but include many other multidisciplinary healthcare professionals, such as general practitioners, physicians, oncologists, and pharmacists (Clinical Practice Guidelines for Quality Palliative Care, 2013; World Health Organization, 2002). Therefore, comprehensive education and training programmes that involve multidisciplinary health-care professionals should be developed on the basis of their needs through rigorously designed studies with professional experts and lay experts.

#### **3.2.4.2 Palliative care screening and timely identification**

Palliative care is recommended to be incorporated early into curative treatments when patients are diagnosed with a life-limiting disease (World Health Organization, 2002) or when the palliative care needs of patients are identified (Waller et al., 2008); however, the referral time is late in Mainland China, with the median time interval being less than 1 month before the death of patients. In Mainland China, patients with cancer in palliative care units are commonly transferred from general wards, which means that their cancer diagnoses have generally been confirmed long before their referral to the palliative care units. Late referrals prevent palliative care units from having adequate time to provide specific care services for the achievement of palliative care goals. Therefore, relevant screening checklists or criteria and palliative care needs assessment tools can be used to promote timely referral. In certain palliative care guidelines, comprehensive screening checklists or criteria for referral were pointed out. For instance, “life expectancy of 6 months or less” (p. MS-10) was recommended as one of the major criteria (National Comprehensive Cancer Network, 2016). Screening checklists or criteria like this could be further clarified and validated within the Chinese cultural context. Moreover, prospective observational studies that aim at exploring prognostic factors for predicting life expectancy could be performed in future to develop accurate and context-specific screening models for the timely identification of palliative care services in Mainland China.

In addition to the lack of screening checklists and palliative care needs assessment tools, poor awareness of the early implementation of palliative care among most Chinese patients, families, and health-care professionals may partly contribute to late referrals (Gu et al., 2016a, 2016b). Certain inappropriate notions held by families or physicians, such as palliative care means giving up treatment and waiting for the death of patients, and health-care professionals should try their best to save patients’ lives at all costs and should not stop anticancer treatment until the death of patients (Dong & Ding, 2009; Wang et al., 2004), could also partly result in late referrals. Other potential factors in late referrals in Mainland China might include the heavy clinical workload and the limited number of health-care professionals, the lack of

health-care insurance, and the absence of comprehensive and holistic assessments and standard referral procedures.

### **3.2.4.3 Palliative care needs assessment and implementation**

A good understanding of the needs of patients and relevant factors could provide considerable evidence to health-care professionals as to how to respond to patients' needs (Wen & Gustafson, 2004). Many specific palliative care needs assessment tools, particularly for patients with cancer, have been developed in Western countries [e.g., Needs Assessment Tool: Progressive Disease—Cancer (NAT: PD-C) (Waller et al., 2010) and Problems and Needs in Palliative Care questionnaire (PNPC) (Osse, Vernooij, Schadé, & Grol, 2004, 2007)], but none of them was validated and utilized in the studies included in the current review. Although quality-of-life measurements generally serve as needs assessment tools in clinical management (Awad & Voruganti, 2000), they did not remain tools specifically for needs assessment. The POS was originally designed for palliative care quality evaluations, which might not be the best option for palliative care needs assessment. Thus, specific tools should be developed or validated within the Chinese context to assess a patient's palliative care needs and to further facilitate timely referrals and promote tailored palliative care interventions. The majority of the included studies explored the palliative care needs of patients from patients' own perspectives only. According to the principles of health-care needs assessment, such needs should be assessed from the perspectives of all relevant stakeholders, including patients, informal caregivers, and health-care professionals (Field & Clark, 2001). Furthermore, few of the studies adopted qualitative study designs to explore palliative care needs. Health-care needs are caused by not only physical burdens but also by psychosocial distress, including undesirable mental health experiences, as well as the interactions between physical symptoms and mental health experiences. Apart from quantitative studies, qualitative studies are also necessary. Compared to quantitative approaches, qualitative research could bring the experiences and perspectives of participants that are associated with the target issues to the forefront as qualitative data are by definition more in-depth and detailed and as their scope is usually very broad (Grypdonck, 2006; Britten et al., 2002).

The WHO-recommended palliative care definition highlights the importance of palliative care for family members and patients without cancer (World Health Organization, 2002). However, according to the findings of this review, current palliative care research in Mainland China is still mainly focused on patients with cancer only. Similarly, although many guidelines emphasize that palliative care should be a multidisciplinary support, palliative care providers in majority of the included interventional studies (studies within the category of “palliative care implementation”) were nurses only. Therefore, several studies involving multidisciplinary health-care professionals should be performed in future to address the needs of patients with cancer and other life-limiting diseases and their families. In addition, given the unsatisfactory quality of the current interventional studies of palliative care in Mainland China, numerous rigorous studies should be conducted to fill the identified research gaps in the current studies. **First**, palliative care intervention protocols should be evidence based with their components generated from critical literature reviews, comprehensive needs assessment, and expert consensus. The MRC guidelines (Craig et al., 2011) should be considered when developing and evaluating such complex interventions. **Second**, future research should elaborate more on the needs assessment, the intervention components and procedures, the practitioners, the duration of interventions, and the dynamic adjustment of the interventions to promote the replication of intervention protocols. **Third**, although improving the quality of life of patients and their families/informal caregivers (World Health Organization, 2002) is the goal of palliative care, any other secondary outcomes identified through needs assessments should also be evaluated. **Moreover**, the effectiveness of palliative care intervention protocols should be examined via a series of rigorously designed trials that follow the CONSORT guidelines (Schulz, Altman, & Moher, 2010). **Furthermore**, except for holistic palliative care interventions, considerable attention should be paid to symptom management, particularly the management of symptom clusters in palliative care settings as multiple symptoms commonly occur simultaneously in the form of symptom clusters for patients who suffer from life-limiting diseases (Chen et al., 2012). **In addition**, patients and caregivers as a ‘whole unit’ for interventions (partnership-based) could be considered in future studies, as the health outcomes

of patients and caregivers have been shown to be closely linked to one another (Milbury et al., 2013).

#### **3.2.4.4 Advanced decision-making such as advance directives**

Many palliative care guidelines have emphasized that the discussion of advanced decision-making among patients and their families should be initiated when patients still possess decision-making capacity. However, the acceptance rate of advanced decision-making in Mainland China was low, particularly for family members of patients (51.4%-58.0%). Similar to patients from many Eastern countries, patients in Mainland China always play passive roles during the decision-making process (Kumar & Temel, 2013; Zhang et al., 2016c). The scenario that families help make decisions for their patients is common in Mainland China, for instance, choosing life-sustaining treatment although it might be unnecessary for patients who are at the terminal stage. Given the mistrust in physician–patient relationships and the absence of national policy and guidelines in Mainland China (Liu et al., 2015), health-care professionals generally have to “respect” any decision made by the families and try their best to “save” patients’ lives using many life-sustaining treatments although they generally hold negative attitudes toward such unnecessary life-sustaining treatments. Such an approach is regarded as an appropriate measure in terms of protecting themselves from medical conflicts (Liu et al., 2015). Given the passive decision-making role of patients in Mainland China, additional studies should be conducted to explore culturally tailored advanced decision-making models in Mainland China in future. Moreover, factors that can facilitate or hinder the implementation of advanced decision-making services among Chinese patients should be further examined.

#### **3.2.4.5 Caring for patients at the end of life**

Family members/informal caregivers face the death of their loved ones, and the health outcomes of patients and families/informal caregivers are closely associated with one another (Milbury et al., 2013), and so the experiences and needs of families/informal caregivers should also be explored. However, none of the studies reviewed focused on families/informal caregivers. Moreover, given the poor practices surrounding advanced decision-making and the

lack of relevant legislative support, many ethical and cultural dilemmas arise during the caregiving process of health-care professionals, which makes realizing medically sound and concordant treatment decisions based on the needs of patients and their caregivers difficult. Health-care professionals not only experience positive self-growth but also have compassion fatigue, negative emotions, poor sleep quality, and poor appetite during the caring process (National Comprehensive Cancer Network, 2016). However, relevant studies and support systems were absent in the current palliative care research. As the majority of patients with cancer and their families/informal caregivers preferred to die at home, homebased end-of-life care could be one research direction for future studies, and more studies are needed to obtain considerable reliable evidence.

### **3.3 Summary of the identified research gaps and targeted population for this doctoral research project**

#### **3.3.1 Summary of the research gaps**

The findings of this review corroborate that palliative care has been gradually developing in Mainland China over the past decades, but the current research status of palliative care remains to be at an early stage. The quality and availability of palliative care in Mainland China are suboptimal, and standardized and comprehensive palliative care education and training programmes are lacking. Palliative care needs assessment is commonly ignored in practice and research, and early palliative care referral checklists and procedures and culturally tailored palliative care intervention protocols are scant. Although several potential knowledge gaps to be addressed in future research were identified, palliative care needs assessment is the first step that should be addressed given that appropriate and ongoing needs assessment from the perspectives of patients, informal caregivers, and health-care professionals could support the construction of comprehensive palliative care education and training programmes, the identification of prognostic factors for timely referrals, the development of evidence-based and tailored intervention protocols, and the establishment of culturally tailored palliative care services.

More specifically, the purpose of palliative care education and training programme is to help healthcare professionals and trainees meet the needs of both patients and their families better. In order to make the programmes more tailored and effective, the modules of the education and training should be constructed based on the needs of patients and informal caregivers. Also, needs assessment would contribute to the timely palliative care referral. The time point of palliative care implementation should be based not only on the diagnosis but also on the identifiable needs from the perspectives of patients, as well as their informal caregivers. Palliative care should be provided at any time for any life-limiting disease once the needs of patients are not addressed. Mismatched healthcare or interventions that are inconsistent with patients and caregivers' needs can increase health care expenditure and can even lead to harmful effects (Wen & Gustafson, 2004). Palliative care intervention or services should be tailored on the basis of assessing their needs of both patients and their informal caregivers (Lam et al., 2011; Valery et al., 2015).

### **3.3.2 Rationale for choosing advanced cancer patients and their informal caregivers**

#### **3.3.2.1 A high incidence of cancer in Mainland China**

As mentioned in **Chapter 2**, cancer has become a major health problem throughout the world. About half of the incidence burden of cancer occurs in Asia and nearly half (21.8%) of the burden is attribute to China (Stewart & Wild, 2014). Approximately 2.6 million new cases of cancer are diagnosed every year in China, of which nearly 80% are already at advanced stage (Li et al., 2011). By 2012 (World Health Organization, 2014), death from cancer in China have accounted for 23% of the total deaths.

#### **3.3.2.2 Cancer patients at an advanced stage have different experiences**

As mentioned in **Chapter 2**, the characteristics of cancer have shifted from the predicable rapid progression to the currently long and uncertain condition in terms of the illness trajectory and prognosis (Thorne et al., 2013). The long-term cancer experience and anti-cancer treatments make patients suffer from a wide range of problems including physical, psychological, social, emotional, spiritual and practical issues (Gysels et al., 2004). Cancer



experiences and symptoms of patients are changeable across the stages of the cancer journey, and patients at advanced stage usually experience different symptoms from those in early phases as patients at an advanced stage usually encounter more difficulties in optimising their well-being (Sanson-Fisher et al., 2000; Waller, et al., 2012a).

### **3.3.2.3 Advanced cancer patients and their informal caregivers are a ‘whole unit’**

As justified in **Chapter 2**, informal caregivers are closest to the patients and have to take care of their loved ones for a long period (Chen et al., 2015a). The long-term caregiving process brings both physical and psychological burden to caregivers, especially patients at an advanced stage (Cui et al., 2014a). Many informal caregivers suffer a wide range of problems such as sleep disturbance, anxiety, depression, and practical and financial difficulties (Lambert et al., 2012). Informal caregivers are the ‘fellow sufferers’ of patients (Proot et al., 2004). Informal caregivers’ undesirable problems are closely linked with patients’ well-being (Milbury et al., 2013). Unsolved problems or unmet needs of caregivers not only decrease caregivers’ own quality of life but also make negative impacts on patients’ health outcomes (Hodgkinson et al., 2007). Informal caregivers and advanced cancer patients are therefore a “whole unit” for fighting the illness (Lambert et al., 2012), which is consistent with the concept of ‘patient-and-family-centered’ that advocated by the WHO.

## **3.4 Summary of this chapter**

This chapter presented a systematic review that summarized the current research status of palliative care in Mainland China. Fifty-four studies that fell into any category of the review guide were included and analysed systematically. The review findings showed that the current research status of palliative care in Mainland China remains at an early stage with minimal palliative care services used. Although several knowledge gaps were identified, the first step, which should be addressed, is needs assessment. An appropriate and ongoing needs assessment could provide important information for constructing comprehensive education and training programmes of palliative care, identifying prognostic factors of timely palliative care referral, and developing evidence-based and tailored palliative care services. Although studies on

palliative care needs in Mainland China is limited, a large number of relevant studies have been performed in other countries over the past decades, particularly in developed countries. However, no systematic review regarding the unmet needs of advanced cancer patients and their informal caregivers has been conducted to identify the current research evidence on this issue by following the concept of ‘fellow sufferers’, ‘a whole unit’, and ‘patient-and-family-centered care’. In order to have a better understanding of the palliative care needs assessment, to identify possible limitations from current studies, and to draw implications for this doctoral research project within the context of Mainland China, the doctoral researcher therefore conducted another systematic review regarding the unmet care needs of advanced cancer patients and informal caregivers, and the details of the systematic review will be presented in the next chapter.

**Chapter Four: Systematic Review II: Identification of Research Gaps in Palliative  
Care Needs Assessment**

## **4.1 Introduction**

The domains and prevalence of unmet care needs and its associated factors in advanced cancer patients and their informal caregivers, needs assessment tools commonly used in current studies as well as the limitations of current studies were identified and summarized through a systematic review. The limitations retrieved from the included studies served as potential research gaps of this doctoral research project. Based on the identified unmet needs domains, associated factors of unmet needs and needs assessment tools in current studies, some implications for future research and practice were concluded and used in this doctoral research project regarding the study design, and selection of outcome variables and assessment tools. This chapter will present the systematic review of the current research evidence on unmet needs of advanced cancer patients and their informal caregivers. It consists of four sections. Section 4.1 is a general introduction of this chapter. The whole content of this systematic review will be presented in Section 4.2, which includes study objectives, study methods, review findings (results), discussion of the study results and limitations. Identified implications and research gaps will be displayed in Section 4.3. A summary of this chapter will be shown in Section 4.4. It should be noted that the following systematic review has already been published in an international peer-reviewed journal (Wang et al., 2018b). According to the publisher, the published systematic review is “an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited” (Source: <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-018-0346-9/open-peer-review>). In this doctoral thesis, we slightly modified the major contents, and styles of text citations and reference list of the published systematic review to fit the structure and organization of this doctoral thesis.

## 4.2 Systematic review: Unmet Needs of Advanced Cancer Patients and their Informal Caregivers

### 4.2.1 Study objectives

Specific objectives of this review included: (1) to identify the unmet care needs and their associated factors in patients with advanced cancer and their informal caregivers, and (2) to summarize needs assessment tools that were used in the included studies.

### 4.2.2 Methods

#### 4.2.2.1 Search Strategies

With consideration of the language expertise of the review authors, English and Chinese databases were included. Ten databases, including PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBase, Cochrane Central Register of Controlled Trials (CENTRAL), PsycINFO, Web of Science, Wan Fang Data, China National Knowledge Infrastructure (CNKI), Chongqing VIP (CQVIP), and Chinese Biomedical Literature Database (CBM), were searched systematically from inception of each database to December 2016. Restrictions regarding study design were not set. The used MeSH terms, key words, and free words included needs assessment, assessment of healthcare needs, unmet needs, neoplasms, advanced cancer, terminal cancer, metastatic cancer, and the forth. Manual searches were also conducted by examining the reference lists of the included studies. Three representative search strategies of this systematic review are listed in **Table 4.1** below:

**Table 4.1** Selected search strategies

PubMed	
#1	Search (((("needs assessment"[MeSH Terms]) OR "needs assessment"[Title/Abstract]) OR "assessment of healthcare needs"[Title/Abstract]) OR "assessment of health care needs"[Title/Abstract]) OR "unmet needs"[Title/Abstract]
#2	Search (((((((("palliative care"[MeSH Terms]) OR "palliative medicine"[MeSH Terms]) OR "hospice care"[MeSH Terms]) OR "supportive care"[Title/Abstract]) OR "palliative nursing"[Title/Abstract]) OR "palliative care nursing"[Title/Abstract]) OR "terminal care"[Title/Abstract]) OR "hospice nursing care"[Title/Abstract]
#3	Search (((((((("neoplasms"[MeSH Terms]) OR "advanced cancer"[Title/Abstract]) OR "terminal cancer"[Title/Abstract]) OR "metastatic cancer"[Title/Abstract]) OR "tumor"[Title]) OR "cancer"[Title])
#4	#1 AND #2 AND #3
CINAHL	

#1	TI needs assessment OR TI assessment of healthcare needs OR TI assessment of health care needs OR TI unmet needs
#2	AB needs assessment OR AB assessment of healthcare needs OR AB assessment of health care needs OR AB unmet needs
#3	AB palliative care OR AB palliative medicine OR AB hospice care OR AB supportive care OR AB palliative nursing OR AB palliative care nursing OR AB terminal care OR AB hospice nursing
#4	TI palliative care OR TI palliative medicine OR TI hospice care OR TI supportive care OR TI palliative nursing OR TI palliative care nursing OR TI terminal care OR TI hospice nursing
#5	TI neoplasms OR TI tumor OR TI cancer OR TI advanced cancer OR TI terminal cancer OR TI metastatic cancer
#6	AB neoplasms OR AB tumor OR AB cancer OR AB advanced cancer OR AB terminal cancer OR AB metastatic cancer
#7	#1 OR #2
#8	#3 OR #4
#9	#5 OR #6
#10	#7 AND #8 AND #9
EMBase	
#1	'needs assessment'/exp
#2	'needs assessment':ab,ti OR (assessment:ab,ti AND of:ab,ti AND healthcare:ab,ti AND needs:ab,ti) OR (assessment:ab,ti AND of:ab,ti AND health:ab,ti AND care:ab,ti AND needs:ab,ti) OR 'unmet needs':ab,ti
#3	#1 OR #2
#4	'palliative care':ab,ti OR 'palliative medicine':ab,ti OR 'hospice care':ab,ti OR 'supportive care':ab,ti OR 'palliative nursing':ab,ti OR 'terminal care':ab,ti OR 'hospice nursing':ab,ti
#5	'palliative nursing'/exp
#6	#4 OR #5
#7	'advanced cancer'/exp
#8	'neoplasm'/exp
#9	'advanced cancer':ab,ti OR (terminal:ab,ti AND cancer:ab,ti) OR (metastatic:ab,ti AND cancer:ab,ti) OR neoplasm:ab,ti OR cancer:ab,ti OR tumor:ab,ti
#10	#7 OR #8 OR #9
#11	#3 AND #6 AND #10

#### 4.2.2.2 Study identification and data extraction

Duplications were identified and eliminated through a reference management software (NoteExpress). Titles and abstracts of the remaining studies were screened independently by two review authors (WT and TJY), and full text of potentially eligible studies were subsequently located for further screening. Studies satisfying the following inclusion criteria were included: (1) studies that included either adult ( $\geq 18$  years old) patients with advanced cancer or adult informal caregivers of patients with advanced cancer; (2) studies that reported data in terms of unmet care needs or concerns that are directly linked to the unmet care needs

of patients with advanced cancer and/or their informal caregivers, regardless of the study design; and (3) accessible full texts were published in peer-reviewed journals. Exclusion criteria were: (1) studies with mixed sample of patients with cancer at any cancer stage (except those patients with advanced cancer who were analyzed separately); (2) studies solely focusing on quality of life (Harrison et al., 2009), satisfaction with healthcare services, care service utilization, or presence of symptoms/problems; (3) studies focusing on instrument development, translation, or evaluation; and (4) conference articles with only abstracts, editorial comments, guidelines, policies, or treatment recommendations. Data were extracted by two independent review authors. These data included information regarding the first author of the study, year of publication, country of origin, research setting, research design, sampling approach, sample size, need assessment methods (interview or other instruments), prevalence of unmet needs, and related factors for unmet needs. Any disagreement was settled and discussed by the two other review authors (CPM and AM).

#### **4.2.2.3 Methodological quality appraisal of the included studies**

The methodological quality of included studies was assessed by two review authors (WT and TJY) independently with the Mixed Methods Appraisal Tool (MMAT) (Pace et al., 2012). This tool is highly efficient; it takes approximately 14 min to evaluate one study (Pace et al., 2012) with robust consistency among reviewers (intraclass correlation = 0.72 [Pace et al., 2012]); MMAT is specifically designed to assess the quality of either quantitative or qualitative studies. Four different quality criteria for qualitative studies and different types of quantitative studies, including randomized control trials, quantitative nonrandomized trials, and quantitative descriptive studies, were used (Pace et al., 2012). Each criterion was graded as 0 (unmet) or 1 (meet), and the global score of each study was calculated from 0 to 4 (0 = no criterion satisfied, 1 = satisfied one criterion, 2 = satisfied two criteria, 3 = satisfied three criteria, and 4 = satisfied all four criteria). When any disagreement occurred, the review authors conducted a group discussion to reach final agreement.

#### **4.2.2.4 Data analysis**

Content analysis (Hsieh & Shannon, 2005) was used to identify the unmet need domains of patients with advanced cancer and informal caregivers across quantitative and qualitative studies. A priori content categories of patients with advanced cancer were determined on the basis of previous studies; these categories included health system and information, patient care and support, activities of daily living (ADL), physical, psychological, financial, and spiritual (Moghaddam et al., 2016). With regards to informal caregivers, five content categories were determined on the basis of a previous review (Lambert et al., 2012); these categories included cancer care services, information, psychological, spiritual, and social needs. Data of the included studies were compared, combined, and clustered with respect to those domains for patients and informal caregivers. Terms, such as instrumental and personal care, were included in the ADL domain because they were frequently mentioned in several North American studies (Harrison et al., 2009). Summative content analysis was used to identify and extract new categories within content not covered by previous domains. The approach of descriptive analysis was used for the prevalence of unmet needs due to the significant heterogeneity of the included studies (Ryan, 2013). Variables associated with patients and informal caregivers' needs and used instruments were analyzed through descriptive approach.

### **4.2.3 Results**

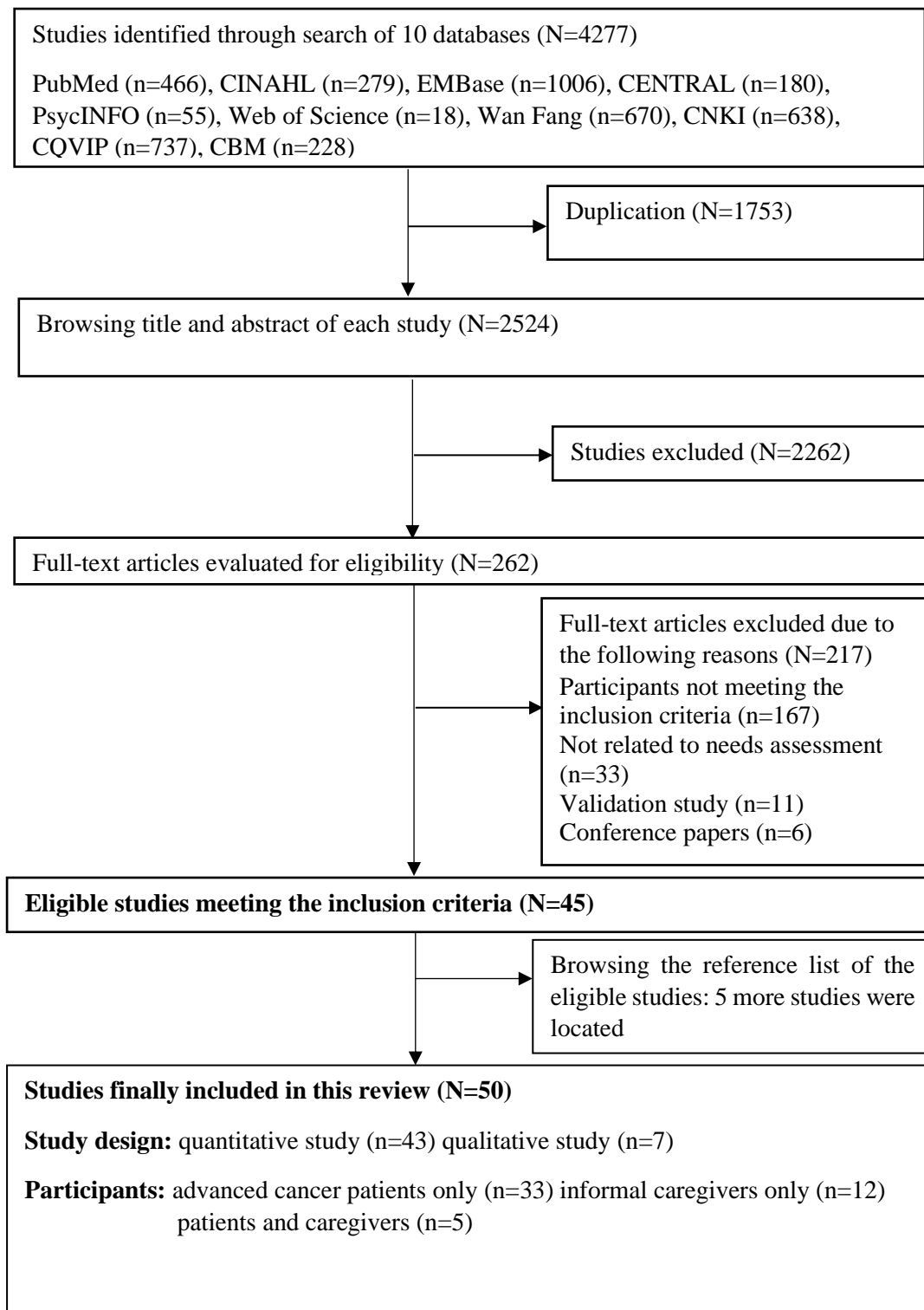
#### **4.2.3.1 Characteristics of the included studies**

Among the 4277 potentially eligible studies, 45 studies were included. After screening the reference lists, five other eligible studies were retrieved. Finally, 50 studies (5 published in Chinese and 45 in English language) were included in this review (see **Figure 4.1**). The majority of the studies (43/50) used quantitative study designs, with 42 surveys (1 longitudinal survey [Lam et al., 2014] and 41 cross-sectional surveys) and 1 (Waller et al., 2012a) pre-post intervention study (only baseline data were used in this review). The seven other studies (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2010, 2011; Dehghan, Ramakrishnan, Uddin-Ahmed, & Harding, 2012; Lee et al., 2014; Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003; Murray, Kendall, Boyd, Worth, & Benton, 2004; Soelver, Rydahl-Hansen,



Oestergaard, & Wagner, 2014) were qualitative designs with individual in-depth interviews and/or focus group. Among the 50 included studies, 33 studies investigated the unmet needs of patients with advanced cancer only, with 31 out of 33 studies from the perspective of patients, one study from the perspective of informal caregivers, and one from the perspectives of both patients and informal caregivers. Twelve studies (Buck & McMillan, 2008; Carter et al., 2010; Chen et al., 2016; Chen et al., 2008; Cui et al., 2014a; DuBenske et al., 2008; Fukui, 2004; Joad, Mayamol, & Chaturvedi, 2011; Lee et al., 2014; Mangan et al., 2003; Osse et al., 2006; Park et al., 2010) explored the unmet needs of informal caregivers, and five other (Dehghan et al., 2012; Hwang et al., 2003; Liu, 2008; Miu, Cao, & Wang, 2016; Wong et al., 2002) studies investigated the unmet needs of patients with advanced cancer and their informal caregivers. With regards to sample sources, six studies (DuBenske et al., 2008; Houts et al., 1988; Johnsen, Petersen, Pedersen, Houmann, & Groenvold, 2013; Lelorain et al., 2015; Mangan et al., 2003; Park et al., 2010) reported no information regarding the recruitment setting, while in the remaining studies patients, and/or caregivers were mainly recruited from outpatient departments (n = 16), inpatient departments (n = 11), home/home-based care units (n = 10), and mixed settings (n = 7). In terms of cancer sites, 29 studies focused on patients with mixed cancer site and/or their caregivers, 11 studies focused on specific patients with cancer and/or caregivers three studies on prostate cancer (Carter et al., 2010; Templeton, & Coates, 2003; Carter et al., 2011), five studies on breast cancer (Aranda et al., 2005; Au et al., 2013; Dehghan et al., 2012; Lam et al., 2014; Uchida, et al., 2011), and three on lung cancer (Chen et al., 2016; Liao et al., 2011; Murray et al., 2004), while other studies (Chen et al., 2008; Deng et al., 2015b; Fitch, 2012; Huang, Xu, & Peng, 2008; Hwang et al., 2003; Joad et al., 2011; Khan et al., 2012; Waller et al., 2012b) reported no information about cancer types. The diagnostic criteria of advanced cancer were presented in 13 studies (13/50), with five studies (Aranda et al., 2005; Lelorain et al., 2015; Osse et al., 2005, 2006; Waller et al., 2012a) adopting the criteria of cancer with metastasis, and seven studies (Au et al., 2013; Cui et al., 2014a; Johnsen et al., 2013; Lam et al., 2014; Liao et al., 2011; Liu, 2008; Uchida et al., 2011) using the stage III/IV criterion according to TNM staging system. With regards to geographic

distribution, nine studies were conducted in the USA (Buck & McMillan, 2008; Carter et al., 2010; Christ & Siegel, 1990; DuBenske et al., 2008; Houts et al., 1988; Hwang et al., 2003; Hwang et al., 2004; Mangan et al., 2003; Schenker, Park, Maciasz, & Arnold, 2014), seven were in mainland China (six of which were conducted in Shanghai) (Chen et al., 2008; Cui et al., 2014a; Deng et al., 2015b; Gu, Shi, & Yuan, 2015; Liu, 2008; Miu et al., 2016), five in Australia (Aranda et al., 2005; Rachakonda, George, Shafiei, & Oldmeadow, 2015; Rainbird, Perkins, Sanson-Fisher, Rolfe, & Anseline, 2009; Waller et al., 2012a; Waller et al., 2012b), five in the Netherlands (Osse et al., 2005, 2006; Teunissen et al., 2006; Uitdehaag, et al., 2015; Voogt, van Leeuwen, Visser, van der Heide, & van der Maas, 2005), four in Canada (Carter et al., 2011; Fitch, 2012; Khan et al., 2012; Wong et al., 2002;), three in Japan (Fukui, 2004; Hasegawa, et al., 2016; Uchida, et al., 2011), three in Taiwan (Chen et al., 2016; Liao et al., 2011; Lee et al., 2014), two in the UK (Murray et al., 2004; Templeton & Coates, 2003), two in Denmark (Johnsen et al., 2013; Soelver et al., 2014), two in Hong Kong (Au et al., 2013; Lam et al., 2014), and one each in Italy (Morasso et al., 1999), France (Lelorain et al., 2015), South Korea (Park et al., 2010), Spain (Vilalta, Valls, Porta, & Viñas, 2014), Indonesia (Effendy et al., 2015a), the Czech Republic (Bužgová, Hajnová, Sikorová, & Jarošová, 2014), India (Joad et al., 2011), and Bangladesh (Dehghan et al., 2012). Characteristics and main findings of all included studies are presented in **Table 4.2** below:



**Figure 4.1** Flowchart of study selection

**Table 4.2** Characteristics and main findings of the included studies

Studies Regarding Advanced Cancer Patients (n=33)							
Author, Year, & QS	Country/Region	Setting	Study Design	Participants	Diagnosis	Response Rate	Data Collection Method/ Instrument & Findings
S1: Morasso, et al., 1999, QS:3	Italy	Inpatients	Semi-structured interview survey	<b>Sampling:</b> Random sampling <b>Sample size:</b> 94 <b>Age (yr):</b> 64.8±11.1 <b>Gender:</b> 38/89 (F)	Terminal cancer patients (mixed cancer sites)	89/94 (94.7%)	<b>Interviews guide:</b> 5 domains and 41 items: “physiological needs”, “safety needs”, “loved and belonging needs”, “self-esteem needs” and “self-fulfillment needs” (p.404) <b>Unmet needs (p.406):</b> 1) symptoms control (62.8%), 2) occupational functioning (62.1%), 3) emotional support (51.7%), 4) Nutrition (43.2%), 5) sleep (37.1%), 6) self-fulfillment (32.5%), 7) communication (27.7%), 8) information (25.0%), 9) personal care (14.6%), 10) financial support (14.1%) and 11) emotional closeness (13.8%)
S2: Waller, et al., 2012a, QS: 4	Australia	Outpatients	Multiple time points pre-post intervention study <sup>a</sup>	<b>Sampling:</b> unclear (219/613) <b>Sample size:</b> 219 <b>Age (yr):</b> 66.1±10.7 <b>Gender:</b> 91/195 (F)	Advanced cancer patients (extensive local, regional or metastatic) (mixed cancer sites)	195/219 (89.0%)	<b>Supportive Care Needs Survey (SCNS-SF34):</b> 5 domains and 34 items <b>Needs Assessment for Advanced Cancer Patients (NA-ACP):</b> only used 6 items on spiritual needs <b>Moderate-to-high unmet needs:</b> 1) “not being able to do the things you used to do” (33.0%), 2) “concerns about the worries of those close to you” (27.9%), 3) “lack of energy, tiredness” (26.2%), 4) “work around the home” (23.0%), 5) “uncertainty about the future” (21.4%), 6) “pain” (20.9%), 7) “worry that results of treatment are beyond your control” (19.4%), 8) “fears about the cancer spreading” (18.8%), 9) “feeling unwell a lot of the time” (17.3%), and 10) “anxiety” (15.3%)
S3: Teunissen, SC, et al., 2006 QS: 3	Netherlands	Inpatients	Structured interview survey	<b>Sampling:</b> unclear <b>Sample size:</b> 181 <b>Age (median, yr):</b> 18-79 <b>Gender:</b> 101/181 (F)	Advanced cancer patients (mixed cancer sites)	181/181 (100%)	<b>Structured interview with a standard list:</b> 4 domains: emotional needs, social needs, spiritual needs, and functional needs. (p.153) Each item including 2 parts: 1) if the issue is a “problem”; 2) actual wishes to receive professional support were labelled as palliative care needs. (p. 153) <b>Unmet needs:</b> 1) functional support (62.4%), 2) support in coping (57.5%), 3) emotional support (53.1%), 4) support of informal caregivers (34.3%), 5) spiritual support (7.7%), 6) co-ordination of care (9.9%), 7) relational support (9.9%), and 8) support in communication (7.7%).
S5: Osse BHP, et al., 2005, QS: 3	Netherlands	Home-based	Questionnaire survey	<b>Sampling:</b> unclear? <b>Sample size:</b> 112 <b>Age (yr):</b> 58±12.3 (30-87) <b>Gender:</b> 66/94 (F)	Distant metastatic cancer (mixed cancer sites)	94/112 (84.0%)	<b>Problems and Needs in Palliative Care questionnaire (PNPC):</b> 10 domains and 90 items <b>Top 10 unmet needs:</b> 1) “difficulty coping with the unpredictability of the future” (25%), 2) “fear of metastases” (25%), 3) “fear of physical suffering” (24%), 4) “experiencing difficulties in remembering what was told” (24%), 5) “difficulties to accept the disease” (23%), 6) “extra expenditure because of disease” (23%), 7) “fear of

							death” (21%), 8) “frustrations because I can do less than before” (20%); 9) “experiencing loss of control over one’s life” (19%); 10) “fear of treatments” (19%)
S7: Hasegawa, et al., 2016 QS: 3	Japan	Inpatients	Questionnaire survey	<b>Sampling:</b> random sampling <b>Sample size:</b> 45 <b>Age (yr):</b> 66.6±9.8 <b>Gender:</b> 21/45 (F)	Advanced cancer patients (mixed cancer sites)	NR	<b>Supportive Care Needs Survey (SCNS-SF34):</b> 5 domains and 34 items <b>Hospital Anxiety and Depression Scale (HADS)</b> <b>Functional Independence Measure (FIM)</b>  <b>Top 10 Moderate-to-high unmet needs:</b> 1) “Being informed about things you can do to help yourself to get well” (51.1%); 2) “Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up” (51.1%); 3) “Concerns about the worries of those close to you”(44.1%); 4) “Anxiety”(41.8%); 5) “Not being able to do the things you used to do” (37.2%); 6) “Feeling down or depressed” (37.2%); 7) “Being treated like a person not just another case” (34.8%); 8) “Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs” (34.8%); 9) “Hospital staff attending promptly to your physical needs” (34.8%); 10) “Feelings of sadness” (32.5%); 11) “Feelings about death and dying”; (32.5%); 12) “Reassurance by medical staff that the way you feel is normal” (32.5%); 13) “Learning to feel in control of your situation” (32.5%);
S8: Uitdehaag MJ et al., 2015 QS: 4	Netherlands	Outpatients	Questionnaire survey	<b>Sampling:</b> consecutive sampling <b>Sample size:</b> 57 <b>Age (yr):</b> EC: 65±11.8 PBC: 64±12.2 <b>Gender:</b> EC: 2/24 (F) PBC:10/33 (F)	Incurable EC or PBC cancer patients	57/90 (63%), with 24 EC and 33 PBC	<b>Problems and Needs in Palliative Care questionnaire (PNPC):</b> 9 domains and 90 items <b>EORTC QLQ-OES18</b> <b>EORTC QLQ-PAN26</b>  <b>Unmet needs:</b> <b>EC:</b> 1) “fatigue” (21%); 2) “frustration can do less than usual” (21%); 3) “shortness of breath” (17%) <b>PBC:</b> 1) “fear of physical suffering” (34%), 2) “lack of written information” (28%), 3) “fatigue” (22%).
S10: Effendy, C, et al., 2015a QS: 2	Indonesia	Outpatients	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 180 <b>Age (yr):</b> Indonesian: 49.3±10.7 Netherlands: 58±12.3 <b>Gender:</b> Indonesian: 133/180(F) Netherlands: 66/94 (F)	Advanced cancer (mixed cancer sites)	NR	<b>Revised Problems and Needs in Palliative Care questionnaire-short version</b> (PNPC-sv,24 items): adjusted within Indonesian context and deleted 9 items, and 24 items were maintained  <b>Unmet needs:</b> <b>Physical:</b> sweating (76.2%), sexuality (75%), short of breathless (67.3%), pain (66.4%) <b>Autonomy:</b> “difficulties in finding someone to talk to” (82.8%); <b>Psychological:</b> “difficulties showing emotions” (84.4%) <b>Spiritual:</b> “difficulties about the meaning of death” (85.4%) <b>Financial:</b> “extra expenses because of the disease” (72%)
S11:	Spain	Outpatients		<b>Sampling:</b> unclear		NR	<b>Self-designed questionnaire for spiritual needs:</b> 11 domains and 28 items

Vilalta, A, et al., 2014 <b>QS: 3</b>			Questionnaire survey	<b>Sample size: 50</b> <b>Age (yr):</b> Mean 60.9 (33-81) <b>Gender:</b> 19/50 (F)	Advanced cancer (mixed cancer sites)		<b>Top 10 spiritual needs</b> (p. 594): 1) “to be recognized as a person until the end of life” (8.6±1.3); 2) “the need for truth” (8.3±2.7); 3) “to reinterpret life” (6.2±1.9); 4) “to look for a meaning to existence” (5.7±2.5); 5) “the need for hope” (5.7±3.5); 6) “to see life beyond the individual” (5.2±2.5); 7) “the need for religious expression” (4.9±2.5); 8) “the needs for continuity and an afterlife” (4.0±2.0); 9) “the need for freedom and to be free” (3.8±3.4); 10) “to be free blame and to forgive others” (1.5±2.0).
S12: Schenker Y. et al., 2014 <b>QS: 3</b>	USA	Outpatients	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 169 <b>Age (yr):</b> 62.3±11.6 <b>Gender:</b> 107/169 (F)	Advanced cancer (mixed cancer sites)	169/272 (62.1%)	<b>Adapted Needs Assessment of Advanced Cancer Patients (NA-ACP):</b> 32 items and 6 domains, without reporting psychological properties <b>Unmet needs:</b> 1) symptom (62%); 2) psychological (62%); 3) medical communication/information (39%); 4) daily living (27%); 5) spiritual (23%); 6) social (20%)
S16: Uchida M, et al., 2011 <b>QS: 4</b>	Japan	Outpatients	Questionnaire survey	<b>Sampling:</b> random sampling <b>Sample size:</b> 85 <b>Age (yr):</b> 58.6±11.9 <b>Gender:</b> 85/87 (F)	Advanced breast cancer patients (stage IV)	85/87 (97.7%)	<b>Supportive Care Needs Survey (SCNS-SF34):</b> 5 domains and 34 items <b>Hospital Anxiety and Depression Scale (HADS)</b> <b>EOERC-QLQ-C30</b> <b>Top 10 moderate-to-high unmet needs:</b> 1) “Fears about the cancer spreading” (78.8%); 2) “Worry that the results of treatment are beyond your control” (71.8%); 3) “Concerns about the worries of those close to you” (68.2%); 4) “Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up” (67.1%); 5) “Being informed about things you can do to help yourself to get well” (65.9%); 6) “Anxiety” (65.9%); 7) “Feeling down or depressed” (62.4%); 8) “Uncertainty about the future” (62.4%); 9) “Feeling about death and dying” (62.4%); 10) “Having access to professional counseling if you, family or friends need it” (57.6%);
S17: Liao YC, et al., 2011 <b>QS: 3</b>	Taiwan	Mixed	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 152 <b>Age (yr):</b> 60.2±11.0 <b>Gender:</b> 73/152 (F)	Advanced lung cancer patients (95.4% stage III-IV or extensive metastasis)	152/188 (80.9%)	<b>Cancer Needs Questionnaire (CNQ)-Chinese version:</b> 5 domains and 32 items <b>Hospital Anxiety and Depression Scale (HADS)</b> <b>Symptom Severity Scale (SSS)</b> <b>Items of highest unmet needs by each domain:</b> 1) “things helping self get well” (65.8%), 2) “cancer remission” (63.8%), 3) “benefit and side-effects of treatment” (63.8%), 4) “test results as soon as possible” (62.5%); 5) “dealing with fears about disease spreading and return” (40.2%), 6) “doctor acknowledges and shows sensitivity to your feelings and emotional needs” (39.5%), 7) “dealing with lack of energy and tiredness” (28.3%)

S18: BUŽG OVÁ, et al., 2014  <b>QS: 2</b>	Czech Republic	Inpatients	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 93 <b>Age (yr):</b> 61.6±16.8 <b>Gender:</b> 41/93 (F)	Advanced cancer (mixed cancer sites)	NR	<b>Patient Needs Assessment in Palliative Care (PNAP):</b> 5 domains and 42 items <b>Hospital Anxiety and Depression Scale (HADS)</b> <b>EOERC-QLQ-C30</b> <b>Items of highest unmet needs by each domain:</b> <b>1) Spiritual:</b> “attending religious services or other ceremonies” (44%); <b>2) Autonomy:</b> “continue my usual activities” (38%); <b>3) Social:</b> “being financially secure” (27%); <b>4) psychological:</b> “fear of dependence on help from others” (30%); <b>5) physical:</b> “fatigue” (30%);
S19: Voogt E, et al., 2005  <b>QS: 4</b>	Netherlands	Home-based	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 128 <b>Age (yr):</b> 63.6±10.5 <b>Gender:</b> 66/128 (F)	Advanced cancer (mixed cancer sites)	128/192 (66.7%)	<b>Problems and Needs in Palliative Care questionnaire (PNPC):</b> used the 12 items on information needs <b>Hospital Anxiety and Depression Scale (HADS)</b> <b>Utrecht Coping List</b> to measure disease-specific coping <b>Unmet information:</b> 1) complementary care (93%); 2) alternative medicine (86%); 3) euthanasia: (83%); 4) care settings (78%); 5) Sexuality and cancer (72%); 6) psychological care (71%); 7) cause of cancer (65%); 8) food and diet (44%); 9) helpful devices (33%); 10) organizations that offer help (32%); 11) expected physical (20%); 12) treatment options and side effects (4%)
S20: Johnsen AT, et al., 2013 <b>QS: 4</b>	Denmark	NR	Questionnaire survey	<b>Sampling:</b> random sampling <b>Sample size:</b> 977 <b>Age (yr):</b> mean 64 <b>Gender:</b> 547/977 (F)	Advanced cancer with mixed sites (95% at stage III/IV )	977/1630 (60%)	<b>3-Levels-of-Needs Questionnaire (3LNQ):</b> 12 items <b>Unmet needs:</b> 1) fatigue (35%); 2) physical activities (32%); 3) work and daily activities (29%); 4) worry (31%); 5) sexuality (28%); 6) pain (23%); 7) concentration (25%); 8) depression (24%); 9) dyspnea (19%); 10) nausea (12%); 11) lack of appetite (13%); 12) difficulties with family life and contact with friends (11%)
S21: Houts P, et al., 1988 <b>QS: 4</b>	USA	NR	Semi-structured interview survey (retrospective)	<b>Sampling:</b> stratified random sampling <b>Sample size:</b> 433 <b>Age (yr):</b> ≥20y <b>Gender:</b> unclear	Caregivers of terminal cancer (mixed cancer sites)	433/515 (84.0%)	<b>Self-designed questionnaire of needs in cancer patients,</b> including 14 areas: physical, activities of daily lives, reaction to treatment, nutrition, emotional, life purpose, social, family, financial, insurance, getting health care, medical staff, home health care, and transportation (p. 629) <b>Unmet needs:</b> 1) activities of daily lives (42%); 2) emotional (21%); 3) physical (21%); 4) insurance (19%); 5) financial (15%); 6) medical staffs (20%)
S22: Khan L, et al., 2012 <b>QS: 3</b>	Canada	Outpatients	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 40 (patients= 20, caregivers=20) <b>Age (yr):</b>	Advanced cancer patients and their caregivers	NR	<b>Problems and Needs in Palliative Care- short version (PNPC-sv):</b> 8 domains and 33 items <b>Patients’ unmet needs from their own perspectives:</b> 1) “doing light housework” (25%); 2) “pain” (25%), 3) “fatigue” (25%), 4) “personal transportation” (22.2%); 5) “sleeping problems” (21.1%); 6) “body care, washing,

				Patients: unclear Caregivers: unclear <b>Gender:</b> unclear	(cancer site unclear)		dressing, or toilet" (20%); 7) "fear of metastases" (17.6%); 8) "pricking or numb sensation" (16.7%); 9) "experiencing loss of control over one's life" (16.7%), 10) "fear of physical suffering" (16.7%) <b>Patients' unmet needs from caregivers' perspectives:</b> 1) "sexual dysfunction" (100%); 2) "problems in relationship with life companion" (100%); 3) "finding others not receptive to talking about the disease" (100%); 4) "difficulties to show emotions" (100%), 5) "difficulties to be of avail for others" (100%), 6) "difficulties to accept the disease" (100%), 7) "extra expenditures because of the disease" (100%), 8) "loss of income because of the disease" (100%), 9) "pain" (35%), 10) "fear of physical suffering" (29.4%)
S25: Fitch MI, 2012 <b>QS: 4</b>	Canada	Outpatients	Questionnaire survey	<b>Sampling:</b> convenience sampling <b>Sample size:</b> 69 <b>Age (yr):</b> mean 65y (35-84y) <b>Gender:</b> 34/69 (F)	Advanced cancer patients (cancer sites unclear)	69/106 (65.1%)	<b>Adapted Supportive Care Needs Survey (SCNS):</b> 7 domains and 61 items: information, physical symptoms, psychological, emotional, spiritual, social, and practical, Cronbach's $\alpha=0.35-0.81$ <b>Unmet needs in terms of issues reported by 50% patients:</b> 1) "pain" (63.5%); 2) "fear of pain" (62.9%); 3) "lack of energy" (52.8%); 4) "fear about physical disability or deterioration" (50%); 5) "fear about cancer spreading" (51.4%); 6) "not being able to do things you used to" (46.9%); 7) "decreased appetite" (47.4%); 8) "feeling unwell" (44.7%); 8) "feeling down or depressed" (30%), 9) "not being able to work around at home" (44.2%); 10) "concerns about the worries of those close to you" (29.4%)
S28 : Deng D et al. 2015b <b>QS: 2</b>	China	Home-based	Interview survey	<b>Sampling:</b> unclear <b>Sample size:</b> 107 <b>Age (yr):</b> mean 57y (18-87y) <b>Gender:</b> 58/107 (F)	Advanced cancer patients (cancer sites unclear)	NR	<b>Guided life review</b> (2-3 times in-depth interview) <b>Three expectations (spiritual needs)</b> (p.728): 1) have a nice day without pain (14.3%) 2) wish family health and happiness (37.6%) 3) fulfill patients' dreams (witness future family events, company of their families, etc.) (45.8%)
S29: Rachakonda, et al., 2015 <b>QS: 1</b>	Australia	Inpatients	Questionnaire survey	<b>Sampling:</b> unclear <b>Eligible sample:</b> unclear <b>Sample size:</b> 75 <b>Age (yr):</b> 68±12 <b>Gender:</b> 32/75 (F)	Advanced cancer patients (mixed cancer sites)	NR	<b>Needs Assessment of Advanced Cancer Patients (NA-ACP):</b> 7 domains and 132 items <b>Items of highest unmet needs by each domain:</b> <b>1) symptom</b> "dealing with lack of energy or tiredness" (30.7%); <b>2) psychological</b> "coping with frustration at not being able to do the things you used to do" (24.3%); <b>3) daily livings</b> "getting assistance with preparing meals" (12%); <b>4) social</b> "receiving emotional support from friends and family" (12.2%); <b>5) medical information and communication</b> (9.3-14.9%), "getting information about non-conventional treatments" (14.9%); <b>6) financial</b> "paying the non-medical costs of



							your illness”; (17.3%); <b>7) spiritual</b> “being able to choose the place where you want to die” (11%).
S30: Rainbird K, et al 2009 <b>QS: 3</b>	Australia	Home- based	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 246 <b>Age (yr):</b> 61±11.9 <b>Gender:</b> 131/246 (F)	Advanced cancer patients (mixed cancer sites)	246/418 (59%)	<b>Needs Assessment of Advanced Cancer Patients (NA-ACP):</b> 7 domains and 132 items <b>Items of highest unmet needs by each domain:</b> <b>1) symptom</b> (15-22%) “dealing with loss of appetite” (22%); <b>2) psychological (39-40%)</b> , “coping with fears about the cancer spreading” (40%) and “coping with frustration at not being able to do the things you used to do” (40%); <b>3) daily livings</b> (10-30%), “dealing with doing work around the house” (30%); <b>4) social</b> (10-13%), “being able to express feeling with friends and/or family” (13%); <b>5) medical information and communication</b> (31-35%), “getting information about factors, which could influence the course of the cancer” (35%); <b>6) financial</b> (11-12%), “dealing with concerns about your financial situation” (12%); <b>7) spiritual</b> (11-15%), “being able to choose the place where you want to die” (15%)
S33: Au A, et al., 2013, <b>QS: 4</b>	Hong Kong	Outpatients	Questionnaire survey	<b>Sampling:</b> consecutive sampling <b>Sample size:</b> 198 <b>Age (yr):</b> 53.4±9.74 <b>Gender:</b> 198/198 (F)	Advanced breast cancer patients (stage III/IV)	198/220 (90%)	<b>Chinese version of Supportive Care Needs Survey (SCNS-SF33-C):</b> 4 domains and 33 items: physical and daily living, psychological, sexuality, health system, information and patient support (HSIPS) <b>Hospital Anxiety and Depression Scale (HADS)</b> <b>Memorial Symptom Assessment Scale Short-Form (MSAS-SF)</b> <b>Chinese Patient Satisfaction Questionnaire</b> <b>Top 10 moderate-to-high unmet needs:</b> 1) “Having one member of hospital staff with whom you can talk to about your concerns” (63.7%); 2) “informed about cancer is under control or diminishing” (61.6%); 3) “Informed about things you can do to get well” (58.6%); 4) “Informed about your test results” (51%); 5) “Given written information” (46.9%); 6) “given information about aspects of managing illness and side-effects at home” (39.9%); 7) “adequately information about the benefits and side-effects of treatments” (39.3%); 8) “given explanations of those tests for which you would like explanations” (36.9%); 9) “being treated like a person” (35.4%); 10) “more choice about cancer specialists” (31.8%)
S35: Aranda S, et al., 2005 <b>QS: 4</b>	Australia	Outpatients	Questionnaire survey	<b>Sampling:</b> consecutive sampling <b>Sample size:</b> 105 <b>Age (yr):</b> (34-85, median 57) <b>Gender:</b> 105/105(F)	Metastatic breast cancer	105/172 (61%)	<b>Supportive Care Needs Questionnaire (SCNQ):</b> 5 domains and 59 items <b>Moderate to high unmet needs:</b> <b>1) Psychological needs (24-41%):</b> “concerns about the worries of those close to you” (41%), “uncertainty about the future” (38%), etc.

							<p><b>2)Information needs (26-41%):</b> “informed about things you can do to help yourself get well” (41%), “one member of hospital staff with whom you can talk” (32%), etc.</p> <p><b>3)Physical and daily living needs (25-28%):</b> “pain” (28%), “not being able to do the things you used to” (25%).</p>
S36: Lelorain S, et al., 2015 <b>QS: 2</b>	France	NR	Questionnaire survey	<p><b>Sampling:</b> consecutive sampling</p> <p><b>Sample size:</b> 201</p> <p><b>Age (yr):</b> mean 62</p> <p><b>Gender:</b> 146/201 (F)</p>	Metastatic cancer (mixed cancer sites)	NR	<p><b>Adapted Supportive Care Needs Survey (SCNS):</b> 2 domains and 13 items: psychological dimension, and staff-related dimension. Seven-point scale (1-7): 1= no need at all, 7= a total need of help</p> <p><b>Unmet needs:</b></p> <p><b>1) psychological needs:</b> “being informed about things you can do to help yourself to get well” (3.83±2.24), etc.</p> <p><b>2) staff-related needs:</b> “being informed about your test results as soon as feasible”(3.44±2.27), etc.</p>
S40: Gu WJ, et al., 2015 <b>QS: 3</b>	Shanghai, China	Inpatients	Questionnaire survey	<p><b>Sampling:</b> convenience sampling</p> <p><b>Sample size:</b> 134</p> <p><b>Age (yr):</b> 75.9±10.5</p> <p><b>Gender:</b> 62/134 (F)</p>	Advance cancer (mixed cancer sites)	134/134 (100%)	<p><b>Self-designed questionnaire for needs including 4 parts (26 items)</b> (p. 2656): basic information, quality of life, health care service needs and attitudes towards disease and death</p> <p><b>Needs:</b> 1) psychological (47%); 2) daily living (31.3%); 3) spiritual (13.4%); 4) families’ support and accompany (67.9%); 5) needs of volunteers (18.7%); 6) friends’ support and accompany (59%)</p>
S41: Huang J, et al., 2008 <b>QS: 3</b>	Shanghai, China	Home-based	Questionnaire survey	<p><b>Sampling:</b> random sampling</p> <p><b>Sample size:</b> 113</p> <p><b>Age (yr):</b> 58.31±8.7</p> <p><b>Gender:</b> 54/113 (F)</p>	Advance cancer (cancer sites unclear)	113/116 (97.4%)	<p><b>Self-designed questionnaire for needs including</b> (items: not described)</p> <p><b>Needs on community wards:</b> (pp. 34-35)</p> <p>1) treatment care like transfusion, injection (77%); 2) pain (46.9%); 3) constipation, nausea (45.1%); 4) information about disease (37.2%) and rehabilitation (32.7%), psychological like anxiety (38.9%), sense of fear (20.4%).</p> <p><b>Needs on home-based care:</b></p> <p>1) treatment care like transfusion, injection (71.7%); 2) regular health assessment (43.4%); 3) knowledge about nutrition (31.0%) and care skills (23.9%), pain (36.3%), communication (28.3%).</p> <p><b>Needs on day care center:</b></p> <p>1) treatment care like transfusion, injection (69%); 2) regular health assessment (42.5%); 3) information and education (28.3%) ; 4) communication (18.6%); 5) nutrition (38.9%)</p>
S43: Waller	Australia	Mixed	Multi-center	<b>Sampling:</b> unclear	Advance cancer	36%	<b>Needs Assessment Tool: Progressive Disease-Cancer (NAT: PD-C):</b> 4 sections and 18 items (significant)

A, et al., 2012b <b>QS: 2</b>			questionnaire survey	<b>Sample size:</b> 219 patients NAT: PD-Cs were completed on 120 patients <b>Age (yr):</b> 66.1±10.7 <b>Gender:</b> 90/198 (F)	(cancer sites unclear)		<b>Overall:</b> 80% had at least one concern <b>Patients' well-being:</b> 1) physical:58% 2) daily living: 29% 3) psychological:19%
S44: Templeton & Coates, 2003 <b>QS: 4</b>	UK	Home-based	Structured interview survey	<b>Sampling:</b> unclear <b>Sample size:</b> 90 <b>Age (yr):</b> 71-80 (48.9%) <b>Gender:</b> 90 (M)	Advance prostate cancer	79%	<b>Adapted Toronto Information Needs Questionnaire (TINQ-BC):</b> 5 domains and 29 items <b>Unmet needs:</b> 82.2% of the patients need more information: 1) "side effects of treatment" (66.7%); 2) "how to ease side effects of treatment" (64.4%)
S45: Hwang, S, et al., 2004 <b>QS:3</b>	USA	Mixed	Questionnaire survey	<b>Sampling:</b> consecutive sampling <b>Sample size:</b> 296 <b>Age (yr):</b> median 68 (29-96) <b>Gender:</b> 296 (M)	Advance cancer (mixed cancer sites)	296/312 (94.9%)	<b>14-item unmet needs questionnaire:</b> 5 domains and 14 items <b>Unmet needs:</b> <b>1) physical:</b> 46.1%-80%; <b>2) emotional/social:</b> 10.1%-32.5% <b>3) economic:</b> 6.6%-17.3% <b>4) medical:</b> 12.5%-13.6% <b>5) community:</b> 0-14.3%
S46: Murray, SA, et al., 2004 <b>QS: 4</b>	UK	Outpatients	Semi-structured interview	<b>Sampling:</b> purposive sampling <b>Sample size:</b> 20 <b>Age (yr):</b> median 65 <b>Gender:</b> unclear	Advance lung cancer	NA	Semi-structured interview, 40mins- 2 hours, tape recorded <b>Unmet needs:</b> 1) "fear, distress and uncertainty" (p. 41)" 2) review "what they had achieved, what still needed to be done before death" (p. 42), and establish themselves as they 'really' are" (p. 41) 3) "feeling of loss of control" (p. 42) 4) "hard to find hope," and "questioned their faith wonder why God had not heeded their prayers" (p.42)
S47: Soelver L, et al., 2014 <b>QS: 4</b>	Denmark	Inpatients	Semi-structured interview	<b>Sampling:</b> open and strategic sampling <b>Sample size:</b> 11 <b>Age (yr):</b> median 71.3 (54-86) <b>Gender:</b> 7/11 (F)	Advance cancer (mixed cancer sites)	NA	Semi-structured interview, 30mins- 1 hour <b>Unmet needs</b> (pp. 177-180): 1) professionals failed to provide patients timely information; 2) patients experienced that "professionals failed to give much help in terms of physical and emotional burden"; 3) Not being regarded as a person: "lack of dialogue with professionals make patients feel neglected and uncertain in the sense of belonging"; 4) autonomy: "patients wanted to be

							proactive in problem solving, but did not know how to do”; 5) lack of help for their physical and emotional problem
S48: Cater N, et al., 2011 QS: 2	Canada	Outpatients	Semi-structured focus group and in-depth interview	<b>Sampling:</b> unclear <b>Sample size:</b> 29 <b>Age (yr):</b> mean 75 (59-88) <b>Gender:</b> 29 (M)	Advance prostate cancer	NA	Semi-structured focus group (90-120 minutes) and in-depth interview (30-60 minutes), tape recorded <b>Unmet needs</b> (pp. 191-193): 1) function issues: pain, fatigue, side (e. g., urinary incontinence issues, loss of sexual function, etc.); 2) information needs of treatment, medication, side effects and health care service etc.; 3) emotional distress: sadness, anger, frustration and regret which associated with some unsolved issues about diagnosis and treatment decisions.
S49: Christ, & Siegel 1990 QS: 1	USA	Outpatients	Interview survey	<b>Sampling:</b> unclear <b>Sample size:</b> 200 <b>Age (yr):</b> 45-64 (54%) <b>Gender:</b> 62% (F)	Advance cancer (mixed cancer sites)	NR	Structured in-depth telephone interview (30 minutes) <b>Unmet needs</b> (p. 762): 1) personal: 6%; 2) instrumental: 43%; 3) administrative: 38%; 4) medical: 18%
S50: Lam W. W.T, ET AL., 2014 QS: 4	Hong Kong	Outpatients	Questionnaire survey (longitudinal)	<b>Sampling:</b> consecutive sampling <b>Sample size:</b> 228 <b>Age (yr):</b> 53.4±9.79 <b>Gender:</b> 228 (F)	Advance breast cancer (stage III/IV)	228/262 (87.0%)	<b>Supportive Care Needs Survey- Chinese version (SCNS-SF33):</b> 4 domains and 33 items <b>Hospital Anxiety and Depression scale (HADS):</b> 14 items <b>Memorial Symptom Assessment Scale Short-form (MSAS-SF)- Chinese version:</b> 32 items <b>Top 10 Moderate-to-high unmet needs:</b> 1) “Having one member of staff with whom you can talk to about all aspects of your condition” (64.5 %), 2) “Being informed about cancer which is under control” (60.4 %), 3) “Being informed about things you can do to help yourself to get well” (57.4%), 4) “Being informed about your test results as soon as feasible” (50.8 %), 5) “Being given written information about the important aspects of your care” (42.3 %), 6) “Being adequately informed about the benefits and side effects of treatments before you choose to have them” (42.3 %), 7) “Being given explanations of those tests for which you would like explanations” (37.6 %), 8) “Being treated like a person not just another case” (34.5 %), 9) “Being given information about aspects of managing your illness and side effects at home” (34.2 %), 10) “More choice about which cancer specialists you see” (30.5 %).

Studies Regarding Informal Caregivers (n=12)							
Author, Year, & QS	Region	Setting	Study Design	Participants	Diagnosis	Response Rate	Data Collection Method/ Instrument
S4: Osse BHP, et al., 2006 QS: 3	Netherlands	Home-based	Questionnaire survey	<b>Sampling:</b> unclear? <b>Sample size:</b> 81 <b>Age (yr):</b> mean 54y (28-78y) <b>Gender:</b> 30/76 (F)	Informal caregivers of mixed advanced cancer patients (distant metastasis)	76/81 (93.8%)	<b>Problems and Needs in Palliative Care questionnaire-caregiver form (PNPC-c):</b> 67 items <b>Unmet needs (top 10):</b> 1) “knowing physical signs what I should notice” (25%), 2) “lacking of information in writing” (23%); 3) “fear of an unpredictable future” (22%), 4) “difficulty in coordinating the care of different professionals” (22%), 5) “difficulty in getting access to help from agencies/professional organizations” (22%); 6) “difficulty in getting a second opinion from another doctor” (21%), 7) “how I should handle the patient’s pain” (21%), 8) “extra expenditure because of the disease” (17%), 9) “insufficient adjustment of hospital care to the home situation” (17%), 10) “the possibility to choosing another care provider” (14%) <b>Information needs:</b> information on 1) “the physical problems” (69%), 2) “expectations for the future” (59%), 3) “the possibilities of treatment and side effects” (52%); 4) “euthanasia” (41%); 5) “cause on cancer”(39%), 6) “on nourishment” (37%); 7) “on places and agency that provide help” (30%); 8) “aids to help me” (29%)
S6: Park SM, et al., 2010 QS: 1	South Korea	NR	Questionnaire survey (retrospective)	<b>Sampling:</b> unclear? <b>Sample size:</b> 1662 <b>Age (yr):</b> not report <b>Gender:</b> 1099/1662 (F)	Informal caregivers of mixed advanced cancer patients (patients died)	1662/4042 (41.4%)	<b>Self-designed needs questionnaire:</b> including 5 domains: 1) symptom management, 2) psychosocial support, 3) financial support, (4) community support, including volunteer assistance, and 5) religious support.. (p.701) <b>Unmet needs (p. 703):</b> 1) symptom support (42.8%), 2) financial support (42.7%), 3) psychological support (20.6%), 4) community support (19.7%), and 5) religious support (3.8%)
S9: Chen SC, et al., 2016 QS: 4	Taiwan	Mixed	Questionnaire survey	<b>Sampling:</b> consecutive sampling <b>Sample size:</b> 166 <b>Age (yr):</b> 49.6±12.0 <b>Gender:</b> 71/166 (F)	Informal caregivers of advanced lung cancer patients	166/190 (87.4%)	<b>1) Partners and Caregivers supportive care needs survey (SCNS-P&amp;C):</b> 6 domains and 44 items <b>2) Numerical rating scale (NRS)</b> (0-10, 0= no fatigue or sleep disturbance, 10=worst imaginable): fatigue or sleep disturbance <b>Top 10 unmet needs:</b> 1) “Managing concerns about the cancer coming back (78.3%); 2) “Addressing fears about the person with cancer’s physical or mental deterioration” (72.3%); 3) “Ensuring there is an ongoing case manager to coordinate services for the person with cancer” (71.1%); 4) “Accessing information on what the person with cancer’s physical needs are likely to be” (68.7%); 5) “Accessing information about the person with cancer’s prognosis, or likely outcome” (65.1%); 6)

							<p>“Accessing information about the benefits and side-effects of treatments so you can participate in decision making about the person with cancer’s treatment” (62.1%); 7) “Obtaining adequate pain control for the person with cancer” (61.5%); 8) “Finding out about financial support and government benefits for you and/or the person with cancer” (60.9%); 9) “Understanding the experience of the person with cancer” (58.5%); 10) “Reducing stress in the person with cancer’s life” (56.1%)</p>
S13: Cui J, et al., 2014 a QS: 4	Shanghai, China	Inpatients	Questionnaire survey	<p><b>Sampling:</b> convenience sampling  <b>Sample size:</b> 649  <b>Age (yr):</b> 49.2±13.18  <b>Gender:</b> 369/649 (F)</p>	Family caregivers of mixed advanced cancer patients (stage IV)	649/700 (95.6%)	<p><b>Self-designed needs questionnaire:</b> 7 dimensions and 36 items (p. 567)  Cronbach’s <math>\alpha</math>=0.902</p> <p><b>Scores of Needs</b> (p. 567):  1) “maintaining health” (3.48±1.04); 2) “support from professionals” (4.11±0.84); 3) “knowledge about disease and treatment” (4.37±0.81); 4) “funeral support” (2.85±1.30); 5) “information for hospice care” (3.01±1.14); 6) “psychological support from patients” (3.08±1.18); 7) “symptom control for patients” (4.26±0.95); 8) overall (3.6±0.75)</p>
S14: Fukui S,2004 QS: 2	Japan	Inpatients	Questionnaire survey	<p><b>Sampling:</b> convenience sampling  <b>Sample size:</b> 66  <b>Age (yr):</b> 55.6±12.1  <b>Gender:</b> 46/66 (F)</p>	Family caregivers of mixed advanced cancer patients	66/125 (52.8%)	<p><b>Self-designed information needs questionnaire:</b> 7 items</p> <p><b>Information needs</b> (p. 32):  <b>Disease-related Information</b>  1) Information on disease (54, 82%); 2) Information on treatment (48, 73%); 3) Information on prognosis (43,65%)  <b>Care-related information</b>  1) Patients’ physical care (40, 61%); 2) Patients’ psychological care (33,56%); 3) Family care (31,47%)</p>
S15: Dubenske LL, et al., 2008 QS: 3	USA	NR	Questionnaire survey	<p><b>Sampling:</b> convenience sampling  <b>Sample size:</b> 159  <b>Age (yr):</b> 50.28±12.91  <b>Gender:</b> 159/159 (F)</p>	Informal female caregivers of mixed advanced cancer patients	NR	<p><b>Self-designed Cancer Caregiver Needs Checklist:</b> 9 domains and 104 items</p> <p><b>Information needs</b> (p. 269):  1) Disease/ medical (0.59±0.29); 2) Caregiving (0.56±0.27); 3) Relating with the patient (0.59±0.31)  4) Caregiver well-being (0.41±0.30); 5) Financial/legal (0.28±0.35); 6) Family and close others (0.42±0.33)  7) Future outlook (0.42±0.39); 8) Dying (0.48±0.33); 9) Spirituality (0.19±0.27)</p>
S24: Mangan PA, et al 2003 QS: 3	USA	NR	Qualitative study (focus group)	<p><b>Sample size:</b> 32  Active caregivers (n=17)  Bereaved caregivers (n=15)  <b>Sampling:</b> unclear</p>	Informal caregivers of mixed advanced cancer	56/60 (93.3%)	<p>Semi-structured focus groups interview (audiotaped) and constant-comparative for analysis</p> <p><b>Unmet needs</b> (p. 247):  1) Medical care such as provision of information, coordination of care; 2) quality of life (caregiver well-being including physical and emotional, caregivers roles); 3) help from</p>

					patients (metastasis)		others (practical assistance and social support) 4) unsolicited needs such as non-professional information needs, impacts on their family
S26: Joad ASK, et al., 2011 QS: 2	India	Mixed	Interview survey with semi- structured questionnaire	<b>Sampling:</b> unclear <b>Sample size:</b> 56 <b>Age (yr):</b> 36 caregivers aged 30-60 <b>Gender:</b> unclear	Family caregivers 3-6 months after the death of patients (cancer sites unclear)	NR	Semi-structured questionnaire <b>Unmet needs</b> (pp. 192-193): 1) <b>Medical needs:</b> “lack of home -care services” (17%); “training in “care giving”” (71%); “need for an admission to a hospice/hospital” (40%). 2) <b>Psychological needs:</b> 1) “felling of tense” (39%); 2) “anxious” (17%); 3) “depressed” (32%); 3) <b>Financial needs:</b> “need financial help from other families or friends” (55.6%); 4) <b>Information needs:</b> “help in communicating disease status and prognosis with their loved one” (35%); 5) <b>Social needs:</b> “lack of social life” (71.4%); “affected the relationships and interactions with others” (42.9%)
S27: Buck HG, et al., 2008 QS: 2	USA	Home- based	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 110 <b>Age (yr):</b> 64.7±14.6 <b>Gender:</b> 83/110 (F)	Informal caregivers of mixed advanced cancer patients	NR	<b>Spiritual Needs Inventory (SNI):</b> 17 items <b>Top 10 unmet needs of each item:</b> 1) “be with family” (20%); 2) “laugh”(16%); 3) “be with friends”(12%); 4) “see smiles of others”(12%), 5) “think happy thoughts”(11%), 6) “be around children” (10%); 7) “go to religious services” (10%); 8) “talk about day-to-day things” (8%); 9) “read inspirational materials” (8%), 10) “talk with someone about spiritual issues” (6%)
S32: Carter N, et al., 2010 QS: 3	USA	Mixed	Qualitative study (semi- structured in-depth interview and focus group)	<b>Sampling:</b> unclear <b>Sample size:</b> 19 (16 wives, 3 children) <b>Gender:</b> unclear	Family caregivers of advanced prostate cancer	NA	Semi-structured in-depth interview (40-90mins) and focus group (60-90mins), audiotaped <b>Needs</b> (pp. 167-168): 1) information needs regarding disease, treatment, side effects and care services, etc. 2) “uncertainty about the future” 3) caregiver burden including supporting the physical, functional and emotions needs of patients 4) “practical assistance needs like household chores” 5) “feelings of isolation as lack of social activities”
S37: Lee HTS, et al., 2013 QS: 3	Taiwan	Home- based	Qualitative study (in- depth interview)	<b>Sampling:</b> consecutive sampling <b>Sample size:</b> 44	Family caregivers of terminal cancer patients (mixed cancer sites)	44/49 (89.8%)	In-depth interview with open-ended questionnaire (30-40mins) (tape recorded) <b>Needs:</b> 1) Emotional support from families and professionals including listening, encouragement, etc. 2) Information needs regarding “symptom management, nutrition, concerns about dying, medication and nursing aids” (p. 633).

S39 : Chen HY, et al.,2008 <b>QS: 2</b>	Shanghai, China	Inpatients	Questionnaire survey	<b>Sampling:</b> convenience sampling <b>Sample size:</b> 89 <b>Age (yr):</b> (23-72, median 52.1) <b>Gender:</b> 58/89 (F)	Family caregivers of advanced cancer patients (cancer sites unclear)	89/100 (89.0%)	Self-designed questionnaire (unclear items) <b>Needs (p. 19):</b> 1) prognosis of disease (100%); 2) help to realize patient's wishes(100%); 3) continuous support after discharge from hospital(100%); 4) knowledge of self-care(100%); 5) relevant knowledge of disease(98.9%); 6) regular counseling service (84.3%); 7) emotional support(69.7%); 8) pain management of patients(59.6%); 9) accompany (50.6%)
<b>Studies Regarding Both Advanced Cancer Patients and Their Informal Caregivers (n=5)</b>							
<b>Author, Year &amp; QS</b>	<b>Region</b>	<b>Setting</b>	<b>Study Design</b>	<b>Participants</b>	<b>Diagnosis</b>	<b>Response Rate</b>	<b>Data Collection Method/ Instrument &amp; Findings</b>
S23: Dehghan R, et al., 2012 <b>QS: 4</b>	Bangladesh	Outpatients	Qualitative study (in-depth interview)	<b>Sampling:</b> convenience sampling <b>Sample size:</b> 20 Patients (n=3), Family members (n=9), Clinical staffs (n=8)	Advanced breast cancer and family members	NA	Semi-structured in-depth interview with open-ended questions (tape recorded) and qualitative description for analysis <b>Needs (pp. 147-148):</b> 1) "social needs of patients and families" due to financial impact, economic uncertainty and needs for social security; 2) "psychological and spiritual needs of patients and families": feeling of sadness, anxiety, anger, abandonment, fear and hopeless; 3) "need for information among patients and families". 4) "Access to and receipt of care from professional systems and providers"
S31: Wong R.K.S, et al, 2002 <b>QS: 2</b>	Canada	Outpatients	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 144 Patients: n=71 Caregivers: n=73 <b>Age (yr):</b> Patients: unclear Caregivers: unclear <b>Gender:</b> unclear	Mixed advanced cancer patients and their caregivers	144/264 (55%)	<b>Advanced Cancer Information Needs Survey (ACIN): 22 items</b> <b>Needs for patients:</b> 1) "pain control" (75%), 2) "weakness and fatigue" (58%), 3) "shortness of breath" (52%), 4) "what cause cancer" (48%), 5) "home care services" (46%), 6) "communicating with loved ones" (46%) <b>Needs for caregivers:</b> 1) "pain control" (82%), 2) "weakness and fatigue" (66%), 3) "home care services" (58%), 3) "what cause cancer" (53%), 4) "how can we prevent cancer" (58%), 5) "why are some cancers not curable" (56%)
S34 : Hwang SS, et al., 2003 <b>QS: 4</b>	USA	Mixed	Questionnaire survey	<b>Sampling:</b> consecutive sampling <b>Sample size:</b> 100 <b>Age (yr):</b> (27-85, median 62) <b>Gender:</b> unclear	Informal caregivers of advanced cancer patients (cancer sites unclear)	100/ 149 (67.1%)	<b>The Family Inventory of Needs (FIN): 20 items</b> <b>Caregiver's Perception of Patients' Unmet Needs (PPUN): 14 items</b> <b>Perception of Patients' Unmet Needs (PPUN):</b> 1) physical (80%), 2) nutritional (51%), 3) daily living (44%), 4) emotional (33%). <b>Caregiver unmet needs (FIN):</b> 1) "having information about what to do for the patient at home" (37%); 2) "knowing when to expect symptoms to occur" (31%); 3) "being told about people who could



							help with problems” (26%); 4) “knowing the probable outcome of the patient’s illness” (26%)
S38: Liu Y, 2008 QS: 3	Shanghai, China	Home-based	Questionnaire survey	<b>Sampling:</b> convenience sampling <b>Sample size:</b> 400 <b>Age (yr):</b> Patients:60.61±12.67 Caregivers: 56.04±12.57 <b>Gender:</b> Patients:63/115(F) Caregivers:29/113(F)	Mixed cancer patients at stage III/IV and their caregivers	228/400 (57%) (patients:15, caregiver:113)	<b>Self-designed needs questionnaire for advanced cancer patients and their caregivers</b> <b>Needs for patients</b> (pp. 30-31): <b>1) psychological:</b> families’ understanding and support(96.5%), etc. <b>2) Physical care:</b> information of treatment, rehabilitation (80.9%), etc. <b>3) Social:</b> peer activities and support (54.8%), etc. <b>Needs for caregivers</b> (p. 38): <b>1) psychological:</b> communication with families and professionals (76.1%), etc. <b>2) social:</b> information about treatment and prognosis(81.4%) etc. <b>3) educational:</b> medication guidance(80.5%) etc.
S42: Miu J, et al., 2016 QS: 2	Shanghai, China	Inpatients	Questionnaire survey	<b>Sampling:</b> unclear <b>Sample size:</b> 42 (42 patients and 42 family caregivers) <b>Age (yr):</b> Patients:72.9±11.6 Caregivers: 55.9±13.45 <b>Gender:</b> Patients:18/42 (F) Caregivers:23/42 (F)	Mixed advanced cancer patients and their caregivers	42/45 (93.3%)	<b>Self-designed needs questionnaire for advanced cancer patients and their caregivers</b> (Liu, 2008) <b>Needs for patients</b> (p. 2387): 1) “families’ understanding and support” (2.43±0.59); 2) “relieving constipation” (2.38±0.62) 3) “psychological support for caregivers after the death of themselves” (2.36±0.66); 4) “pain assessment” (2.33±0.61); 5) “pain management” (2.31±0.64); 6) “improving appetite” (2.31±0.6) <b>Needs for caregivers:</b> 1) “dietary and nutrition” (2.38±0.66); 2) “guidance about how to help patients do activities” (2.38±0.66); 3) “pain assessment” (2.38±0.73); 4) “communication between families and professionals” (2.36±0.58); 5) “information about treatment and prognosis” (2.33±0.65)

**Notes 1:** QS: overall quality score; ADL: Activities of daily living; M: male; F: female; G1: group1; G2: group2; G3: group3; EC: Oesophageal; PBC: Pancreaticobiliary; EORTC QLQ-OES18: EORTC QLQ-Oesophagus (OES) 18 (oesophagus cancer module) questionnaire; EORTC QLQ-PAN26: EORTC QLQ-Pancreatic (PAN) 26 (Pancreatic cancer module) questionnaire; EORTC QLQ-C30: European Organisation for Research and Treatment of Cancer Quality of Life Core 30; a: only the baseline data was used in this review.

**Notes 2:** in the “Data Collection Method/ Instrument & Findings” column, direct quotations from several included quantitative studies using commonly utilized research scales with documented psychometric properties were details of each of the used research questionnaire items. Thus, information regarding page numbers was not provided, but that for direct quotations from studies using self-designed semi-structured questionnaires and/or qualitative methods, as well as page numbers for such quotations, was provided.

#### 4.2.3.2 Quality of the included studies

The methodological quality of the included studies was generally robust, with 17 and 18 studies satisfying all four criteria (34%) and three of the four criteria (36%), respectively. The prominent weaknesses of 43 quantitative studies were poor sampling strategy and low response rate. The response rates of 16 studies (Bužgová, et al., 2014; Buck & McMillan., 2008; Christ & Siegel, 1990; Deng et al., 2015b; DuBenske et al., 2008; Fukui, 2004; Hasegawa et al., 2016; Khan et al., 2012; Lelorain et al., 2015; Liu, 2008; Park et al., 2010; Rachakonda et al., 2015; Rainbird et al., 2009; Vilalta et al., 2014; Waller et al., 2012b; Wong et al., 2002) were lower than 60%, and 14 studies (Buck & McMillan, 2008; Bužgová et al., 2014; Christ & Siegel, 1990; Deng et al., 2015b; Hwang et al., 2004; Joad et al., 2011; Liao et al., 2011; Miu et al., 2016; Osse et al., 2005, 2006; Park et al., 2010; Rachakonda et al., 2015; Schenker et al., 2014; Waller et al., 2012b) failed to report the sampling method, sampling procedure, or sample size justification. Among the seven other qualitative studies, three studies (3/7, 42.9%) (Carter et al., 2011; Lee et al., 2014; Mangan et al., 2003) failed to interpret how findings were related to the study context, and two studies (2/7, 28.6%) (Carter et al., 2010, 2011) provided no explanation on how the research process was influenced by the researchers. The overall quality score of each study is presented in the first column of **Table 4.2**.

#### 4.2.3.3 Unmet needs of patients with advanced cancer

A total of 12 domains of unmet needs were identified from 34 quantitative and four qualitative studies. These domains included physical, ADL, psychological, health system and information, patient care and support, social, communication, financial, spiritual, autonomy, sexuality, and nutritional needs.

**Unmet patient needs based on quantitative studies.** Study sample sizes ranged from 40 to 977, with the average sample size being 165 and the response rate ranging from 36 to 100%. Physical needs were reported in 24 studies, and the most prominent physical unmet need was fatigue (Bužgová et al., 2014; Fitch 2012; Hasegawa et al., 2016; Johnsen et al., 2013; Khan et al., 2012; Liao et al., 2011; Liu et al., 2008; Osse et al., 2005; Rachakonda et al., 2015;

Uitdehaag et al., 2015; Waller et al., 2012a; Wong et al., 2002). In terms of ADL, 11 studies were included, and the most highlighted item was ‘not being able to do the things you used to do’ (Aranda et al., 2005; Au et al., 2013; Fitch 2012; Hasegawa et al., 2016; Waller et al., 2012a). Twenty-eight studies reported psychological needs, and the most common item was ‘emotional support’ (Carter et al., 2011; Effendy et al., 2015a; Fitch 2012; Hasegawa et al., 2016; Houts et al., 1988; Hwang et al., 2004; Johnsen et al., 2013; Morasso et al., 1999; Osse et al., 2005; Soelver et al., 2014; Teunissen et al., 2006; Uchida et al., 2011; Waller et al., 2012a). In terms of health system and information, ‘being informed about benefits and side-effects of treatment’ was the most common one (Huang et al., 2008; Lam et al., 2014; Lelorain et al., 2015; Liao et al., 2011; Liu, 2008; Osse et al., 2005; Rachakonda et al., 2015; Templeton & Coates, 2003; Uchida et al., 2011; Voogt et al., 2005). With regards to patient care and support needs, two prominent unmet needs, namely, ‘reassurance by medical staff that the way you feel is normal’ (Hasegawa et al., 2016; Uchida et al., 2011) and ‘doctor acknowledges and shows sensitivity to your feelings and emotional needs’ (Hasegawa et al., 2016; Liao et al., 2011), were identified. ‘Family and friends’ support’ was the most common social unmet need (Gu et al., 2015; Johnsen et al., 2013; Liu, 2008; Miu et al., 2016; Rachakonda et al., 2015; Rainbird et al., 2009; Teunissen et al., 2006). Communication and financial support needs were also reported (Bužgová et al., 2014; Effendy et al., 2015a; Houts et al., 1988; Huang et al., 2008; Hwang et al., 2004; Liu, 2008; Morasso et al., 1999; Osse et al., 2005; Rachakonda et al., 2015; Rainbird et al., 2009; Teunissen et al., 2006; Wong et al., 2002). ‘Meaning of death’ (Effendy et al., 2015a; Osse et al., 2005) was the most commonly mentioned spiritual need. ‘I can do less than before’ (Bužgová et al., 2014; Osse et al., 2005; Uitdehaag et al., 2015) was the most prominent unmet autonomy need. Detailed unmet needs and their prevalence are presented in **Table 4.3**.

**Unmet patient needs extracted from qualitative studies.** According to four qualitative studies (Carter et al., 2011; Dehghan et al., 2012; Murray et al., 2004; Soelver et al., 2014), several unmet needs that were similar to those identified in quantitative studies were extracted and categorized. For instance, patients commonly expressed ‘pain, fatigue or side effects of

treatment, such as urinary incontinence and loss of sexual function' (p. 191–192) (physical needs) (Carter et al., 2011), 'feelings of fear, hopelessness and uncertainty about the future' (Dehghan, et al., 2012; Murray et al., 2004) or 'feelings of sadness, anger, anxiety, frustration and desperation' (Carter et al., 2011; Dehghan et al., 2012; Murray et al., 2004) (psychological and spiritual needs), 'insufficient information from professional staff' (information needs) (Carter et al., 2011; Dehghan et al., 2012; Soelver et al., 2014), 'need more social security' (social needs) (Dehghan et al., 2012), and 'not being regarded as a person' (p. 178) (healthcare service and information needs) (Soelver et al., 2014). However, the needs in qualitative studies were more detailed than those in quantitative studies, and the specific causes of unmet needs were identified. For example, patients elaborated that 'lack of dialogue with the professionals led some patients to feel neglected and uncertain in their sense of belonging' (p. 178) (Soelver et al., 2014) was the cause of 'not being regarded as a person' (p. 178). Additionally, 'sadness, anger, frustration and regret' resulted from 'some unsolved issues about diagnosis and treatment decisions' (Carter et al., 2011). Several unmet needs identified from the qualitative data were not identified in quantitative studies. For instance, subjects expressed 'what they had achieved in their lives and what still needed to be done before death' (p. 42), 'establish themselves as they "really" are' (p. 41) (spiritual needs) (Murray et al., 2004), and 'patients want to be proactive in problem solving' (p. 179), but they did not know how to do it (autonomy needs) (Soelver et al., 2014).

**Table 4.3** Overall unmet needs domains and prevalence ranges of prominent items by each domain (patients)

Domains	Number of Studies	Subdomains/Items	Prevalence Ranges
Physical	22	Fatigue	<b>18%-76.3%</b> (Waller, et al., 2012a; Osse, et al., 2005; Hasegawa, et al., 2016; Uitdehaag, et al., 2015; Liao, et al., 2011; Bužgová, et al., 2014; Johnsen, et al., 2013; Khan, et al., 2012; Fitch, 2012; Rachakonda, et al., 2015; Wong, et al., 2002; Liu, et al.,2008)
		Pain	<b>18%-75%</b> (Waller, et al., 2012a; Osse, et al., 2005; Hasegawa, et al., 2016;Effendy, et al., 2015a;Johnsen, et al., 2013; Khan, et al., 2012; Fitch, 2012;Wong, et al.,2002;Aranda, et al., 2005;Huang, et al., 2008 )
		Sleep problems	<b>21.1%-37.1%</b> (Morasso, et al., 1999; Khan, et al.,2012)
		Dyspnea	<b>19%-67.3%</b> (Effendy, et al., 2015a; Johnsen, et al., 2013;Wong, et al.,2002)
		Lack of appetite	<b>13%-80%</b> (Johnsen, et al., 2013;Rainbird, et al., 2009;Liu, 2008;Fitch, 2012))
		gastrointestinal symptoms	<b>12%-45.1%</b> (Johnsen, et al., 2013;Huang, et al.,2008)
		‘Felling unwell a lot of the time’	<b>17.3%-44.7%</b> (Waller, et al., 2012a;Hasegawa, et al., 2016; Fitch, 2012)
Activities of Daily Living (ADL)	11	‘not being able to do the things you used to do’	<b>19%-46.9%</b> (Waller, et al., 2012a;Hasegawa, et al., 2016;Au, et al., 2013;Aranda, et al.,2005;Fitch, 2012)
		‘Work around the home’	<b>18.6%-44.2%</b> (Waller, et al., 2012a;Hasegawa, et al., 2016; Rainbird, et al., 2009; Fitch, 2012)
Psychological	25	‘Uncertainty about the future’	<b>21.4%-62.4%</b> (Waller, et al., 2012a; Osse, et al., 2005; Hasegawa, et al., 2016;Uchida, et al., 2011;Aranda,et al., 2005)
		Emotional Support	<b>10.1-84.4%</b> (Waller, et al., 2012a; Morasso, et al., 1999; Teunissen, et al., 2006; Osse, et al.,2005; Hasegawa, et al.,2016; Effendy, et al., 2015a; Uchida, et al., 2011; Johnsen, et al., 2013; Fitch, 2012; Houts, et al., 1988; Hwang, et al., 2004; Soelver, et al., 2014; Carter, et al., 2011) (Anxiety [Waller, et al., 2012a;Hasegawa, et al., 2016]: 15.3-41.8%; Depression [Hasegawa, et al., 2016; Uchida, et al., 2011; Osse, et al., 2005;Fitch, 2012]:15-62.4%)
		‘worry that the results of treatment are beyond your control’	<b>19-71.8%</b> (Waller, et al., 2012a;Au, et al., 2013;Uchida, et al., 2011;Aranda,et al., 2005;Fitch, 2012)
		‘Feeling about death and dying’	<b>32.5-62.4%</b> (Uchida, et al., 2011;Hasegawa, et al., 2016)
		‘Fears about the cancer spreading’	<b>17.6-78.8%</b> (Waller, et al., 2012a;Uchida, et al., 2011;Liao, et al.,2011;Rainbird, et al., 2009;Khan, et al., 2012;Osse, et al., 2005; Fitch, 2012)
		‘concerns about the worries of those close to you’	<b>27.9-68.2%</b> (Waller, et al., 2012a;Hasegawa, et al., 2016;Uchida, et al., 2011;Aranda,et al., 2005; Fitch, 2012)
		‘Support in coping’	<b>24.3-57.5%</b> (Teunissen, et al.,2006;Rachakonda, et al.,2015;Rainbird, et al.,2009)

		‘Learning to feel in control of your situation’	<b>32.5%-56.5%</b> (Hasegawa, et al., 2016;Uchida, et al., 2011)
		‘Fear of physical suffering’	<b>16.7-62.9%</b> (Osse, et al., 2005;Uitdehaag, et al.,2015;Khan, et al., 2012;Effendy, et al., 2015a; Fitch, 2012))
Social	9	family and friends’ support	<b>9.9-96.5%</b> (Johnsen, et al.,2013;Rachakonda, et al.,2015;Rainbird, et al.,2009; Gu, et al., 2015; Teunissen, et al.,2006;Liu,2008;Miu, et al.,2016)
		volunteers	<b>18.7%</b> (Gu, et al., 2015)
Communication	5	Communication	<b>7.7%-87.9%</b> (Morasso, et al.,1999;Teunissen, et al.,2006;Huang, et al.,2008;Wong, et al., 2002;Liu,2008))
Financial	8	Financial	<b>6.6%-72%</b> (Morasso, et al.,1999;Osse, et al., 2005;Effendy, et al., 2015a;Bužgová, et al.,2014;Houts, et al.,1988;Rachakonda, et al.,2015; Rainbird, et al.,2009;Hwang, et al.,2004)
Spiritual	5	Meaning of death	<b>15-85.4%</b> (Osse, et al., 2005;Effendy, et al., 2015a)
		Religious	<b>44%</b> (Bužgová, et al.,2014))
		‘being able to choose the place where you want to die’	<b>11-15%</b> (Rachakonda, et al.,2015; Rainbird, et al.,2009)
Autonomy	5	‘I can do less than before’	<b>17-83%</b> (Osse, et al., 2005; Uitdehaag, et al.,2015;Bužgová, et al.,2014)
		‘experiencing loss of control over one’s life’	<b>16-19%</b> (Osse, et al., 2005;Khan, et al.,2012)
Patients care and support	3	‘Reassurance by medical staff that the way you feel is normal’	<b>32.5-56.5%</b> (Hasegawa, et al., 2016; Uchida, et al., 2011)
		‘doctor acknowledges and shows sensitivity to your feelings and emotional needs’	<b>34.8-39.5%</b> (Hasegawa, et al., 2016;Liao, et al.,2011)
Healthcare service and information	14	‘Being informed about things you can do to help yourself to get well’	<b>41-65.9%</b> ] (Hasegawa, et al., 2016; Uchida, et al., 2011;Liao, et al.,2011;Aranda, et al.,2005;Lam, et al.,2014)
		“Having one member of hospital staff with whom you can talk to”	<b>32-72%</b> (Hasegawa, et al., 2016; Uchida, et al., 2011;Lam, et al.,2014;Au, et al., 2013;Aranda, et al.,2005)
		‘Being informed about your test results as soon as feasible’	<b>50.8-62.5%</b> (Uchida, et al., 2011; Liao, et al.,2011;Lam, et al.,2014)
		‘benefit and side-effects of treatment’	<b>4-66.7%</b> (Osse, et al., 2005;Rachakonda, et al.,2015;Templeton & Coates,2003;Voogt, et al.,2005;Liu, 2008;Huang, et al.,2008;Uchida, et al., 2011;Liao, et al.,2011;Lam, et al.,2014)
		‘Being given written information about the important aspects of your care’	<b>42.3-52.9%</b> (Uchida, et al., 2011;Lam, et al.,2014)
		‘Being treated like a person not just another case’	<b>34.5-54.1%</b> (Vilalta, et al., 2014;Uchida, et al., 2011;Lelorain, et al.,2015;Lam, et al.,2014)
		‘Being informed about cancer which is under control’	<b>54.1-60.4%</b> (Uchida, et al., 2011;Lam, et al.,2014)

Sexuality	4	Sexuality	<b>5-75%</b> (Osse, et al., 2005;Effendy, et al.,2015a;Johnsen, et al.,2013;Au, et al., 2013)
Nutrition	2	Nutrition	<b>38.9-43.2%</b> (Morasso, et al.,1999; Huang, et al., 2008)
Counseling	1		<b>17-24%</b> (Osse, et al., 2005)

**Notes:** Needs items (sentences or phrases) which were put in the quotation marks were directly extracted from the corresponding included studies.

#### 4.2.3.4 Unmet needs of informal caregivers

Seven unmet need domains were extracted on the basis of qualitative (n = 4) and quantitative (n = 13) studies.

**In terms of the quantitative studies**, the sample size ranged from 42 to 1662, with the mean sample size being 259. The response rates ranged from 41.4 to 95.6%. Seven domains, including information, physical, psychological, financial, cancer care service, spiritual, and social needs, were identified. Information domain included two subdomains, namely, illness and treatment and care-related information. Unmet needs regarding illness and treatment information were mentioned in nine studies, and the prevalence ranged from 26 to 100% (Chen et al., 2016; Cui et al., 2014a; DuBenske et al., 2008; Fukui, 2004; Joad et al., 2011; Liu, 2008; Miu et al., 2016; Osse et al., 2006; Wong et al., 2002), Care-related information was reported in 10 studies with the prevalence rate in the range of 21–100% (Chen et al., 2016; Chen et al., 2008; Cui et al., 2014a; DuBenske et al., 2008; Fukui, 2004; Hwang et al., 2003; Joad et al., 2011; Liu, 2008; Miu et al., 2016; Osse et al., 2006 ). With regard to cancer care services, 21–72.3% of the informal caregivers presented unmet needs in terms of quality of care (Chen et al., 2016; Osse et al., 2006; Teunissen et al., 2006), and 14–100% reported unmet needs on transitional care services (Chen et al., 2008; Joad et al., 2011; Osse et al., 2006; Park et al., 2010). The percentages of the five other domains, including physical, psychological, financial, spiritual, and social unmet needs, were 42.8% (Park et al., 2010), 17–78.3% (Chen et al., 2016; Chen et al., 2008; Joad et al., 2011; Liu, 2008; Park et al., 2010), 17–67.3% (Chen et al., 2016; Joad et al., 2011; Osse et al., 2006; Park et al., 2010;), 3.8–100% (Buck & McMillan, 2008; Chen et al., 2008; Osse et al., 2006; Park et al., 2010), and 42.9–71.4% (Joad et al., 2011), respectively. Furthermore, ‘managing concerns about the cancer coming back’ (78.3%) (Chen et al., 2016), ‘finding out about financial support and government benefits for you and/or the person with cancer’ (60.9%) (Chen et al., 2016), ‘help to realize patient’s wishes’ (100%) (Chen et al., 2008) and ‘lack of social life’ (71.4%) (Joad et al., 2011) were reported as the most common psychological, financial, spiritual, and social needs.



**According to four qualitative studies** (Carter et al., 2010; Dehghan et al., 2012; Lee et al., 2014; Mangan et al., 2003), three similar unmet need domains, namely, information, psychological, and social needs, were identified through summative content analysis. Informal caregivers commonly stated about “unmet information needs in terms of disease, treatment, side effects, care services, symptom management, nutrition, medication and nursing aids” (information) (Carter et al., 2010; Dehghan et al., 2012; Lee et al., 2014), ‘feelings of sadness and loneliness, as well as a sense of abandonment, fear and helplessness’ (p. 147) (Dehghan et al., 2012) or ‘insufficient listening and encouragement from other family members and professionals’ (Lee et al., 2014) (psychological), and ‘feelings of isolation due to the lack of social activities’ (social) (Carter et al., 2010). Several specific unmet needs, including the manner of communication between professional staff and caregivers or patients, the administration and function of the healthcare system, and some practical assistance, such as cleaning the house and walking the dog (Mangan et al., 2003), were also identified in qualitative studies (Mangan et al., 2003).

#### **4.2.3.5 Variables associated with the unmet needs of patients with advanced cancer**

Variables associated with the unmet needs of patients with advanced cancer are summarized in **Table 4.4**. Relevant variables were categorized as patient-related variables (demographics, disease-related, physical, and psychological) and informal caregiver-related variables (age, gender, and psychological distress of informal caregivers).

In several studies, age, gender, marital status, education level, and income level were insignificantly associated with patients’ unmet needs. Although a significant relationship was reported, results were inconsistent across studies in terms of age and marital status. With regards to gender, three studies (Hasegawa et al., 2016; Liu, 2008; Morasso et al., 1999) reported that female patients indicated more physical and psychological unmet needs than those of male patients. Patients who were living alone experienced high psychological needs (Morasso et al., 1999), and patients with high educational level presented considerable unmet needs in physical (Liao et al., 2011), ADL (Liao et al., 2011), information (Voogt et al., 2005),

community service (Houts et al., 1988), and sexuality (Au et al., 2013) domains. Moreover, financial needs were less reported in patients with high income (Houts et al., 1988; Liu, 2008). Four studies (Au et al., 2013; Hwang et al., 2004; Lam et al., 2014; Liao et al., 2011) explored the relationships between symptom distress and unmet needs, and all these studies showed that patients with symptom distress experienced more unmet needs in the psychological, physical, and ADL domains. Patients with poor ability in daily living (Morasso et al., 1999) indicated more unmet needs than those of independent patients, especially in terms of information, communication, psychological, and occupational needs. Two studies (Morasso et al., 1999; Hwang et al., 2004) showed that no relationships were observed between the cancer site and their unmet needs, but two other studies (Houts et al., 1988; Liu, 2008) showed opposite results. Two (Lam et al., 2014; Liao et al., 2011) out of five studies reported that no relationship was observed between cancer stage (only stages III and IV) and unmet needs, and three other ones (Au et al., 2013; Hwang et al., 2004; Liu, 2008) indicated that patients with stage IV cancer presented more unmet needs than those with stage III cancer. Results were inconsistent across studies for cancer treatment, with two studies showing no relationship (Liao et al., 2011; Voogt et al., 2005) and two other studies suggesting either positive (Lam et al., 2014) or negative (Au et al., 2013) relationship.

Patients with anxiety experienced high levels of physical, psychological, healthcare, and information, as well as ADL unmet needs, which was confirmed across several studies (Au et al., 2013; Hasegawa et al., 2016; Liao et al., 2011; Uchida et al., 2011; Voogt et al., 2005). Patients with depression (Au et al., 2013; Hwang et al., 2004; Liao et al., 2011; Voogt et al., 2005) demonstrated varied results. Patients with low quality of life showed high unmet needs, especially in physical and psychological domains (Bužgová et al., 2014; Uchida et al., 2011). Patients reported more unmet needs when their caregivers were male (Morasso et al., 1999) young people (Morasso et al., 1999), or those who suffered from psychological distress (Morasso et al., 1999).

#### **4.2.3.6 Variables associated with the unmet needs of informal caregivers**

Older caregivers (Chen et al., 2016; Osse et al., 2006) showed less unmet needs in terms of financial, social, and care-related information needs than those of younger caregivers. Caregivers in different caregiving settings reported different levels of unmet needs (home>general hospital>hospice care unit) (Fukui, 2004; Park et al. 2010). Caregivers with many physical problems experienced many unmet needs (Chen et al., 2016; Liu, 2008). Caregivers had higher levels of unmet needs when patients suffered from anxiety (Chen et al., 2016), depression (Chen et al., 2016), or low physical performance (Chen et al., 2016). Results varied across studies in terms of gender (Osse et al., 2006), length of caregiving (Cui et al., 2014a; Liu, 2008), and education level of caregivers (Liu, 2008) (see **Table 4.5**). Similarly, results were conflicting with regard to the relationships between caregivers and patients. One study (Fukui, 2004) showed that spousal caregivers presented many information needs, and another study (Liu, 2008) indicated that non-spousal caregivers reported many unmet needs.

**Table 4.4** Summary of the variables associated with advanced cancer patients' unmet needs

Study	Demographics						Physical		Disease-related			Psychosocial			Caregiver		
	Older	Female	Living Alone	Married	High Education	High Income	Physical	ADL (dependent)	Cancer Sites	Stage	Treatment	Anxiety	Depression	High QOL	Distress (anxiety/depression)	Older	Female
Morasso, et al., 1999	+	+	+	-	↔			+	↔								
Teunissen et al., 2006	-																
Osse et al., 2005	-(fin, psys.)																
Hasegawa, et al., 2016	↔	+		+								+(phy, psys, ADL)					
Uchida, et al., 2011												+(psy, phy, ADL, HSIPS)		-(psy, phy, ADL, HSIPS)			
Liao et al., 2011	-(psy)	↔			+(phy ADL)		+(phy, psys, ADL)		↔	↔		+(psy, ADL, phy, HSIPS)	-(HSIPS) +(psy)				
Bužgová et al., 2014														-(phy, psy, spiri)			

Voogt et al., 2005	↔	↔		-(info)	+(info)					↔	+(info)	↔				
Houts et al., 1988	-(phy, psys, fin)	↔		↔	+(community)	-(fin)			+/ ↔*							
Au et al., 2013	↔			-(phy, ADL) +(sex)	+	↔	+(phy, ADL, psy, HSIPS)		↔	-(HSIPS)	+(psy)	↔				
Liu, 2008	-(phy)	+(phy)		-(phy, soc)		-			+/ ↔*					+	-(psy)	-(psy)
Hwang et al., 2004	-(phy, fin, med)						+(phy, psy, fin, med)		↔	+		+(psy, fin, med)				
Lam et al., 2014							+(HSIPS, psy, phy, ADL)		↔	+(psy)						

**Notes:** “-”: negative relationship; “+”: positive relationship; “↔”: no significant relationship; “\*”: relationship variable across different types of cancer; “fin”: financial needs; “PM”: pain management; “soc”: social needs; “phy”: physical needs; “psy”: psychological needs; “psys”: psychosocial needs; “inf”: information needs; “com”: communication needs; “occup”: occupational needs; “HSIPS”: health system, information, and patient care support; “med”: medical needs; “spiri”: spiritual needs.

**Table 4.5** Summary of the variables associated with informal caregivers' unmet needs

Study	Demographics of caregivers					Caregivers' physical symptom	Relationship	Patients-related		
	Older	Female	Education level	Length of caregiving	Care setting			Spousal caregivers	Patients' anxiety	Patients' depression
Osse et al, 2006	-(fin, PM, soc,)	F (+phy) M (+ inf)								
Parket al, 2010					Conventional hospital care > hospice care (symptom management, psy support, religious support )					
Chen et al, 2016						+ (overall)		+(overall)	+(overall)	+(overall)
Cui et al, 2014a				-						
Fukui, 2004	-				Home > hospital (inf)		+			
Liu, 2008	-(soc,psy,inf)		-(psy) +(soc)	+(soc)		+	-(inf)			

**Notes:** “-”: negative relationship; “+”: positive relationship; “fin”: financial needs; “PM”: pain management; “soc”: social needs; “phy”: physical needs; “inf”: information needs; “overall”: overall needs

#### 4.2.3.7 Summary of the needs assessment instruments used in the included studies

For patients with advanced cancer, the most commonly used multidimensional instruments were Supportive Care Needs Survey (SCNS,  $n = 8$ ) (Aranda et al., 2005; Au et al., 2013; Fitch, 2012; Hasegawa et al., 2016; Lam, et al., 2014; Lelorain et al., 2015; Uchida et al., 2011; Waller et al., 2012a), Problems and Needs in Palliative Care questionnaire (PNPC,  $n = 5$ ) (Effendy et al., 2015a; Khan et al., 2012; Osse et al., 2005; Uitdehaag et al., 2015; Voogt et al., 2005), and Needs Assessment of Advanced Cancer Patients (NA-ACP,  $n = 3$ ) (Rachakonda et al., 2015; Rainbird et al., 2009; Schenker et al., 2014). Other multidimensional instruments that were adopted included Cancer Needs Questionnaire (CNQ) (Liao et al., 2011), Patient Needs Assessment in Palliative Care (PNAP) (Bužgová et al., 2014), 3-Levels-of-Needs Questionnaire (3LNQ) (Johnsen et al., 2013), Needs Assessment Tool: Progressive Disease–Cancer (NAT: PD-C) (Waller et al., 2012b), Caregiver’s Perception of Patients’ Unmet Needs (PPUN) (Hwang et al., 2003), and other instruments without reporting their psychometric properties. Among studies that focused on one specific need domain ( $n = 4$ ), three explored information needs (Templeton & Coates, 2003; Voogt et al., 2005; Wong et al., 2002), and one investigated spiritual needs (Vilalta et al., 2014). The unidimensional instruments adopted included the following: Toronto Information Needs Questionnaire (TINQ-BC) (Templeton & Coates, 2003), Advanced Cancer Information Needs (ACIN) (Wong et al., 2002), PNPC (only used the items of the information domain) (Voogt et al., 2005), and an instrument (Vilalta et al., 2014) for spiritual needs assessment without specifying its psychometric properties. Overall, more than half of the quantitative studies (20/34) adopted instruments with acceptable validity and reliability. Details of those instrument are presented in **Table 4.6**.

Among the 13 quantitative studies reporting unmet needs of informal caregivers, comprehensive unmet needs (multiple domains) were explored in 10 studies (Chen et al., 2016; Chen et al., 2008; Cui et al., 2014; DuBenske et al., 2008; Hwang et al., 2003; Joad et al., 2011; Liu, 2008; Miu et al., 2016; Osse et al., 2006; Park et al., 2010). Different quantitative studies used different measures, which included PNPC questionnaire-caregiver form (PNPC-

c) (Osse et al., 2006), Family Inventory of Needs (FIN) (Hwang et al., 2003), Partners and Caregivers supportive care needs survey (SCNS-P&C) (Chen et al., 2016), needs of family caregivers of patients with advanced cancer (Cui et al., 2014), and other self-designed instruments (Chen et al., 2008; DuBenske et al., 2008; Joad et al., 2011; Liu, 2008; Miu et al., 2016; Park et al., 2010). Among the three other studies that focused on unidimensional needs assessment, two (Fukui, 2004; Wong et al., 2002) measured information needs, and one (Buck & McMillan, 2008) explored spiritual needs. The scales used were Spiritual Needs Inventory (Buck & McMillan, 2008) and two other self-designed instruments, namely, with (Wong et al., 2002) or without (Fukui, 2004) psychometric property testing. Among all the 13 studies, only four studies used scales with documented psychometric properties. Details of those validated instrument are presented in **Table 4.7** below:



**Table 4.6** Validated tools used in the included studies (patients)

Tool	Dimension	Item Scoring	Domains and Items	Psychometric Properties	Assessment Method
Supportive Care Needs Survey (SCNS-SF34) (Waller, et al., 2012a; Hasegawa, et al., 2016; Uchida, et al., 2011; Fitch, 2012*; Au, et al., 2013*; Lelorain, et al., 2015*; Lam, et al., 2014)	Multidimensional	<b>Five-point scale (1-5):</b> 1=no need/not applicable, 2= no need/satisfied, 3=low need, 4= moderate need, 5=high need <b>Higher score means higher needs.</b>	5 domains: physical and daily living, patients care and support, sexuality, psychological, and health system and information; 34 items	<b>Validity</b> (1) Content validity: review by oncologist and patients (2) Construct validity: 5 factors were revealed by factor analysis, and explaining 73% of the variance (3) Convergent validity: correlation with Distress HADS, Thermometer, EORCT-C30 (r=0.48-0.56) <b>Reliability</b> (1) Internal reliability: Cronbach's $\alpha$ =0.86-0.96 <b>Responsiveness:</b> NR <b>Feasibility:</b> reading level 7 <sup>th</sup> -8 <sup>th</sup> grade education	Patient completed
Supportive Care Needs Questionnaire (SCNQ) (Aranda, et al., 2005*)	Multidimensional	<b>5-point scale (1-5):</b> 1=no need/not applicable, 2= no need/satisfied, 3=low need, 4= moderate need, 5=high need. <b>Higher score means higher needs.</b>	5 domains: physical and daily living, patients care and support, psychological, sexuality, and health information. 59 items	<b>Validity</b> (1) <b>Content validity:</b> review by oncologist and patients (2) <b>Construct validity:</b> 5 factors were revealed by factor analysis, and explaining 64% of the variance (3) Convergent validity: NR <b>Reliability</b> (1) <b>Internal reliability:</b> Cronbach's $\alpha$ =0.87-0.97. <b>Responsiveness:</b> NR <b>Feasibility:</b> reading level 4 <sup>th</sup> -5 <sup>th</sup> grade education, completed within 20 minutes	Patient completed
Problems and Needs in Palliative Care questionnaire (PNPC) (Osse, et al., 2005; Uitdehaag, et al., 2015; Effendy, et al., 2015a**; Voogt, et al., 2005**)	Multidimensional	Including two parts: 1) problem checklist: "is this a problem?" (yes, somewhat, no) and 2) if need any support for this problem, "do you want professional attention for this?" (yes, as much as now, no)	10 domains: activities of daily life, physical, role activities, financial and administrative, autonomy, spiritual, social, psychological, counselling, and information. 90 items	<b>Validity</b> (1) <b>Content validity:</b> interviews with patients, their close people, followed by pilot test and expert review (2) <b>Convergent validity:</b> correlation with EORCT- C30 and COOP WONCA QOL <b>Reliability</b> (1) <b>Internal reliability:</b> <b>Part 1 (problem checklist):</b> Cronbach's $\alpha$ =0.67-0.89 <b>Part 2 (needs support):</b> Cronbach's $\alpha$ =0.73-0.92 <b>Responsiveness:</b> NR <b>Feasibility:</b> NR	Patient completed
Problems and Needs in Palliative Care- short version (PNPC-sv) (Khan, et al., 2012)	Multidimensional	Including two parts: 1) problem checklist: "is this a problem?" (yes, somewhat, no) and 2) if	8 domains: daily activities, physical symptoms, autonomy, social issues,	<b>Validity</b> (1) <b>Content validity:</b> interviews with patients, their close people, and followed by pilot test and expert review	Patient completed

		need any support for this problem, “do you want professional attention for this?” (yes, as much as now, no)	psychological issues, spiritual issues, information needs, and financial. 33 items	(2) <b>Convergent validity:</b> correlation with EORCT- C30 and COOP WONCA QOL <b>Reliability</b> (1) <b>Internal reliability:</b> <b>Part 1 (problem checklist):</b> Internal reliability (8 domains): Cronbach’s $\alpha=0.61-0.86$ <b>Part 2 (needs support):</b> Internal reliability (8 domains): Cronbach’s $\alpha=0.70-0.86$ <b>Responsiveness:</b> NR <b>Feasibility:</b> completed with 5-10minutes	
Needs Assessment of Advanced Cancer Patients (NA-ACP) ( Schenker, et al., 2014*; Rachakonda, et al., 2015; Rainbird, et al.,2009)	Multidimensional	Five-point scale (1-5): 1=not applicable, 2=satisfied, 3-5=low, moderate and high level of need	7 domains: activities of daily living, symptom, psychological, social, financial, spiritual, and medical information and communication; 132 items	<b>Validity</b> (1) <b>Content validity:</b> literature review, focus group with patients, and expert opinion (2) <b>Construct validity:</b> 25 factors were revealed by factor analysis, and explaining 55% of the variance <b>Reliability</b> (1) Internal reliability: Cronbach’s $\alpha=0.79-0.98$ (2) <b>Test-retest:</b> 0.67-0.93 <b>Responsiveness:</b> NR <b>Feasibility:</b> <b>Reading level:</b> 90% (25–64 years old) and 77% (aged 65+ years) of the participants can easily understand the questionnaire <b>Acceptability questions:</b> 86% of participants reported that the questions were clear and understandable.	Patient completed
Cancer Needs Questionnaire (CNQ) (Liao, et al., 2011)	Multidimensional	Five-point scale Standardized scores of each domain ranged 0-100, higher score means greater unmet needs	5 domains: healthy system/information, physical and daily living care, psychological, patient care and support, and interpersonal communication. 32 items	<b>Validity</b> (1) <b>Construct validity:</b> 5 factors were revealed by factor analysis, and explaining 68% of the variance (2) <b>Convergent validity:</b> correlation with EORCT- C30 and Beck depression inventory (short-form) <b>Reliability</b> (1) Internal reliability: Cronbach’s $\alpha=0.77-0.94$ (0.83-0.95) <b>Responsiveness:</b> NR <b>Feasibility:</b> NR	Patient completed

<p>Patient Needs Assessment in Palliative Care (PNAP) (Bužgová, et al., 2014)</p>	<p>Multidimensional</p>	<p>Including two parts: 1) if an issue was important (five-point scale 1-5): 1=not at all, 5=very important; higher score means greater importance; 2) if the issue was met ( five-point scale 1-5): 1=not at all, 5=yes, very much; lower score means greater unmet needs</p>	<p>5 domains: psychological, physical, social, spiritual, autonomy. 42 items</p>	<p>Not available (not in English language)</p>	<p>Patient completed</p>
<p>3-Levels-of-Needs Questionnaire (3LNQ) (Johnsen, et al., 2013)</p>	<p>Multidimensional</p>	<p>Including two parts: 1) problem intensity: “not at all”, “a little”, “quite a bit” “very much” 2) felt need including 4 sub-items: if they do not have the problem; if it is a problem, have got help or not? (“yes” “no”); if yes, if the help adequate? (inadequate partly, adequate; no interested in the help or not); if not, if they want help? (“yes” “no”);</p>	<p>12 items</p>	<p><b>Validity</b> <b>(1) Content validity:</b> literature review and comparison of patients’ written comments to questionnaire with the researchers’ interview Agreement between observers: 67%-100%, and the median kappa=0.91</p>	<p>Patient completed</p>
<p>Needs Assessment Tool: Progressive Disease-Cancer (NAT: PD-C) (Waller, et al., 2012b)</p>	<p>Multidimensional</p>	<p>Section 1: (yes, no) Section 2-4: (none, some, significant)</p>	<p>Including 4 sections and 18 items: 1) referral to SPCS; 2) patient’s well-being; 3) caregiver’s ability for taking care of patients; 4) caregiver’s well-being</p>	<p><b>Validity</b> <b>(1) Concurrent validity:</b> PABAK value: 0.24-0.48, Cohen’s kappa: 0.25-0.47. <b>Reliability</b> <b>(1) Inter-rater reliability:</b> Cohen’s kappa= 0.02-0.59, percentage of agreement=48%-88%.</p>	<p>Professionals completed</p>

Adapted Toronto Information Needs Questionnaire (TINQ) (Templeton & Coates, 2003)	Unidimensional	Five-point scale (1-5): 1= not important 5= extremely important	5 domains: disease, treatment, physical, psychological, and investigative tests 29 items	<b>Validity</b> (1) <b>Content validity:</b> expert opinion and patients' interview (2) <b>Construct validity:</b> factor analysis (details were not reported) <b>Reliability</b> (1) <b>Inter-rater reliability:</b> Cronbach's $\alpha=0.73-0.92$	Patient completed
Caregiver's Perception of Patients' Unmet Needs (PPUN) (Hwang, et al., 2003)	Multidimensional	Including two parts: 1) if it is a problem (very much, some, a little problem) 2) if need relevant help (need help, somewhat need, not at all)	14 items	<b>Validity</b> <b>Construct validity:</b> factor analysis, but details was not reported <b>Reliability</b> <b>Internal reliability:</b> Cronbach's $s=0.74$	Caregiver completed
Self-designed questionnaire for spiritual needs (Vilalta, et al., 2014)	Unidimensional	Five-point scale (1-5): (1=not at all, 2=a little, 3= quite a lot, 4= a lot, 5=totally)	11 components of spiritual needs and 28 items	Not report but specified the process of compiling the questionnaire	Patient completed
Advanced Cancer Information Needs (ACIN) (Wong, et al., 2002)	Unidimensional	Five-point scale (1-5): (0= not at all interested, 4=very interested)	Information needs and 22 items	A pilot study with 10 patients was conducted to test the face validity, readability and acceptance, but details were not reported.	Patient completed

**Notes:** \*: variants of the original scales with testing the psychometric properties; \*\*: variants without testing the psychometric properties. Sentences and phrases which were put in the quotation marks were directly extracted from the corresponding included studies.

**Table 4.7** Validated tools used in the included studies (caregivers)

Tool	Dimension	Item Scoring	Domains and Items	Psychometric Properties	Assessment Method
The Family Inventory of Needs (FIN)  (Hwang, et al., 2003)	Multidimensional	Including two parts: 1) the importance of the family needs (0-10, 0=extremely unimportant, 10=important) 2) fulfillment of care needs (0=not met, 1=met)	<b>20 item</b>	<b>Validity</b> (1) <b>Construct validity:</b> factor analysis, but details were not reported <b>Reliability</b> (1) <b>Internal reliability:</b> Cronbach's=0.92	Caregiver completed
Partners and Caregivers supportive care needs survey (SCNS-P&C)  (Chen, et al., 2016)	Multidimensional	Five-point scale (1-5): 1= no need, 2=needs already satisfied, 3=some need, 4= low need, 5=moderate or high level of need	<b>6 domains:</b> information, health care service, daily living, communication, legal/financial, psychological and other needs <b>44 items</b>	<b>Validity</b> (1) <b>Content validity:</b> literature review and expert opinion (2) <b>Construct validity:</b> factor analysis, revealed 4 factors <b>Reliability</b> (1) <b>Inter-rater reliability:</b> Cronbach's $\alpha=0.73-0.92$ <b>Chinese version- Taiwan</b> (6 domains and 44 items): Cronbach's $\alpha=0.96$	Caregiver completed
Needs of family caregivers of advanced cancer patients  (Cui, et al., 2014a)	Multidimensional	Five-point scale (1-5): 1=no need, 5=badly in need	<b>7 domains:</b> maintaining health, professional support, funeral support, knowledge about disease and treatment, information for hospice care, psychological support for patients, symptom control for patients. <b>36 items</b>	<b>Chinese Version</b> <b>Validity</b> (1) <b>Content validity:</b> literature review researcher's clinical experience, and reviewed by experts and patients (2) <b>Construct validity:</b> 4 factors were revealed by factor analysis, and explaining 66.15% of the variance <b>Reliability</b> (1) <b>Internal reliability:</b> Cronbach's $\alpha= 0.785-0.89$	Caregiver completed
Spiritual Needs Inventory (SNI)  (Buck & McMillan, 2008)	Unidimensional	Including two parts: 1) rate the item (1-5,1= never, 5= always, higher score= greater needs); 2) if the needs met or not (yes, no).	17 items	<b>Validity</b> (1) <b>Content validity:</b> interviews with patients (2) <b>Construct validity:</b> factor analysis, revealed 5 factors, explaining 63.7% of the variance <b>Reliability</b> (1) <b>Internal reliability:</b> Cronbach's $\alpha=0.85$	Caregiver completed

#### **4.2.4 Discussion of the study results and limitations**

The included studies highlighted that both advanced cancer patients and their informal caregivers possess a wide range of unmet needs. Psychological and physical unmet needs are two areas of focus for patients with advanced cancer; this result is consistent with a previously published review (Moghaddam et al., 2016). Among informal caregivers who had experience in managing patients' negative emotions, more than 30% of them reported that emotional management is the most challenging part of caregiving (Deshields et al., 2012). Three other unmet needs, namely, the need for autonomy, communication, and nutrition, were identified in this review compared with the previous review (Moghaddam et al., 2016). These needs may be related to the differences in cultural contexts, healthcare systems, and economic levels because several included studies in this review were conducted in eastern and developing countries. For instance, the need for autonomy is commonly culture-related (Effendy et al., 2015a). Family members usually make decisions for patients in eastern cultures because family-collective decision-making is much more popular there than in other cultures (Gu et al., 2016b). This result showed the importance of developing tailored healthcare services or interventions based on context-specific unmet needs. Disease-related information needs were the most commonly reported unmet needs of informal caregivers. Considerably fewer studies reported unmet needs that are associated with the caregivers' own well-being, as they generally focus more on the patients' well-being than their own (Osse et al., 2006). The prominent care needs of each domain were identified for patients with advanced cancer and informal caregivers in this review provide useful information and evidence for the development and implementation of tailored healthcare services. For example, emotional support was identified as the most commonly unmet need in the psychological domain for patients, thereby indicating that emotional distress (e.g., anxiety and depression) management should be a priority when providing mental health services. In addition, patients with advanced cancer and informal caregivers' unmet need domains involved multiple disciplines, which indicated that healthcare services should be multidisciplinary. The value of multidisciplinary care for patients with cancer has been well recognized (Health Care Guideline, 2013). Support for informal

caregivers is suboptimal in many instances (Hudson et al., 2012). The unmet needs of informal caregivers are often ignored and excluded from healthcare planning (Halkett et al., 2015; Sealey, Breen, O'Connor, & Aoun, 2015).

The prevalence of unmet needs varied across the quantitative studies for both patients and caregivers. This variability may be caused by the heterogeneity of the included studies, which were conducted within different cultural contexts, healthcare systems, and economic levels that may be associated with unmet needs. High-income countries or regions generally present well-established healthcare service systems, which can facilitate the timely identification and resolution of healthcare problems (several physical symptoms particularly require high-quality professional support [Morasso et al., 1999]). Different study designs, especially the diverse instruments used, for unmet needs assessment also contribute to this heterogeneity. The highlighted heterogeneity makes it difficult to gauge and pool the percentages of unmet needs by domains. SCNS was the most commonly used instrument, which was used in eight studies. However, these eight studies adopted five different variants of the same scale, with 13 (Lelorain et al., 2015), 33 (Au et al., 2013), 34 (Hasegawa et al., 2016; Uchida et al., 2011; Waller et al., 2012a), 59 (Aranda et al., 2005), and 61 items (Fitch, 2012) for each of the five versions. Different methods of need classification are also a major barrier in gauging unmet needs by domains. For instance, in SCNS, several items were classified as spiritual needs (e.g., [Fitch, 2012]). In other studies, the same items were coded as psychological needs (e.g., [Uchida et al., 2011]). Moreover, approaches in defining unmet needs were inconsistent. Among studies that utilized the SCNS, several of them regarded moderate and high levels of need as unmet needs (e.g., [Uchida et al., 2011]). In other studies, low need level was calculated as an unmet need (e.g., [Fitch, 2012]). Different reporting methods also caused heterogeneity. Several studies reported the prevalence of unmet needs by domains without specifying the percentage of items within each domain. Some studies (e.g., [Hasegawa et al., 2016]) only listed the prevalence of the top 10 or 20 items without reporting the prevalence by domain. Thus, directly combining the prevalence of reported items within a domain may increase the risk of overestimating the actual unmet need level (Harrison et al., 2009).

Although consistent results across studies showed that patients with advanced cancer with symptoms of distress and anxiety and low quality of life are more likely to report high demands of unmet needs, the conclusion must be interpreted with caution. Causality cannot be established because almost all of the included studies were cross-section in design. Other patient-related variables with inconsistent results, (e.g., gender, marital status, education level, cancer site, and depression) may be caused by cultural differences and/or methodological flaws (e.g., insufficient sample size to explore relationships between two factors) of the included studies. Hence, more longitudinal studies with rigorous study designs should be adopted. In addition, whether caregivers' health outcomes were associated with the unmet needs of patients is still unclear because of the limited evidence that can be drawn from current studies. Therefore, more studies should focus on caregiver-related variables. Relevant studies regarding variables associated with informal caregivers' unmet needs are limited, and no conclusion can be drawn from the current findings.

The strength of this systematic review is that a large number of studies with considerable information were assimilated and analysed through a systematic method, which can minimise biases and facilitate reliable conclusions. This work is the first systematic review conducted by considering patients with advanced cancer and their informal caregivers as a whole unit. However, this review also presents several limitations. First, subgroup analysis in terms of contexts and economic levels was not conducted. Second, given the confounding factors and insufficient number of studies in each subgroup, meta-analysis was also not performed to compare the prevalence of each identified need domain. Third, language bias cannot be excluded because only papers that were published in English or Chinese language were included. Finally, instruments for needs assessments were only summarized from the included studies, and studies in terms of instrument development were excluded.

### **4.3 Implications and research gaps**



Several implications and research gaps were identified in a number of current studies exploring unmet needs of patients with advanced cancer and their informal caregivers via this systematic review.

#### **4.3.1 Unmet needs investigated only at a single time point**

Patients with cancer at an advanced stage commonly experience fluctuating unmet needs over time due to rapid disease progression (Waller et al., 2012a). Nevertheless, little is known about how patients with advanced cancer and/or their informal caregivers' unmet needs change across the illness trajectory. Almost all the included quantitative studies investigated unmet needs at a single time point with cross-sectional study designs.

#### **4.3.2 Unmet needs were mainly assessed through a biomedical lens only**

Unmet care needs assessment in the majority of the included studies is mainly problem-oriented from a biomedical lens. Few studies considered contextual issues (sociocultural and healthcare service provisions) when assessing and interpreting results in a given context although it will be of benefit to the development and implementation of tailored interventions at a local level. Accordingly, qualitative studies are an appropriate approach because it can explore participants' in-depth experience and subjective feelings that cannot be measured by quantitative methods; additionally, the scope can be much broader than those of quantitative methods (Grypdonck, 2006; Britten et al., 2002). Deeper understanding of unmet needs can be extracted from the qualitative studies than from quantitative findings. However, limited studies adopted qualitative study designs, and only few studies utilized multimethod methods.

#### **4.3.3 Patients and their informal caregivers not regarded as a 'whole unit'**

Care needs should be comprehensively evaluated from all stakeholders, including patients, caregivers, and healthcare providers (Field & Clark, 2001). A comprehensive understanding of both patients with advanced cancer and informal caregivers' unmet needs can enable healthcare providers to develop evidence-based and tailored interventions (Valery et al., 2015). Nevertheless, the majority of the included studies assessed patients' unmet needs only rather than from the perspectives of all relevant stakeholders. Despite that the concept of 'patient-

and-family-centered care' is advocated by the WHO (2002), structured unmet needs assessment of informal caregivers is still an uncommon practice. Only a few studies assessed the unmet needs of patients and informal caregivers, and their unmet needs were assessed separately. Whether advanced cancer patients' unmet needs and their informal caregivers' unmet needs are interdependent should be explored in future, which would provide information for developing specific interventions that focus on both patients and their informal caregivers. The mechanism of integrating the data of patients and caregivers should be considered to further embody the conceptualization as a "whole unit". Focused group with mixed samples, including patients and informal caregivers in the same group, may be an appropriate approach.

#### **4.3.4 Unsatisfactory outcome assessments**

Finally, research instruments used for needs assessment in several included studies were inappropriate. Some scales are generic ones used for supportive care needs assessment, and more specific and validated instrument should be used in future studies.

#### **4.4 Summary of this chapter**

This chapter presented a systematic review that summarized the current research evidence on unmet needs of advanced cancer patients and their informal caregivers. Fifty available studies were included and analysed in this systematic review. The review findings support that a wide range of unmet care needs existed in both advanced cancer patients and informal caregivers. Given the context-bound feature, their unmet needs should be comprehensively assessed and interpreted within a given context by using rigorous multimethod research design. Assessing unmet care needs by viewing patients with advanced cancer and their informal caregivers as a "whole unit" is highly desirable. Associated factors of their unmet needs should not be ignored, which can provide evidence for decision-making with regards to healthcare resource allocation. The value of better examining unmet needs and their associated factors in advanced cancer patients and informal caregivers ultimately depends on how well it could inform the development and implementation of tailored healthcare service or intervention. The current doctoral research project was therefore

designed to address majority of the identified research gaps that mentioned above. The next chapter will comprehensively present the research aim and objectives, research questions and hypotheses, as well as the detailed research methodology of this doctoral research project, which include the development of a conceptual framework to guide the research direction and variables selection of this research project in a more evidence-based and structured approach, the design of the cross-sectional survey to examine the care needs of both advanced cancer patients and their informal caregivers and the associated factors of their needs, and the design of the semi-structured interview to further explore the experience of the most commonly reported unmet needs that identified in the cross-sectional survey in both advanced cancer patients and their informal caregivers.

## **Chapter Five: Research Methodology**

## **5.1 Introduction**

Research gaps for this doctoral research project were identified in the systematic review in Chapter Four. This chapter, which consists of seven major sections, will present the research methodology of this doctoral research project. This doctoral research project adopted a two-phase multimethod research design that involved two discreet but linked studies (phase one was a cross-sectional survey and phase two was semi-structured qualitative interviews). Section 5.1 will provide a general introduction of this chapter, and the research aim, objectives, questions, and hypotheses will be presented in Section 5.2. In Section 5.3, the multimethod research design, including the definition, strengths, and types of multimethod study designs, and the rationale for choosing the multimethod research design for the current doctoral research project will be described. Section 5.4 will detail the study design of the cross-sectional survey (phase one) to quantify the unmet needs of both patients with advanced cancer and their informal caregivers, their interrelationships, and the predictors of their needs. The design of the phase two semi-structured interviews to further elaborate and explore the perceptions and experiences of patients and their informal caregivers in relation to the most common unmet needs that were identified in the cross-sectional survey will be presented in Section 5.5. The study team, the study's quality assurance, and the ethical considerations of this project will be described in Section 5.6, and Section 5.7 will summarize this chapter.

## **5.2 Research aim, objectives, questions, and hypotheses**

### **5.2.1 Research aim and objectives**

The overall intention of this study was to provide preliminary evidence to researchers and policymakers in relation to developing tailored palliative care interventions and services to better meet the palliative care needs of Chinese patients with advanced cancer and their informal caregivers. This study proceeded in two phases. Phase One aimed to identify the palliative care needs of Chinese patients with advanced cancer and the needs of their informal caregivers, with the following objectives:

- (1) To identify the prevalence of unmet palliative care needs among patients with advanced cancer;
- (2) To determine the unique contribution of each hypothesized predictor to the palliative care needs of patients with advanced cancer;
- (3) To identify the prevalence of unmet care needs among informal caregivers of advanced cancer patients;
- (4) To determine the unique contribution of each hypothesized predictor to the needs of informal caregivers;
- (5) To preliminary determine the relationship between the palliative care needs of patients with advanced cancer and the needs of their informal caregivers; and
- (6) To identify the frequently reported unmet needs in both patients with advanced cancer and their informal caregivers.

Phase Two of this study aimed to explore more details in relation to the common unmet needs that were identified in Phase One for both patients and their informal caregivers. Two main objectives are listed as follows:

- (7) To further clarify and elaborate the identified unmet needs of both advanced cancer patients and their informal caregivers; and
- (8) To further explore the perceptions and experiences of advanced cancer patients and their informal caregivers in relation to the identified unmet needs.

### **5.2.2 Research questions**

The specific research questions for the cross-sectional survey (questions 1 to 6) and the semi-structured interviews (questions 7 and 8) are as follows:

- (1) What are the unmet palliative care needs of patients with advanced cancer and the prevalence of each unmet palliative care need?
- (2) What are the predictors of the palliative care needs of patients with advanced cancer?

- (3) What are the unmet needs of informal caregivers of advanced cancer patients and the prevalence of each unmet need?
- (4) What are the predictors of the needs of informal caregivers?
- (5) What is the relationship between the palliative care needs of advanced cancer patients and the needs of their informal caregivers?
- (6) What are the common and prominent unmet needs of advanced cancer patients and their informal caregivers?
- (7) What are the perceptions and experiences of advanced cancer patients in terms of the identified commonly reported unmet needs?
- (8) What are the perceptions and experiences of informal caregivers in terms of the identified commonly reported unmet needs?

### **5.2.3 Research hypotheses**

Determining the predictors of the palliative care needs of advanced cancer patients and the predictors of the needs of informal caregivers, as well as the relationship between the palliative care needs of advanced cancer patients and the needs of their informal caregivers, were three important objectives in this doctoral research project. The research hypotheses therefore were proposed as follows:

- (1) Advanced cancer patients' personal characteristics (sociodemographic, illness-related, physical, and psychological characteristics), social support, coping strategies, and quality of life will be significantly associated with their palliative care needs;
- (2) Informal caregivers' personal characteristics (sociodemographic and psychological characteristics), social support, coping strategies, and quality of life will be significantly associated with the palliative care needs of their advanced cancer patients;

- (3) Informal caregivers' personal characteristics (sociodemographic and psychological characteristics), social support, coping strategies, and quality of life will be associated with their unmet needs;
- (4) Advanced cancer patients' personal characteristics (sociodemographic, illness-related, physical, and psychological characteristics), social support, coping strategies, and quality of life will be associated with the needs of their informal caregivers; and
- (5) There will be significant correlations between the palliative care needs of advanced cancer patients and the needs of their informal caregivers.

### **5.3 Multimethod research design**

#### **5.3.1 Definition of the multimethod design**

The multiple methods design, along with qualitative research and quantitative research, is regarded as another major research approach, and it has been widely used in many fields, including social and behavioural research (Tashakkori & Teddlie, 2003) and health science (Johnson, Onwuegbuzie, & Turner, 2007). The definition of the multimethod research design varies across the literature as different definitions have been proposed by different researchers (Stange, Crabtree, & Miller, 2006). As Stange et al. (2006, p. 292) stated, 'Multimethod research brings together numbers and narratives, description, hypothesis testing, hypothesis generation, and understanding of meaning and context to provide fuller discernment and greater transportability of the phenomenon under study.' According to Morse (2003, p. 190), a multimethod design is 'the conduct of two or more research methods, each conducted rigorously and complete in itself, in one project. The results are then triangulated to form a complete whole.'

Although differences in the definitions exist, there is strong agreement that the multimethod research design refers to the concurrent or sequential use of more than one method or more than one worldview in a study at the methodological level (Schoonenboom & Johnson, 2017). The multimethod research design can refer to the combination of solely multiple qualitative



approaches or solely multiple quantitative approaches in one project (Schoonenboom & Johnson, 2017; Swartz, Amatucci, & Coleman, 2016); it can also include both quantitative and qualitative approaches in one project, where the qualitative and quantitative studies are relatively complete but are used together to form the essential components of one research project (Morse, 2003, p. 191). Morse (2003, p. 199) emphasized that multimethod designs are different from mixed methods designs, and ‘the major difference between multimethod and mixed methods designs is that in multimethod design all projects are complete in themselves. The major research question or problem drives the research program, but the program consists of two or more interrelated studies.’ In the multimethod research design, each study is conducted to answer a particular sub-question (Morse, 2003). However, mixed method design is usually used to answer and add to the understandings of one research question (fuller and richer information) by mixing quantitative and qualitative findings.

### **5.3.2 Strengths of the multimethod design**

Generally, the purpose of a quantitative method is to understand variations and generalization among the elements of a phenomenon in a study using a deductive research process, whereas a qualitative method is an inductive research process that generalizes the concepts to develop themes and theoretical frameworks (Teddlie & Tashakkori, 2009). Based on the view of pragmatists, many research questions cannot be addressed with a single research method as each method has its own limitations. Quantitative methods emphasize numbers, which might ignore complex human experiences and thus fail to capture the full and detailed context of a situation; however, such an issue can be supplemented with a qualitative method, which allows greater flexibility and obtains in-depth information about complex phenomena under investigation (Lyu, 2016). In this situation, a multimethod research design is often needed to expand both the breadth and depth of a study. According to Sandelowski (1995), the obvious strength of using the multimethod research design is to obtain different levels of data, and there are many other strengths in applying a multimethod design in research (Morse, 2003; Schutz, Chambless, & DeCuir, 2004).

A multimethod research design can provide researchers with the opportunity to look for corroboration when using at least two approaches to investigate the same aspects of one phenomenon (Schutz et al., 2004). When the focus of a research project is to study different aspects of a phenomenon, rather than the same aspect, the multimethod design has the potential to achieve complementarity (Schutz et al., 2004). Different from corroboration, the goal of complementarity is ‘to elaborate and enhance the results of one method with the results of another method’ (Schutz et al., 2004, p. 278). For example, a quantitative study may use a follow-up qualitative dimension to help explain unusual or unexpected results that were identified in the quantitative approach (Schutz et al., 2004). Moreover, a multimethod design can be a means of advancing a study or a research programme, which is that the result from one method can be used to guide the development of the next phase of the study (Schutz et al., 2004).

### **5.3.3 Types of multimethod designs**

According to Morse (2003, p. 196), one of the most important principles in designing multimethod research is to ‘identify the theoretical drive of the research project,’ which may be inductive (qualitative) or deductive (quantitative). In a multimethod research design, there is a ‘driven’ method and a ‘supplemental’ method (Morse, 2003; Schoonenboom & Johnson, 2017). If the major thrust of a project is to test a theory or hypothesis, to answer questions like how much and how many, and to determine interrelationships, the project is therefore defined as deductive (quantitative) driven even if the project incorporates qualitative inductive components, because the deductive (quantitative) component is the major direction of thinking used in the project as a whole (Morse, 2003). Similarly, the project is inductive (qualitative) driven when the major thrust is discovery (Morse, 2003).

In addition to the thrust of a project, the researcher needs to consider whether an inductive or deductive component should be conducted in a given time, which is the sequence of the qualitative component and the quantitative component. Quantitative and qualitative components can be conducted sequentially or simultaneously (Morse, 2003). Regarding the

sequential design, the particular sequence is usually determined by the research purpose and particular research questions (Andrew & Halcomb, 2009, as cited by Courtney, 2012). As Schoonenboom and Johnson (2017, pp. 114-115) have stated, a sequential multimethod design is usually ‘using the outcomes of the first research component, the researcher decides *what to do* in the second component.’ Sequential designs may be either explanatory or exploratory. In a study with an explanatory sequential design, the first phase of the quantitative data collection and analysis is followed by a qualitative [QUAN→qual] or a second quantitative [QUAN→quan] phase to further explain the initial quantitative results (Schoonenboom & Johnson, 2017). For an exploratory sequential design, the qualitative data is collected first, and then followed by a quantitative [QUAL→quan] or a second qualitative [QUAL→qual] element of the study (Creswell & Clark, 2017). For a simultaneous design, it can be either quantitative driven or qualitative driven, but the driven and supplemental components are conducted simultaneously, with the following possibilities: QUAN + qual, QUAN + quan, QUAL + quan, and QUAL + qual.

#### **5.3.4 Rationale for the multimethod design in the current study**

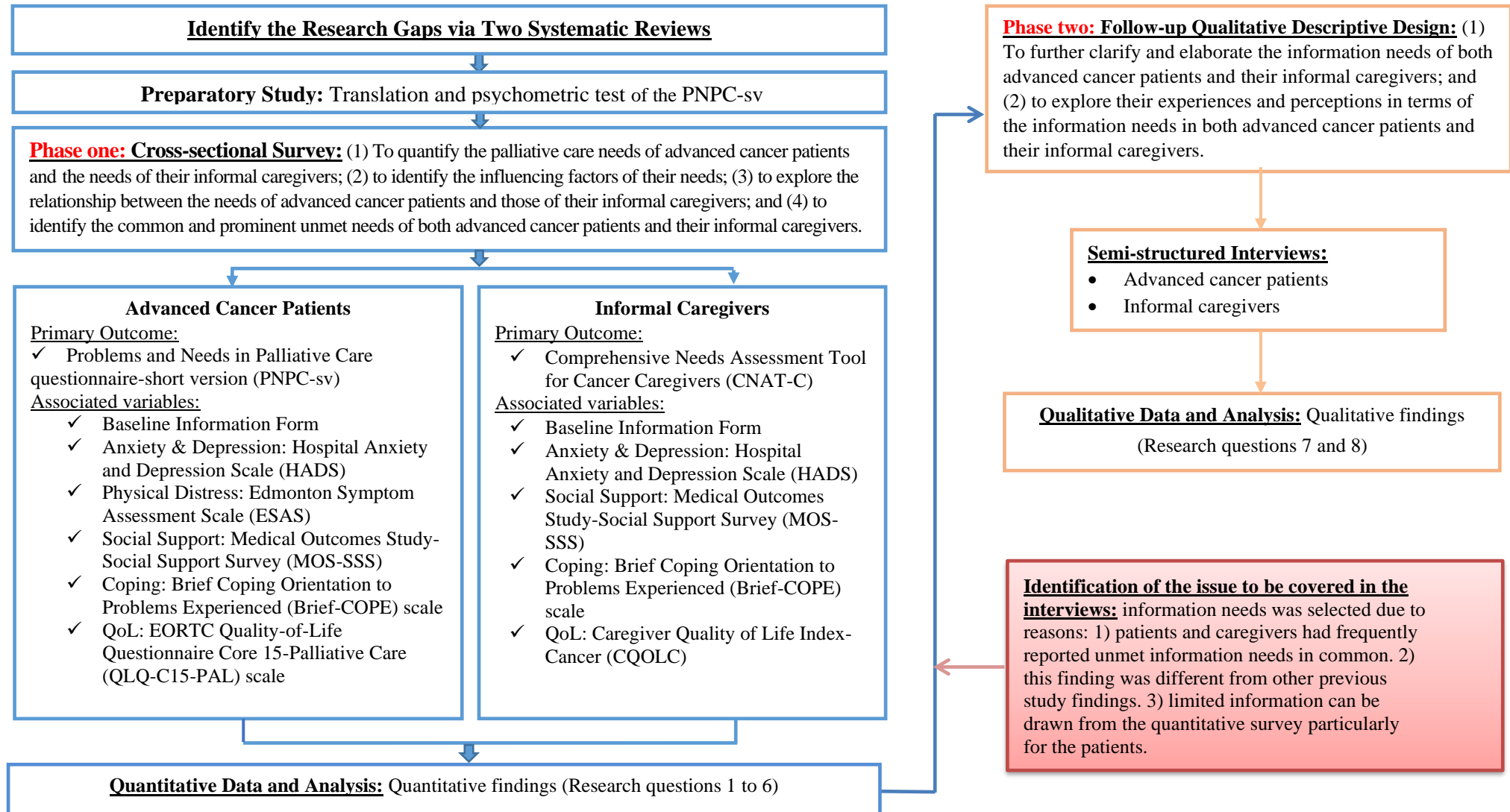
As previously outlined, the overall intention of this study was to provide preliminary evidence to researchers and policymakers in relation to developing tailored palliative care interventions and services based on the specific palliative care needs of Chinese patients with advanced cancer and the needs of their informal caregivers. This study was therefore designed to examine these care needs within the context of China. As presented in Chapter Four, several instruments specifically designed for advanced cancer patients and their informal caregivers have been developed and used outside China (Wang et al., 2018b). Thus, the quantitative method provides a way to quantify the palliative care needs of advanced cancer patients and the needs of their informal caregivers using validated instruments. Although the quantitative method offers the potential strengths of quantification, precision, and reliability, any other detailed information about the identified unmet needs cannot be drawn from the quantitative method (Courtney, 2012). Care needs are not only a biomedical phenomenon but also a result

produced within a multifaceted and complex context, including sociocultural and healthcare service provisions (Wang et al., 2018b). Alternatively, the qualitative method can provide in-depth information, and the qualitative data from the patients' and informal caregivers' interviews did give a fuller and more holistic understanding of their unmet needs within a certain context. The information drawn from the qualitative method will be helpful in developing targeted interventions and making beneficial policies. Besides, the research questions of this study could not be addressed comprehensively using a single research method or design. In addition, given that the quantitative study and qualitative study of this research project will be conducted in themselves to answer particular sub- research question rather than to answer and enhance the understandings of one research question by mixing quantitative and qualitative findings. A multimethod design was therefore selected as a more appropriate research design on the basis that each method served as a tool calibrated to answer specific research questions (Courtney, 2012).

A multimethod research design allows the results to be triangulated, that is, it gains different perspectives from the data to give a fuller picture, which enhances the sophistication and rigor of the research (Williamson, 2005). In accordance with the proposed research objectives and questions, this current study employed a quantitatively driven study followed by a qualitative study [QUAN→qual] (Morse, 2003). A cross-sectional survey was conducted first as the driven method to quantify the palliative care needs of advanced cancer patients and the needs of their informal caregivers, the predictors of their needs, and the relationship between the needs of advanced cancer patients and those of their informal caregivers. The quantitative survey addressed a majority of the research questions, and it therefore served as a driven method in this study.

To explain and expand upon the initial quantitative findings, a follow-up qualitative descriptive study was designed and conducted to further explore the perceptions and experiences of the patients and their informal caregivers regarding the prominent unmet needs that were identified in the quantitative survey via semi-structured interviews. The qualitative

interview in this study was built on the previous quantitative survey, but it was a complete study in itself and served as a supplemental method with a different set of strengths that improved the overall ability of the research design to achieve the study's goals. The unmet needs that were explored in the qualitative interviews were determined based on the findings of the quantitative survey. Information needs were explored in the qualitative phase, and the reasons for further exploring these information needs are justified in Section 5.5.1 of this chapter. The study design and process of this doctoral research project is presented in **Figure 5.1** below. Details about the design of the cross-sectional survey and the descriptive qualitative study will be presented in Section 5.4 and Section 5.5, respectively.



**Figure 5.1** Study design and process of the study

## **5.4 Phase One: The cross-sectional survey**

### **5.4.1 Study design**

The cross-sectional study design is regarded as the best way to examine prevalence and is a very useful method for identifying associations between risk factors and outcomes, and many outcomes and risk factors can be assessed at one time point (Levin, 2006; Mann, 2003). The purpose of the quantitative phase was to quantify the prevalence of the palliative care needs of advanced cancer patients and the needs of their informal caregivers, the predictors of their needs, the relationship between the needs of patients and those of their informal caregivers, and the common and prominent unmet needs of both patients and their informal caregivers. Thus, a cross-sectional study design was employed in the quantitative phase in line with the research objectives.

### **5.4.2 Conceptual framework**

To have a better understanding of the concepts that are related to palliative care needs and to guide palliative care needs assessment and the selection of outcome variables for this cross-sectional study in a more evidence-based and structured approach, a preliminary conceptual framework, which will be presented in this section, was developed based on the Supportive Care Needs Framework for Cancer Care (SCNF) (Fitch, 1994), the study findings from systematic review II (Wang et al., 2018b), and the social-ecological theory (Bronfenbrenner, 2009).

The SCNF was originally formulated by Fitch (1994), which was developed as a tool for cancer care professionals and programme managers to conceptualize what types of needs cancer patients and their families and informal caregivers might have and how cancer care services might be approached. The SCNF has been widely adopted in oncology and adapted in many other areas, such as informal caregivers of stroke patients (MacIsaac, Harrison, & Godfrey, 2010) and parents of pediatric cancer patients (Kerr, Harrison, Medves, Tranmer, & Fitch 2007). The SCNF contains three main constructs: six domains of supportive care needs, influencing factors of their supportive care needs, and spectrum of cancer trajectory (Fitch, 1994). The six domains of supportive care needs include practical, spiritual, psychosocial,

information, emotional, and physical needs (Fitch, 1994). The six domains of needs are influenced by different factors, including age, gender, education, religion, family, place of residence, social support, coping resources, and personality (Fitch, 1994). Another important construct of this framework is that both cancer patients and their informal caregivers are exposed to a spectrum of the cancer trajectory, from phases of screening/diagnosis to the palliation stage (Fitch, 1994). Patients and their informal caregivers are a ‘whole unit’ in fighting cancer (Lambert, et al., 2012). The unmet needs of patients can increase caregivers’ burden (Sharpe et al., 2005). Unsolved unmet needs of caregivers, in turn, can affect patients’ health outcomes negatively (Hodgkinson et al., 2007). It has been suggested that patients’ and informal caregivers’ needs are interactive.

Patients and their informal caregivers may enter at any point of the cancer trajectory (spectrum) and move through the spectrum at varying speeds and along different pathways (Fitch, 2000). In this proposed study, the focus was on advanced cancer patients at the palliation stage and their informal caregivers. Cancer experiences and symptoms of patients and their informal caregivers are changeable across the stages of the cancer trajectory (Waller et al., 2012a). The domains of palliative care needs of advanced cancer patients and informal caregivers that were retrieved in systematic review II well covered the six domains that are highlighted in the SCNF and include some other needs domains, such as activities of daily living (ADL), patient care and support, and financial, autonomy, and sexuality needs. For the influencing factors of patients’ and informal caregivers’ needs, apart from those factors identified in the SCNF, many other potential influencing factors were identified in systematic review II as well, including demographic factors such as marital status, living status, length of time since caregiving, and relationship between patients and caregivers; illness-related factors such as cancer sites, length of time since diagnosis, and types of cancer treatment; physical factors such as physical distress; and psychological factors such as anxiety, depression, and QoL. All the new findings, including the domains of palliative care needs and related influencing factors extracted in systematic review II, were included in the SCNF to adapt the preliminary conceptual framework tailored for this doctoral research study.



Moreover, the ‘holistic’ view has been adopted in the area of needs assessment for people living with illness, which is considered different types of needs in composite (Boberg et al., 2003). This ‘holistic’ view of needs assessment might be best understood within the context of Bronfenbrenner’s (2009) social-ecological theory of human behaviour and development. This theory emphasizes not only commonly researched biomedical perspectives but also the relationships between people and the settings and contexts in which they are actively involved. This includes consideration of certain contexts that patients and their informal caregivers are particularly involved in. This theory has been well adapted and used for supportive care needs assessment of gynaecological cancer (Beesley et al., 2008). The social-ecological theory places needs assessment within the contexts of personal characteristics and social/family support (Beesley et al., 2008). Within each context, the potential influencing factors of needs assessment have been summarized and are partially in line with the SCNF and the study findings of systematic review II.

With the combination of the above-mentioned frameworks and the study findings from systematic review II, a more comprehensive picture can be achieved regarding the potential influencing factors of palliative care needs assessment, which include sociodemographic factors such as age, gender, education, social-economic status (SES), place of residence (rural/urban), religion, marital status, length of time since caregiving, and relationship between patients and caregivers; illness-related factors such as cancer stage, cancer sites, length of time since diagnosis, complications, and treatment therapies; physical factors such as physical distress; and psychological factors such as anxiety, depression, coping, and QoL. Social support includes support from families, friends, and care delivery professionals. Based on the SCNF, the findings from systematic review II, and the social-ecological theory, a preliminary conceptual framework for palliative care needs assessment and influencing factors identification was developed for the cross-sectional survey of this doctoral research project (see **Figure 5.2**). This conceptual framework theoretically and empirically suggests that the variables in each context are important factors associated with the palliative care needs of advance cancer patients and the needs of their informal caregivers.

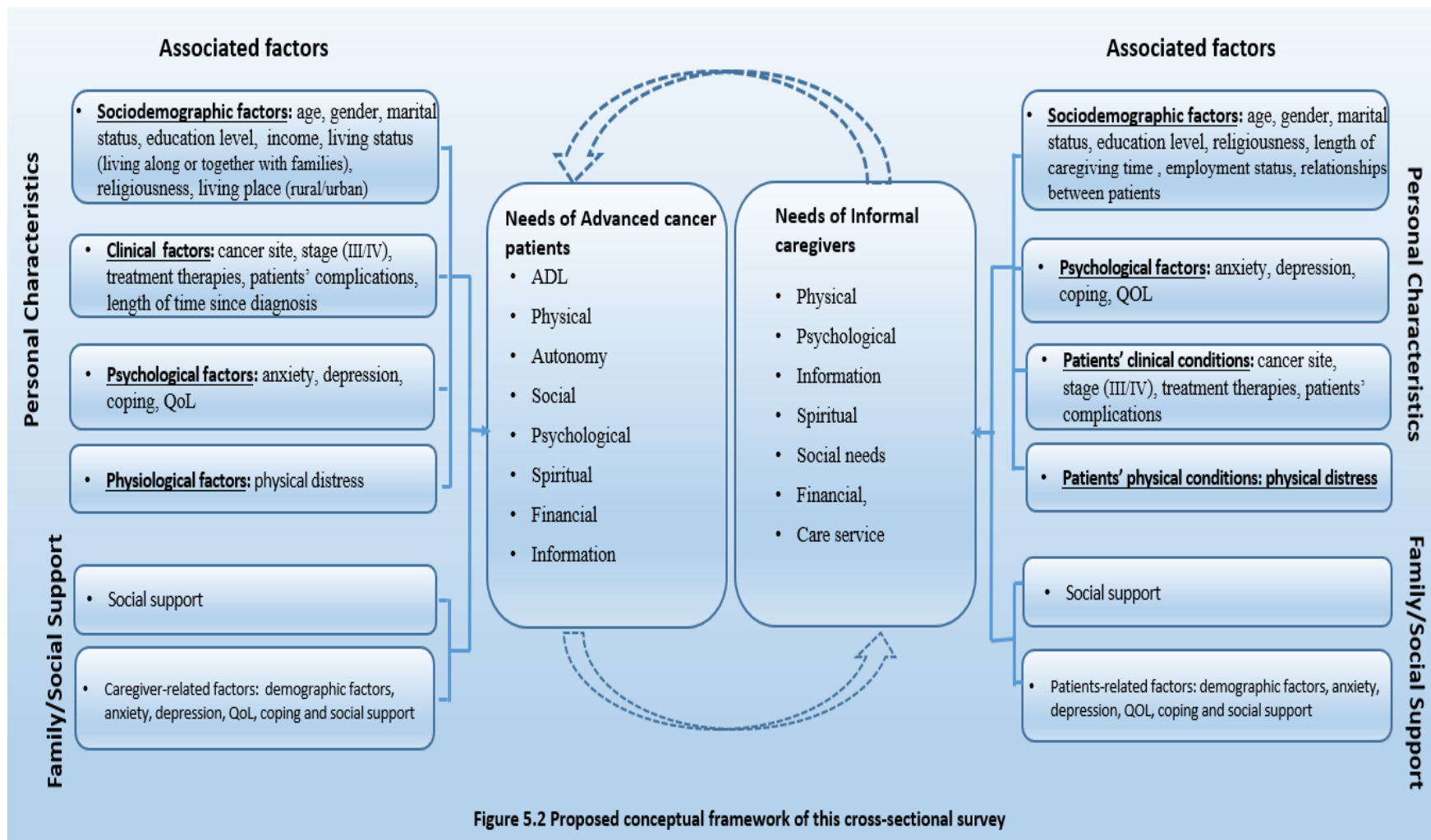


Figure 5.2 Proposed conceptual framework of this cross-sectional survey

### **5.4.3 Study sample and sample size**

#### **5.4.3.1 Participants and eligibility criteria**

Advanced cancer patients and their informal caregivers were the targeted population of this survey. The convenience sampling method was used for subject recruitment from April 2018 to January 2019.

##### **Inclusion criteria:**

- (1) Patients with histologically or cytologically confirmed advanced cancer (no longer amenable to cure, either extensive local, regional, or distant metastasis) that is classified as stage III not amenable to cure or stage IV. (Au et al., 2013; Cancer Council, 2016; Cancer Research UK, 2016; Lam et al., 2014);
- (2) Patients with informal caregivers who are non-employed and nominated by patients, including spouse, daughter/son, daughter-in-law/son-in-law, a very close friend, or a relative;
- (3) Caregivers have no serious diseases that may affect his/her own life;
- (4) Both the patient and the caregiver are adult Chinese (age  $\geq 18$  years);
- (5) Both the patient and the caregiver can communicate in Chinese Mandarin; and
- (6) Both the patient and his/her informal caregiver agree to participate in the survey and are willing to give written informed consent (see **Appendix I**).

##### **Exclusion criteria:**

- (1) Patients with hematologic cancer;
- (2) Patients with “primary” brain cancer; and
- (3) Patients who are participating in any other research project (e.g., intervention of symptom management).

#### **5.4.3.2 Sample size estimation**

In this study, the quantitative cross-sectional survey was mainly used to investigate the prevalence of the palliative care needs of advanced cancer patients and the needs of their

informal caregivers. According to relevant literatures on sample size calculation, the following formula (Naing, Winn, & Rusli, 2006) was adopted to calculate the sample size for this study:

$$n = \frac{Z^2 P (1-P)}{d^2}$$

In the equation,  $n$  = sample size,  $Z$  =  $Z$  statistic for a level of confidence,  $P$  = expected prevalence or proportion, and  $d$  = precision (Naing et al., 2006). When choosing a conventional level of confidence of 95%, the  $Z$  value was 1.96 (Naing et al., 2006). For the expected prevalence ( $P$ ), it was not easy to come up with a good estimation as very few studies were conducted in China in terms of the prevalence of the palliative care needs of advanced cancer patients and the needs of informal caregivers. In this case,  $P = 0.50$  was suggested to be used to achieve the maximum sample size (Naing et al., 2006), and  $d$  was half of the width of the confidence interval. In this study, the sample size was therefore calculated to be 385 using  $Z = 1.96$ ,  $P = 0.50$ , and  $d = 0.05$ . Considering the issues of missing data, potential dropouts, and unusable questionnaires, a sample size of 10% more than 385 was the aim (Naing et al., 2006). Finally, the total sample size was calculated to be 428 for advanced cancer patients and 428 for their informal caregivers, respectively.

#### **5.4.3.3 Study settings**

A convenience sampling method was used to select the study hospitals. This cross-sectional study was carried out at two large medical centres, which included the Affiliated Hospital of Southwest Medical University and the Affiliated Hospital of North Sichuan Medical College.

##### **(1) The Affiliated Hospital of Southwest Medical University**

The Affiliated Hospital of Southwest Medical University is a very large hospital in the south of Sichuan province, with nearly 50 clinical departments and 3,200 beds in total; it also has a very large cancer centre, with nearly 200 beds.

##### **(2) The Affiliated Hospital of North Sichuan Medical College**

The Affiliated Hospital of North Sichuan Medical College is a big medical centre in the north of Sichuan province, and it is also a teaching hospital. There are 44 departments and 2,500 beds in this hospital, and the oncology department has nearly 150 beds.

#### **5.4.4 Data collection procedures**

As the two study hospitals were located in two different cities in China, apart from the researcher, two research assistants with a healthcare research background were invited to participate in this study for data collection in the Affiliated Hospital of Southwest Medical University. One week before the commencement of this study, the researcher provided standard training to the two assistants. The training content included an introduction of the study's aims, objectives, study procedures, the purpose of each questionnaire/scale, communication skills and principles, and standard methods in terms of guiding the participants in completing the instruments. Moreover, a booklet including all the training content mentioned above was developed and provided to the research assistants. After the training, the research assistants were assessed by the researcher to ensure that the research assistants could conduct the data collection independently and to maintain consistency between the researcher and assistants. Process evaluation was performed by the researcher throughout the whole data collection process to ensure the study's quality.

Before the commencement of the data collection, the researcher visited the study hospitals to meet the oncology nurses who were the team members of this study. The oncology nurses were responsible for identifying the eligibility of the potential participants who were attending either outpatient clinics or inpatient departments and for inviting potential participants (patients and their informal caregivers) to take part in this study. All invited participants who were interested in this study were approached in person (face-to-face) by the researcher or the research assistants. An information sheet was given to the eligible participants and detailed information on the study's purpose and procedures were provided by the researcher or the research assistants. Participation in the study was based on the voluntary principle, and all the potential participants were informed and assured that they had the right to refuse or withdraw

from the study at any time, and it would not affect the healthcare services that they received in any way. If the eligible patients agreed to participate in the study, written informed consent was received from them.

In this study, the participants were included only when both patients and their nominated informal caregivers were eligible for and agreed to participate in the study. After obtaining the informed consent, a basic information form and questionnaire booklet, including all the study questionnaires/scales, were given to the patients and their informal caregivers to complete. If the participants felt confused in terms of the questionnaires or the items on the questionnaires, neutral interpretation or other assistance (e.g., reading the questionnaires aloud word by word) was provided by the researcher or the research assistants. After finishing the questionnaires, the researcher or research assistants immediately checked for any missing data or scribbled answers for correction.

#### **5.4.5 Outcome measures**

Several instruments were used to collect the survey data. The primary outcomes, the palliative care needs of the advanced cancer patients, and the needs of their informal caregivers were assessed using the Problems and Needs in Palliative Care-short version (PNPC-sv) questionnaire and the Comprehensive Needs Assessment Tool for Cancer Caregivers (CNAT-C), respectively. The potential influencing factors, in line with the proposed conceptual framework mentioned in Section 5.4.2, including demographic characteristics, psychological distress (anxiety and depression), physical distress, social support, coping strategies, and quality of life, for both the patients and the informal caregivers were measured by several multidimensional scales, including the self-designed Baseline Data Assessment Form, the Hospital Anxiety and Depression Scale (HADS), the Edmonton Symptom Assessment Scale (ESAS), the Medical Outcomes Study-Social Support Survey (MOS-SSS), the Brief Coping Orientation to Problems Experienced (Brief-COPE) scale, the EORTC Quality-of-Life Questionnaire Core 15-Palliative Care (QLQ-C15-PAL), and the Caregiver Quality of Life

Index-Cancer (CQOLC). Details of each outcome measurement will be presented in the following.

#### **5.4.5.1 Baseline Data Assessment Form**

Demographic information and other baseline data were collected via a self-designed Baseline Data Assessment Form (see **Appendix II**). The demographic data of the advanced cancer patients included age, gender, education background, family monthly income level, occupation, place of residence (rural/urban), religion, and marital status; the patients' illness-related information included the type of cancer, length of time since diagnosis, stage of cancer, date of cancer surgery, complications, and treatment therapies; and caregiver-related data included the demographic data of the caregivers (age, gender, education background, religion, and marital status), length of time since caregiving, and relationship between patients and caregivers.

#### **5.4.5.2 Primary outcomes**

##### **5.4.5.2.1 Patients' needs: Problems and Needs in Palliative Care-short version (PNPC-sv)**

###### **(1) Selection of the appropriate scale for measuring the palliative care needs of advanced cancer patients**

According to the study findings of systematic review II, there are many instruments for needs assessment of patients with advanced cancer. The most commonly used multidimensional scales included the Supportive Care Needs Survey (SCNS), the Problems and Needs in Palliative Care (PNPC) questionnaire, and the Needs Assessment of Advanced Cancer Patients (NA-ACP), among which, the SCNS is a generic scale for cancer patients rather than a specifically designed instrument for patients at an advanced stage. The other two instruments, the PNPC and the NA-ACP, were particularly designed to assess the palliative care needs of advanced cancer patients, and both cover a majority of the domains of palliative care needs that were identified in systematic review II. Both the PNPC and the NA-ACP seemed appropriate for this study. However, compared with the PNPC's 90 items (Osse et al., 2005),

the NA-ACP has 132 items (Rainbird, Perkins, & Sanson-Fisher, 2005), which could have presented a greater burden on the participants in completing the questionnaire and may have resulted in a large amount of missing data (Tan, 2017). Therefore, the PNPC was much more appropriate than the NA-ACP. Nevertheless, the 90-item PNPC is still a complicated instrument for advanced cancer patients. A short version of the PNPC, the PNPC-sv, was developed with well-established psychometric properties (Osse et al., 2007), which includes only 33 items but comprehensively covers eight domains of the palliative care needs identified in systematic review II (as presented in chapter 4). Given all the concerns above, the PNPC-sv was chosen for this study as the most appropriate instrument for measuring the palliative care needs of advanced cancer patients.

## **(2) The Problems and Needs in Palliative Care-short version (PNPC-sv) questionnaire**

The PNPC-sv, a self-administered instrument, was developed in The Netherlands to measure the problems and palliative care needs of advanced cancer patients in clinical practice (Osse et al., 2007) (see **Appendix III**). The PNPC-sv covers eight domains of palliative care needs (Osse et al., 2007), which includes daily activities, physical symptoms, autonomy, social issues, psychological issues, spiritual issues, financial issues, and information needs. The PNPC-sv consists of a Problem part and a Need for Care part (Osse et al., 2007). For each item, patients are asked two questions (Osse et al., 2007): (1) ‘Do you experience the item to be a problem?’, which belongs to the Problem part with answers of ‘yes’, ‘somewhat’, and ‘no’; and (2) ‘Do you need (extra) professional attention for the item?’, which belongs to the Need for Care part with answers of ‘yes, more’, ‘as much as now’, and ‘no’. In terms of the PNPC-sv scoring system, ‘yes’=2, ‘somewhat’/‘as much as now’=1, and ‘no’= 0. Higher scores indicate more problems and stronger care needs. After a brief introduction, the participants were instructed to go through the questionnaire and circle a response to each question that was most applicable to their condition.

Internal consistency of the PNPC-sv was determined using Cronbach’s alpha. The Cronbach’s alpha for the Problem part across different domains ranged from 0.61 to 0.86, and the



Cronbach's alpha for the Need for Care part across different domains ranged from 0.70 to 0.86 (Osse et al., 2007). Construct validity was well demonstrated with a high correlation between the PNPC-sv and the PNPC domains, with Spearman's rho correlation well above 0.80 (Osse et al., 2007). Convergent validity of the PNPC-sv was examined with a quality of life measurement, the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (EORTC QLQ-C30), and the correlations between the PNPC-sv and the EORTC QLQ-C30 were above 0.40 (Osse et al., 2007). The feasibility of the PNPC-sv was also well demonstrated with an average of five to 10 minutes to complete the whole scale (Osse et al., 2007). However, there is no Chinese version of the PNPC-sv. Before using the PNPC-sv in this study, a psychometric assessment study was performed first to identify the validity, reliability, and clinical feasibility of the PNPC-sv, Chinese version, for Chinese patients with advanced cancer, and details of this preparatory study will be presented in Chapter 6.

#### **5.4.5.2.2 Caregivers' needs: Comprehensive Needs Assessment Tool for Cancer Caregivers (CNAT-C)**

##### **(1) Selection of the appropriate scale for measuring the needs of informal caregivers**

Based on the study findings of systematic review II, the most commonly used instruments with satisfactory psychometric properties for needs assessment of informal caregivers were the Family Inventory of Needs (FIN), the Needs of Family Caregivers of Advanced Cancer Patients, the Comprehensive Needs Assessment Tool for Cancer Caregivers (CNAT-C), and the Supportive Care Needs Survey-Partners and Caregivers (SCNS-P&C), among which the FIN is a validated scale with 20 items, but this scale failed to identify clear dimensions for different needs (Kristjanson, Atwood, & Degner, 1995) and there is no Chinese version. The other three instruments, including the CNAT-C (Zhang et al., 2015b), the SCNS-P&C (Chen et al., 2014), and the Needs of Family Caregivers of Advanced Cancer Patients (Cui et al., 2014a), are all multidimensional scales for informal caregivers of cancer patients, and their psychometric properties have been well established for the Chinese versions, among which

only the Needs of Family Caregivers of Advanced Cancer Patients is specifically designed for cancer patients at an advanced stage; however, the seven dimensions of this scale do not match the needs domains for caregivers that were identified in systematic review II. In terms of the other two scales (the CNAT-C and the SCNS-P&C), the identified needs domains for informal caregivers are well covered by the dimensions in the CNAT-C (Shin et al., 2011; Zhang et al., 2015b). Considering all the issues mentioned above, the CNAT-C (see **Appendix IV**) was selected as the most appropriate scale for measuring the needs of informal caregivers in this study.

## **(2) The Comprehensive Needs Assessment Tool for Cancer Caregivers (CNAT-C)**

The CNAT-C is a needs assessment scale for the informal caregivers of cancer patients. It was originally developed by Dong Wook Shin et al. (2011) in Korea. This scale has 41 items with seven dimensions, including health and psychological support (six items), family and social support (five items), professional support (eight items), information support (eight items), spiritual support (two items), hospital facilities and services (six items), and practical support (six items) (Shin et al., 2011). Each item is measured with a 4-point Likert-type scale (0=no need, 1=low need, 2=moderate need, 3=high need), referring to the previous month (Shin et al., 2011). Higher scores indicate higher levels of need (Shin et al., 2011). The CNAT-C is a self-reported scale. After brief directions, the informal caregivers were instructed to complete the scale by circling a response to each item that was most suitable for their condition. The CNAT-C was validated in Mandarin Chinese in 2015 (Zhang et al., 2015b). The Chinese version of the CNAT-C scale has adequate validity and reliability. The internal consistency of the Chinese CNAT-C was tested using Cronbach's alpha, with a value of 0.94 for the total score and values of 0.61 to 0.93 for the seven dimensions (Zhang et al., 2015b). Test-retest reliability was reported as 0.85 for the overall scale and 0.80 to 0.97 for the seven dimensions (Zhang et al., 2015b). The split-half coefficient was measured as well, with 0.77 for the overall scale and 0.59 to 0.88 for each dimension (Zhang et al., 2015b). In terms of validity, confirmatory factor analysis was used and the fit indexes were deemed satisfactory, with chi-squared divided by the degrees of freedom equal to 1.98, the root-mean-square error of

approximation was 0.079, and the comparative fit index was 0.91 (Zhang et al., 2015b). The CNAT-C can be completed within 10 minutes, which shows good clinical feasibility (Zhang et al., 2015b).

#### **5.4.5.3 Associated variables**

##### **5.4.5.3.1 Physical distress: Edmonton Symptom Assessment Scale (ESAS)**

###### **(1) Selection of the appropriate scale for measuring the physical distress of patients**

For cancer patients, the Edmonton Symptom Assessment Scale (ESAS), the Memorial Symptom Assessment Scale-Short Form (MSAS-SF), and the M. D. Anderson Symptom Inventory-Cancer (MDASI-C) are three widely used instruments for measuring physical distress, and all three instruments have been validated in Chinese (Wen, Pang, Ding, Lu, & Yang, 2012), among which the ESAS is specifically designed for advanced cancer patients (Carvajal, Centeno, Watson, & Bruera, 2011; Moro et al., 2006; Nekolaichuk, Watanabe, & Beaumont, 2008; Wen et al., 2012). The other two instruments are generic scales for cancer patients at any stage. Therefore, the ESAS was selected as an appropriate instrument for this study to measure the physical distress of advanced cancer patients (see **Appendix V**).

###### **(2) The Edmonton Symptom Assessment Scale (ESAS)**

The ESAS is a valid and reliable tool for assessing common symptoms of advanced cancer patients. Since the development of the scale in 1991 (Bruera, Kuehn, Miller, Selmsler, & Macmillan), it has been adopted nationally across Canada and internationally for clinical, administrative, and research purposes (Carvajal et al., 2011; Moro et al., 2006; Nekolaichuk et al., 2008; Wen et al., 2012). The ESAS consists of 11 visual numerical scales (VNS), from 0 to 10, for pain, fatigue, nausea, depression, anxiety, drowsiness, shortness of breath, appetite, difficulty in sleeping, overall well-being, and 'other' (Dong et al., 2015). It is a self-managed scale, and higher scores indicate a greater severity of symptoms (0=absence of symptom and 10=worst possible intensity). The psychometric properties of the ESAS, Chinese version (C-ESAS), have been well tested (Dong et al., 2015), which showed that the C-ESAS was a good

tool for measuring multidimensional symptoms in Chinese patients. The internal consistency of the C-ESAS was 0.72 (Cronbach's alpha) (Dong et al., 2015). The test-retest reliability of the C-ESAS was reported with a range of 0.47 to 0.92 (Dong et al., 2015). The concurrent validity of the C-ESAS was examined with another symptom scale, the M. D. Anderson Symptom Inventory-Cancer (MDASI-C), and the Pearson's correlation coefficient ranged from 0.70 to 0.96 (Dong et al., 2015).

#### **5.4.5.3.2 Emotional status: Anxiety and Depression**

##### **(1) Selection of the appropriate scale for measuring anxiety and depression of both patients and caregivers**

For anxiety and depression, the commonly used scales include the Hospital Anxiety and Depression Scale (HADS), the Self-Rating Anxiety/Depression Scale, and the Beck Anxiety/Depression Inventory. All of these scales have been well validated in Chinese and have been commonly used for the cancer patients. It seemed that all of the scales would be appropriate for this study. However, compared with the HADS (14 items in total), both the Self-Rating Anxiety/Depression Scale and the Beck Anxiety/Depression Inventory have a larger number of items, which could have placed a greater burden on the participants and may result in more missing data (Tan, 2017). Moreover, only the HADS is a specific scale for individuals within the context of the hospital, and the psychometric properties of the HADS has been tested on Chinese cancer patients and their informal caregivers (Li et al., 2016). Therefore, the HADS was deemed to be the most appropriate scale for measuring the anxiety and depression of both patients and their informal caregivers in this study (see **Appendix VI**).

##### **(2) The Hospital Anxiety and Depression Scale (HADS)**

The HADS is an effective measure for both anxiety and depression, and it has been widely used in many studies in terms of cancer populations and family caregivers (Mitchell, Meader, & Symonds, 2010; Saboonchi, Wennman-Larsen, Alexanderson, & Petersson, 2013). The HADS is a self-reported measure. Participants can complete the scale in a very short time as it contains only 14 items in total with two sub-scales (seven items for the anxiety sub-scale

and seven items for the depression sub-scale) (Zigmond & Snaith, 1983). Each item is rated using a 4-point Likert-type scale, from 0 (not a problem) to 3 (high levels of the problem). The total score for each sub-scale ranges from 0 to 21, which can be obtained by summing up the score of each item (Li et al., 2016). Higher scores in each sub-scale indicate a greater severity of anxiety or depression. Scores between 8 and 10 are considered borderline, and those above 10 are indicative of clinical anxiety or depression (Molassiotis, Wilson, Blair, Howe, & Cavet, 2011a). The psychometric properties of the HADS, Chinese version, for cancer patients and their informal caregiver have been examined (Li et al., 2016). The internal consistency of the anxiety sub-scale (Cronbach's alpha) for cancer patients and informal caregivers was 0.874 and 0.857, respectively, and for the depression sub-scale it was 0.874 and 0.851, respectively (Li et al., 2016). The concurrent validity of the HADS was established by examining the negative correlations with the Medical Outcomes Study 12-item Short Form (SF-12), and the correlation coefficients for cancer patients and informal caregivers were 0.40 to 0.55 and 0.41 to 0.53, respectively (Li et al., 2016).

#### **5.4.5.3.3 Social support: Medical Outcomes Study-Social Support Survey (MOS-SSS)**

##### **(1) Selection of the appropriate scale for measuring the social support of both patients and caregivers**

The Duke-UNC Functional Social Support Scale, the Structural-Functional Social Support Scale (SFSS), and the Medical Outcomes Study-Social Support Survey (MOS-SSS) are three social support tools that have been widely used in cancer populations (Eom et al., 2013; Kalbfleisch, Cyr, Gregorio, & Nyhof-Young, 2015; Lehto-Järnstedt, Ojanen, & Kellokumpu-Lehtinen, 2004). The Duke-UNC Functional Social Support Scale contains 14 items, which measure four aspects, including quantity of support (three items), confidant support (four items), affective support (three items), and instrumental support (four items) (Broadhead, Gehlbach, De Gruy, & Kaplan, 1988). The SFSS is a multidimensional instrument with 12 items that measures the amount of received and needed social support given by supervisors (spouse/partner, families, etc.), relatives, friends, colleagues, and occupational healthcare service providers (physicians, nurses, etc.) (Lehto-Järnstedt et al., 2004); The MOS-SSS is

also a multidimensional instrument (19 items) that was particularly designed for investigating the social support of patients with chronic diseases (Sherbourne & Stewart, 1991). It measures four aspects of functional support, including emotional/informational support, tangible support, affectionate support, and positive social interaction (Sherbourne & Stewart, 1991). All three scales are multidimensional and the number of items is similar, which suggested that all of these were appropriate for use in this study. However, only the MOS-SSS has been validated in Chinese and its psychometric properties have been well documented in both Chinese patients (Yu, Lee, & Woo, 2004) and informal caregivers (Shyu, Tang, Liang, & Weng, 2006). The MOS-SSS therefore was utilized in this study (see **Appendix VII**).

## **(2) The Medical Outcomes Study-Social Support Survey (MOS-SSS)**

The MOS-SSS is a self-reported scale, with 19 items covering four sub-scales (emotional/informational support, tangible support, affectionate support, and positive social interaction) and one additional item measuring the structural dimension of social support and the amount of close relatives and friends of the participants (Kalbfleisch et al., 2015; Sherbourne & Stewart, 1991). Each of the 19 items is measured using a 5-point Likert-type scale to indicate how often the respondent received support, from 1 (none of the time) to 5 (all of the time) (Yu et al., 2004). The total score of each sub-scale can be transformed to a 0 to 100 scale using the following formula:

$$100 \times \frac{(\text{observed score} - \text{minimum possible score})}{(\text{maximum possible score} - \text{minimum possible score})}$$

Higher scores indicate better perceived social support (Yu et al., 2004). The MOS-SSS has been translated into traditional Chinese in Hong Kong (Yu et al., 2004) and Taiwan (Shyu et al., 2006), and its reliability and validity have been examined in heart failure patients (Yu et al., 2004) and informal caregivers of cancer patients (Shyu et al., 2006). In 2012, the MOS-SSS was introduced to mainland China and relevant psychometric properties were examined in patients with chronic diseases. Internal consistency was tested, with a Cronbach's alpha of 0.889 for the total score and 0.759 to 0.863 for the four sub-scales (Li, 2012). Test-retest reliability of the MOS-SSS total score was 0.77. The split-half reliability was 0.933 for the whole instrument and 0.757 to 0.846

for the four sub-scales (Li, 2012). Regarding construct validity, confirmatory factor analysis was used and the fit indexes were satisfactory (Li, 2012).

#### **5.4.5.3.4 Coping strategies: Brief Coping Orientations to Problems Experienced (Brief-COPE) scale**

##### **(1) Selection of the appropriate scale for measuring coping strategies of both patients and caregivers**

The Ways of Coping Scale (WOCS), the Jalowiec Coping Scale (JCS), the Brief Religious Coping Scale (RCOPE), and the Brief Coping Orientation to Problems Experienced (Brief-COPE) scale are the four most popular coping scales used for cancer patients and their informal caregivers. The WOCS is one of the most widely used coping measures, and the assessment of ‘what a person actually does within a specific situation rather than what the person typically does or thinks himself/herself will do’ is one of the strengths of this scale (Rexrode, Petersen, & O’Toole, 2008). However, this scale has up to 66 self-reported items (Lev et al., 2004). As the participants in this study were advanced cancer patients and their informal caregivers, the length of the questionnaire may have been one of the concerns when selecting an appropriate scale. The JCS also contains a large number of items (60 self-reported items) (Jalowiec, Murphy, & Powers, 1984). Moreover, neither the WOCS nor the JCS have been validated in a Chinese version. For the RCOPE, although there are only 14 items, it is a specific coping scale that assesses religious-related coping (Phelps et al., 2009). Therefore, the RCOPE was also not suitable for this study. The Brief-COPE scale is a 28-item self-reported coping scale (Carver, 1997), and it has been translated into Mandarin Chinese and the relevant psychometric properties have been tested. Thus, the Brief-COPE scale was determined to be the most appropriate scale for this study (see **Appendix VIII**).

##### **(2) The Brief Coping Orientations to Problems Experienced (Brief-COPE) scale**

The Brief-COPE scale was abbreviated based on the COPE Inventory (Carver, Scheier, & Weintraub, 1989) in 1997 (Carver). It is a 28-item self-administrated scale that measures both adaptive and maladaptive coping skills (Carver, 1997). It can be used to assess trait coping (the manner in which a person copes with stress in daily life) and state coping (how a person

cope with a specific stressful situation) (Wang, Lambert, & Lambert, 2007). The Brief-COPE scale contains four domains: (1) problem-focused coping (six items); (2) emotion-focused coping (six items); (3) adaptive coping (four items); and (4) maladaptive coping (12 items) (Carver, 1997). Each item is measured using a 4-point scale in terms of the extent to which the participant experienced coping (Carver, 1997), ranging from 0 ('haven't been doing this at all') to 3 ('I've been doing this a lot') (Carver, 1997). Higher scores indicate more frequent use of the coping strategies. The Brief-COPE scale has been translated into Chinese and has been widely used among many patients with chronic diseases, including stroke patients (Qiu & Li, 2008), HIV patients (Su et al., 2015), cancer patients (Li & Lambert, 2007), and informal caregivers of cancer patients (Han et al., 2014), with an internal consistency (Cronbach's alpha) of 0.82 for cancer patients (Li & Lambert, 2007) and 0.85 for informal caregivers of cancer patients (Han et al., 2014).

#### **5.4.5.3.5 Quality of life (QoL)**

##### **Advanced cancer patients**

##### **(1) Selection of the appropriate scale for measuring the quality of life of advanced cancer patients**

Three QoL instruments are commonly used in cancer studies, including the Functional Assessment of Cancer Therapy-General (FACT-G), the European Organisation for Research and Treatment of Cancer (EORTC) Quality-of-Life Questionnaire (EORTC QLQ-C30), and the Short Form (36) Health Survey (SF-36) (Ferrans, 2010). However, all of these tools are generic QoL instruments for cancer patients. For this study, an advanced cancer-specific scale would be much more powerful in terms of exploring these patients' particular QoL (Ferrans, 2010). Moreover, cancer patients at the palliation stage are extremely ill, so the questionnaire should be as brief and as focused as possible (Petersen et al., 2006). Thus, a valid and reliable instrument for advanced cancer patients was developed by Petersen et al. (2006), which was the EORTC Quality-of-Life Questionnaire Core 15-Palliative Care (QLQ-C15-PAL). This instrument is a much more appropriate tool compared with the others, and the psychometric



properties of the Chinese version of the QLQ-C15-PAL have been examined, showing that it is an effective tool for determining health-related QoL in Chinese patients with advanced cancer in Mainland China (Zhang et al., 2016a). Given all the concerns above, the QLQ-C15-PAL was adopted for this study as the most appropriate instrument for measuring the quality of life of patients with advanced cancer.

## **(2) The EORTC Quality-of-Life Questionnaire Core 15-Palliative Care (QLQ-C15-PAL)**

The QLQ-C15-PAL consists of two function scales (physical—three items—and emotional—two items), seven symptom scales, with one to two items for each, and one global quality-of-life item (Zhang et al., 2016a) (see **Appendix IX**). All items are scored with a 4-point Likert scale (1=not at all and 4=very much), with the exception of the one global quality-of-life item, which is scored with a modified 7-point linear analogue scale (Zhang et al., 2016a). The cross-cultural adaptability and validity of the Chinese version of the QLQ-C15-PAL scale have been examined (Zhang et al., 2016a). The completion rate was high, with the highest missing rate for each item at only 2.1% (Zhang et al., 2016a). Internal consistency was tested and the Cronbach's alphas were generally above 0.7 across all the sub-scales (Zhang et al., 2016a). For validity, the patients were divided into two groups based on their Eastern Cooperative Oncology Group Performance Status or divided into three groups according to mental status, and both sets of results showed that the QLQ-C15-PAL could distinguish between the patients in the aforementioned sub-groups (Zhang et al., 2016a). Moreover, the sub-scales of the QLQ-C15-PAL explained 84.8% and 90.3% of the original EORTC QLQ-C30 score distribution, with the proportion of variance ( $R^2$ ) ranging from 0.848 to 0.903 (Zhang et al., 2016a).

## **Informal caregivers**

### **(1) Selection of the appropriate scale for measuring the quality of life of informal caregivers**

Many general quality-of-life measures have been developed, but only a few measurement scales have been designed specifically for informal caregivers (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). The Caregiver Quality-of-Life Index (CQOLI), the Quality of Life

Tool (QOL Tool), and the Caregiver Quality of Life Index-Cancer (CQOLC) are three commonly used instruments for informal caregivers (Deeken et al., 2003), among which the CQOLI and the QOL Tool are two generic instruments. The CQOLC is the only instrument designed specifically for the informal caregivers of cancer patients (Deeken et al., 2003), and it has been translated into Chinese (Duan, 2012). Moreover, the CQOLI is not a multidimensional tool as there are only four items in total. Thus, the CQOLC was the most appropriate instrument for this study (see **Appendix X**).

## **(2) The Caregiver Quality of Life Index-Cancer (CQOLC)**

The CQOLC is a specific scale developed by Weitzner, Jacobsen, Wagner, Friedland, and Cox (1999) to evaluate the QoL of informal caregivers of cancer patients. It is a self-administered rating scale with four domains (burden, disruptiveness, positive adaption, and financial concerns). Each item is scored by a 5-point Likert-type scale (0=not at all, 1=a little bit, 2=somewhat, 3=quite a bit, and 4=very much). A total score is calculated by adding all item scores, which ranges from 0 to 140. Higher scores reflect poorer quality of life (Weitzner et al., 1999). Since 1999, it has been translated into and validated among many languages, such as Korean (Rhee et al., 2005), Turkish (Bektas & Ozer, 2009), traditional Chinese (Tang, Tang, & Kao, 2009), and simplified Chinese (Duan, 2012). The psychometric properties of the simplified Chinese version of the CQOLC have been tested (Duan, 2012). Internal consistency was examined and the Cronbach's alpha was 0.884 for the total score. The test-retest reliability of the total score was 0.821 and split-half reliability was 0.793 (Duan, 2012). For the validity of the scale, exploratory factor analysis was used, and the index ranged from 0.66 to 0.88 and the total cumulative was 59.69% (Duan, 2012). The criterion validity of the CQOLC was judged using the SF-36 and it showed good validity (Duan, 2012).

### **5.4.6 Data analysis**

Data were entered into statistical software to create datasets for statistical analysis. IBM SPSS Statistics for Windows, version 25.0 (IBM Corp., Armonk, NY, USA), was utilized for data analysis. The significance level was set as  $p < 0.05$ , and a two-tailed test was used for all the

statistical analysis. Data management and analysis for this cross-sectional survey involved the following three aspects: (1) data entry and cleaning; (2) descriptive statistics; and (3) hypothesis testing.

#### **5.4.6.1 Data entry and cleaning**

All collected survey data was coded with numbers, and relevant data was entered into the statistical programme directly by the doctoral researcher. The datasets were checked against the paper recordings of raw data to ensure that the data coding was correct. To maintain the validity of statistical analysis, data cleaning is an important procedure (Portney & Watkins, 2000, p. 626). After entering all the data, data cleaning was therefore carried out by the doctoral researcher and another doctoral graduate at The Hong Kong Polytechnic University School of Nursing, including checking for incorrectly entered data, missing data, and outliers. Categorical variables were checked by generating frequency counts to identify the frequency of the codes and possible missing values for each variable (Portney & Watkins, 2000, p. 626). Continuous variables were checked using corresponding descriptive statistics, including the maximum value, minimum value, and mean score, to examine whether the score range fell within the normal scope (Portney & Watkins, 2000, p. 626).

#### **5.4.6.2 Statistical analysis**

Statistical analysis for the cross-sectional survey included both descriptive statistics and inferential statistics. IBM SPSS Statistics for Windows, version 23.0 (IBM Corp., Armonk, NY, USA) was employed.

#### **Descriptive statistics**

Descriptive statistics were used to present response rates during the process of recruitment and to summarize the sample characteristics and outcome measures. For the sample characteristics, continuous data including age were presented as mean (M) and standard deviation (SD), while the categorical data, including education background, marital status, employment status, religious background, family monthly income, types of cancer, length of time since diagnosis, cancer stage, surgery or not, types of treatments, and having complications or not, were

presented as absolute numbers and percentages. For the data of outcome measures, descriptive statistics ( $M \pm SD$ ) was used to describe the characteristics of the palliative care needs of advanced cancer patients, the needs of their informal caregivers, the physical distress of the patients, and anxiety and depression, social support status, coping strategies, and quality of life of both the patients and their informal caregivers.

### **Hypothesis testing**

Inferential statistics was used to test the hypotheses in this study. To perform the most appropriate statistical tests, data distribution for each scale and sub-scale was first assessed using skewness and kurtosis (Hae-Young, 2013). According to the reference values regarding normality test (Hae-Young, 2013), an absolute skew value larger than 2 or an absolute kurtosis value larger than 7 are used as reference values to determine substantial non-normality when the sample size is greater than 300. In this study, the sample size was significantly larger than 300, and both the absolute skew value and kurtosis value were less than 2 and 7; thus, the data was determined as normality and a parametric test was employed in this study. The relationship between the independent and dependent variables was preliminarily explored using univariate analysis for categorical independent variables and correlation analysis for the continuous variables.

In this study, the dependent variables were the palliative care needs of advanced cancer patients and the needs of their informal caregivers, and the independent variables (as per the conceptual framework presented in Chapter 5, page 125) included baseline data, the physical distress of the patients, and anxiety and depression, coping strategies, social support, and quality of life of both the patients and their informal caregivers. For the categorical independent variables, independent t-tests (two means) and one-way ANOVA (three or more means) were conducted to explore the differences in needs in relation to the baseline information (categorical variables) of the patients and their informal caregivers. For continuous independent variables, Pearson's correlation coefficient ( $r$ ) was used to describe the strength and direction of a linear relationship between each potential influencing factor

(independent variables) and the dependent variable. A correlation coefficient of  $r \cong 0.30$  indicates a weak association,  $r=0.30-0.59$  indicates a moderate association, and  $r \cong 0.60$  represents a strong association (Martínez-Martín et al., 2007).

If differences and correlations were identified (either in a positive or a negative direction) with statistically significant ( $p < 0.05$ ), these relevant variables were further introduced into the next multiple regression analysis to quantify the unique contribution of each potential independent variable to the dependent variable. Multiple regression analysis, a form of general linear modelling, is a multivariate statistical method to explore the specific relationships between a single dependent variable and many independent variables and to identify the independent variables necessary to predict the dependent variables (Hair, 2006). The stepwise multiple linear regression approach is a method of regressing multiple independent variables while simultaneously removing those that are not important (Lyu, 2016). The stepwise approach combines the advantages of forward and backward approaches (Lyu, 2016). Hair (2006) suggested that the number of predictor variables to include in the equation should be considered when using regression analysis. It was recommended by Stevens (1996, as cited by Courtney, 2012, p. 72) that ‘for social science research, about 15 subjects per predictor are needed for a reliable equation.’ In this study, the sample size was determined as 428 (428 patients and 428 caregivers) based on research question 1 and question 3, which allowed for the exploration of a maximum of 28 predictor variables for patients and caregivers, respectively. Variables that showed statistical significance (cut-off point  $p < 0.05$ ) in the univariate analysis and correlation analysis were included in the regression analysis using the stepwise variable-selection method with entrance and removal levels of  $p \leq 0.05$  and  $p \geq 0.10$ , respectively. Stepwise multiple linear regression can be regarded as an appropriate approach in this study for identifying potential predictors of dependent variables as long as the predictor variables finally included in the regression analysis were equal to or less than 28. The predictors of the palliative care needs of the patients with advanced cancer and the needs of the informal caregivers were explored separately using stepwise multiple linear regression.

Dummy variables were set in terms of the independent variables (categorical variable) with three or more categories. Pearson's correlation coefficient was employed to preliminarily explore the general linear relationships between the palliative care needs of advanced cancer patients and the needs of their informal caregivers without distinguishing the dependent and independent variables. Additional analysis can be conducted in future to further explore their relationships by considering the identified influencing factors of the needs of both patients and caregivers.

#### **5.4.7 Summary of Phase One**

This section will present a summary of the design of the cross-sectional survey, which aimed to quantify the palliative care needs of patients with advanced cancer and the needs of their informal caregivers, the predictors of their needs, and the relationship between the needs of advanced cancer patients and those of their informal caregivers. Two study sites were involved for subject recruitment, and the sample size was determined to be 428 for advanced cancer patients and 428 for informal caregivers. The advanced cancer patients and their informal caregivers were recruited in dyads using convenience sampling.

The primary outcomes were the palliative care needs of advanced cancer patients and the needs of their informal caregivers, which were measured by the PNPC-sv and the CNAT-C, respectively. The potential associated factors (predictors) of the needs of the patients and their informal caregivers were selected based on a proposed conceptual framework, which included sociodemographic factors (age, gender, marital status, education background, income level, living place, etc.), clinical factors (cancer site, cancer stage, treatment therapies, etc.), psychological factors (anxiety and depression measured by the HADS, coping strategies measured by the Brief-COPE scale, and QoL measured by the QLQ-C15-PAL for the patients and the CQOLC for the informal caregivers), physical factors (physical distress measured by the ESAS), and status of social support (measured by the MOS-SSS). The sociodemographic and clinical variables were collected using a self-designed Baseline Data Assessment Form.

Both descriptive statistics and inferential statistics were utilized for data analysis. The predictors of the palliative care needs of the advanced cancer patients and the needs of their informal caregivers were identified separately using the stepwise multiple linear regression approach. The design of the qualitative study will be detailed in the following.

## **5.5 Phase Two: Qualitative interviews**

### **5.5.1 Reasons for exploring unmet information needs via a qualitative study**

As mentioned in Section 5.3, this doctoral research project employed a quantitatively driven multimethod study design. The quantitative portion, a cross-sectional survey, provided a way to quantify the palliative care needs of advanced cancer patients and their informal caregivers. The follow-up qualitative interviews in this study were designed based on the findings of the quantitative survey, which served as a complementary method with a different set of strengths to improve the overall ability of the research design to achieve the study's goals. According to the quantitative results, information needs as a frequently reported need was identified in both Chinese advanced cancer patients and their informal caregivers (details of the results can be found in Chapter Seven, Section 7.4.1 and Section 7.8, respectively). This finding was different from the findings of our systematic review (Wang et al., 2018b), which showed that physical and psychological needs were much more prevalent than information needs, particularly for the patients. Moreover, this finding was also inconsistent with a study on Dutch patients using the same measurement (PNPC-sv), in which a majority of unmet needs were concentrated in the psychological domain (Osse et al., 2005).

Although information need was identified as a frequently reported unmet need in both patients and their informal caregivers, little information could be drawn from the quantitative results particularly for the patients because only one item was included in the PNPC-sv questionnaire to measure their information needs. Thus, qualitative interviews could further elaborate and clarify patients' unmet information needs in detail. In addition, the identified predictors in the quantitative survey could only partly account for 13.2% and 28.2% occurrence of information needs for advanced cancer patients and their informal caregivers, respectively (details of the

results can be found in Chapter Seven, Section 7.6.8 and Section 7.10, respectively). To further elaborate and to better explain and expand upon the quantitative findings within the Chinese context, the information needs of both patients and their informal caregivers were worth further exploring through a qualitative approach. A qualitative interview was therefore designed to further elaborate the patients' and their informal caregivers' unmet information needs and to further explore their perceptions and experiences regarding the prominent unmet information needs that were identified in the quantitative survey.

### **5.5.2 Study design**

The qualitative descriptive design has been commonly used in qualitative studies, particularly in healthcare sciences and nursing-related phenomena (Polit & Beck, 2009). This design is a 'vast' and 'open' descriptive approach in terms of answering qualitative research questions (Lyu, 2016). According to Sandelowski (2010), the qualitative descriptive design can contribute to a better and in-depth understanding of many human situations, including health and illness experiences. This design underpins the concept of naturalistic inquiry and examines a phenomenon in its natural state (Sandelowski, 2000a). The purpose of a qualitative descriptive study is to achieve a pure description, and it does not always follow a specific qualitative research tradition (Sandelowski, 2000b). The qualitative description was promoted by Sandelowski (2000a, p. 336) as a well-developed method to provide a 'comprehensive summary of an event in the everyday terms of those events.' In this study, the qualitative research objectives (as described in Section 5.2) were to elaborate and clarify the unmet information needs of advanced cancer patients and their informal caregivers, and to gain an in-depth understanding of their perceptions and experiences in relation to their information needs. Given all the concerns mentioned above, the qualitative descriptive design was deemed appropriate to address the research objectives, and therefore it was employed in Phase Two of the doctoral research project.

Data collection techniques for the qualitative descriptive design typically include individual interviews and focus groups using structured or semi-structured interview questions/guides



(Kim, Sefcik, & Bradway, 2017). The technique that was selected and used for data collection in this study will be elaborated in the following section.

#### **5.5.2.1 Reasons for using semi-structured interviews for data collection**

Individual interviews and focus groups are two commonly used qualitative research approaches in health sciences research (Britten, 1999; Legard, Keegan, & Ward, 2003). Using interviews as a data collection technique can help ‘explore the views, experiences, beliefs and/or motivations of individuals on specific matters’ (Gill, Stewart, Treasure, & Chadwick, 2008, p. 292). Structured interviews, semi-structured interviews, and unstructured interviews are three commonly used individual interviews in research.

Structured interviews are usually conducted using questionnaires. The interview questions are predefined and fixed, and no changes and modifications are allowed during the implementation of the interview (Gill et al., 2008). In this study, many questionnaires were used in the quantitative survey, so the method of structured interviews would not allow an in-depth exploration of certain research questions in relation to unmet information needs.

Unstructured interviews are an approach without any predefined questions, which plays a necessary role when a very intensive depth of exploration is needed, particularly when the research questions are totally new topics (Gill et al., 2008). However, having no predefined questions renders the whole interview process weak in management and organization (Gill et al., 2008).

As for semi-structured interviews, it is currently the most popular and commonly used approach for qualitative data collection in healthcare research (Gill et al., 2008) because it combines the strengths and eliminates the weaknesses of structured and unstructured interviews. An interview guide with several predefined questions in relation to the research questions is usually used to provide guidance on what to talk about and allows the interviewer or interviewee to diverge in order to pursue an idea or response in more detail (Gill et al., 2008). The semi-structured interview also leaves some space for researchers to further explore

some particular aspects of the research questions, which can enable an in-depth understanding of the participants' perceptions and/or experiences of the focused research topics (Britten, 1999; Gill et al., 2008).

Focus groups are another type of qualitative data collection method, which can be utilized in healthcare research to explore participants' attitudes, views, experiences, and needs regarding particular research topics (Gill et al., 2008; Kitzinger, 1995). However, this approach usually requires about six to eight participants to participate at a particular time point, which could have been problematic in this study because the majority of the study participants in this doctoral research project came from rural areas and all the patients were at an advanced stage. It would have been difficult to gather sufficient patients and informal caregivers for focus groups.

Given all the concerns mentioned above, the semi-structured interview was selected as the most appropriate approach for this doctoral project to explore the perceptions and experiences of the patients and their informal caregivers regarding the unmet information needs that were identified in the quantitative survey. The study design of the semi-structured interviews will be described in the following sections.

### **5.5.3 Study sample and setting**

Given that the objectives of the qualitative interviews were to further clarify the identified unmet information needs and to explore the perceptions and experiences of advanced cancer patients and their informal caregivers in relation to their unmet information needs, a purposive sampling method was adopted to recruit participants, from early February 2019 to the end of March 2019, until data saturation was reached. The participants, both advanced cancer patients and informal caregivers, from the two study sites who met the following criteria were invited to participate in the interviews: (1) had participated in the Phase One cross-sectional survey and completed all the questionnaires; (2) reported unmet information needs (for patients, it was determined using the PNPC-sv questionnaire with the answer of 'yes, more' for the question 'Do you want professional attention for this?'; for informal caregivers, it was

determined using the CNAT-C with answers of moderate or high levels of need for information); (3) were physically capable of having an interview that lasted 30 to 60 minutes, particularly for patients (if necessary, this was determined by the physicians); and (4) agreed to participate in the interviews and were willing to share their views and/or experiences. Data saturation was achieved through repetition and confirmation of information obtained by the participants (Corbin & Strauss, 2008). The interviews took place in an interview room, demonstration room, ward, or other places at the study hospitals that were quiet and convenient for the interviewees to ensure the participants' privacy.

#### **5.5.4 Study procedure**

The participants, both advanced cancer patients and informal caregivers, who met the inclusion criteria (as described in the section above) were invited to participate in the interviews. If the patients or the informal caregivers showed interest, the doctoral researcher approached them and explained the purpose and the process of the interview to them. All participants were informed and assured that they had the right to refuse or withdraw from the study at any time, and that this would not affect the healthcare services they or their loved ones received in any way. Those who were willing to participate were required to sign a written consent form (see **Appendix I**) and provide their contact details. Then, the doctoral researcher negotiated with each participant to arrange the most appropriate time and location to conduct the interview, and all the interviews were scheduled for the time and location that were convenient for the participants.

All of the interviews were conducted by the doctoral researcher, and the interviews of the patients and informal caregivers were performed separately. Prior to the commencement of each interview, the doctoral researcher gave a brief self-introduction again and repeated the research purposes and procedures of the interview to the participant. During each individual interview, a semi-structured interview guide was used for data collection. The interview guide was developed by the doctoral researcher based on the research question 7 and question 8 (as presented in Section 5.2.2), which aimed to further elaborate the unmet information needs of

both patients and caregivers as well as their experiences in relation to the information needs; because the quantitative findings that information need identified as one frequently reported unmet need in both patients and caregivers were inconsistent with our systematic review (Wang et al., 2018b) and some other previous studies (Osse et al., 2005), and very limited information can be drawn from the Phase One quantitative survey. A series of qualitative studies and mixed-methods studies that investigated patients' and/or informal caregivers' views and/or experiences in relation to information needs (James-Martin, Koczwara, Smith, & Miller, 2014; Jepson, Hewison, Thompson, & Weller, 2007; Kemp et al., 2018; Kwok & White, 2014; O'Callaghan et al., 2016; Taylor, 2011; Tsuchiya & Horn, 2009; Uysal, Toprak, Kutlutsürkan, & Erenel, 2018) were also used as references for the development of the interview guide in this study. Besides, the development of the interview guide also followed the recommendations and suggestions provided by the two academic supervisors of the doctoral researcher, who are familiar with qualitative research. The semi-structured interview guide consisted of six core open-ended questions, and the details of the interview guide (English version and Chinese version) are displayed in **Appendix XI**.

The patients and informal caregivers were invited to express their information interests, as well as their experiences, thoughts, and feelings in terms of their unmet information needs and currently available information resources. Probes were used by the doctoral researcher during the interview process to ask the participants to elaborate more about their thoughts and ideas or to give some examples when describing certain issues. Prior to the commencement of the formal interviews, pilot interviews were conducted by the doctoral researcher to test the validity of the questions in the proposed interview guide and to practice and test the interview skills of the researcher (Griffiee, 2005). The transcript of the pilot interview was reviewed by one of the academic supervisors of the doctoral researcher.

Moreover, before the commencement of this study, the doctoral researcher completed a qualitative research methodology subject and gained some experience in conducting a semi-structured interview and analysing qualitative study data. The process of each interview was

audio-recorded. The confidentiality of the participants' information and discussions were all assured by the doctoral researcher.

### **5.5.5 Data analysis**

The interviews were conducted by the doctoral researcher in Mandarin Chinese, and each interview was audio-recorded using a digital recorder. The doctoral researcher recorded field notes during the interview process and/or immediately after the semi-structured interviews. The interview data were transcribed verbatim by a helper with a master's degree in nursing who was not involved in the qualitative interviews, the doctoral researcher, and another nursing researcher (TJY) with a qualitative research background. After that, the transcripts were checked against the original audio-taped records to ensure that all the records were correct and accurate.

Qualitative content analysis, a commonly used strategy for a qualitative descriptive study, was employed in this study to analyse the data, which allows 'the researchers to stay close to the data, with minimal transformation during analysis' (Kim et al., 2017, p .24). Categories are the primary product of a qualitative content analysis, which mainly refers to 'a descriptive level of content and can thus be seen as an expression of the manifest content of the text' (Chu, 2009, p. 75). A category is a group of content that shares a commonality (Krippendorff, 2018). It has also been pointed out that categories are internally homogeneous and externally heterogeneous (Patton, 1987 as cited by Chu, 2009, p. 75). Some others have emphasized that categories must be mutually exclusive, which indicates that data should not fit into more than one category or between two categories (Elo & Kyngas, 2008; Vaismoradi, Jones, Turunen, & Snelgrove, 2016). To establish analytical categories, a constant comparison method was required to identify and examine whether the data was best fit into the category (Vaismoradi et al., 2016). A category may include several sub-categories, and the sub-categories can be combined and abstracted into a category (Graneheim & Lundman, 2004). Sub-categories focus on one notable specific content or aspect but share the same central organizing concept as the category (Vaismoradi et al., 2016).

The ‘four phases of category development’ method proposed by Vaismoradi et al. (2016) was employed to guide the qualitative data analysis, which includes ‘initialization’, ‘construction’, ‘rectification’, and ‘finalization’. In the initial phase of ‘initialization’, the transcribed data were read and re-read many times by the doctoral researcher to be familiar with the qualitative data, as ‘the ability to generate ideas and make sense of data depends on researchers’ closeness to data through immersion’ (Vaismoradi et al., 2016, p. 103). Contents (phrases, sentences, and/or paragraphs in the transcriptions) that were relevant to the research questions were highlighted as the meaning units. Then, the meaning units were further condensed and coded, which is an important process of data reduction in qualitative approaches (Vaismoradi et al., 2016).

The ‘construction’ phase is a process of classifying and comparing the initial codes in terms of the similarities and diversities, and then assigning the codes to different groups based on the research questions (Vaismoradi et al., 2016). Due to the principle of ‘mutually exclusivity’, a code that is attributed to more than one classification group should be assigned only to the one that fits best (Insch, Moore, & Murphy, 1997; Krauss, 2005). Each group that covers similar codes was then assigned a label to give a sense of the main ideas, and these labels are usually taken from the ‘conversation topics, meaning, feelings, and proverbs found or generated by [the] researcher during reading transcriptions’ (Vaismoradi et al., 2016, p. 105). The next step is defining and describing the label to improve the level of abstraction of data analysis and to generate the initial categories and sub-categories (Vaismoradi et al., 2016).

To achieve a relative certainty about the developed categories and sub-categories, another important phase called ‘rectification’ was conducted. In this phase, the researcher reappraised the analysis process, as researchers are recommended to ‘distance themselves from the data for a period of time so as to increase their sensitivity and reduce any premature and incomplete data analysis’ (Vaismoradi et al., 2016, p. 106). During this process, the initial categories and sub-categories were reviewed and checked at either the level of the coding process or the level of the whole dataset, and further modifications of the categories and sub-categories were made at this stage (Vaismoradi et al., 2016).

After all the categories and sub-categories were identified and confirmed, the final phase of ‘finalization’ took place, which involves reporting the content analysis results to answer the research questions (Vaismoradi et al., 2016). For each category and/or sub-category, representative data (quotes) that extracted from the transcriptions were used to support each of the reported categories and/or sub-categories and a final report was produced.

Descriptive content analysis was used in this study following the ‘four phases of category development’ method. A coding structure was developed first by the doctoral researcher and two other independent qualitative researchers. They coded several transcripts independently and then compared the results to achieve consistency after their discussions. After that, based on the coding structure, the doctoral researcher completed the rest of the analysis. To ensure the objectivity of the data analysis, ongoing discussions among the doctoral researcher, her supervisors, two other independent researchers, and the study participants were performed during the whole process of data analysis. To maintain the study’s trustworthiness, several approaches were used during the processes of study implementation, data analysis, and final report writing, and the relevant strategies will be detailed in Section 5.6.3.

#### **5.5.6 Summary of Phase Two**

This section will presented the design of the semi-structured interviews. The subjects were recruited among those who completed the cross-sectional survey using purposive sampling. A predefined interview guide with several open-ended questions was used to guide the interviews to explore the types of information that the advanced cancer patients and their informal caregivers wanted and to explore the patients’ and informal caregivers’ perceptions and experiences in relation to their information needs. Qualitative content analysis was used to analyse the data.

### **5.6 Study team, study quality assurance, and ethical considerations of the research project**

#### **5.6.1 Study team and training of study team members**

The study team consisted of seven core members, which included the doctoral researcher, her two academic supervisors, two oncology nurses, and two research assistants. The whole study was mainly implemented by the doctoral researcher. The doctoral researcher is a registered nurse in China who has a master's degree in nursing and has experience of conducting cross-sectional surveys with large sample sizes. The doctoral researcher was primarily responsible for subject recruitment and the administration of the whole study. However, given that the study sites were located in two different cities and the doctoral researcher could not collect data from the two study sites at the same time, two research assistants were invited to participate at one of the study sites. Prior to the commencement of the survey, the doctoral researcher visited the study site and provided face-to-face training to the two research assistants to standardize the research procedure, the verbal communication between researchers and the study participants, and the neutral interpretations of the questionnaire items. After the training, an assessment was conducted between the researcher and the research assistants to ensure consistency. The two oncology nurses in this study were responsible for the eligibility assessment of the potential participants (one for each study site). For the interview data collection, all the interviews were conducted by the doctoral researcher. During her doctoral study at The Hong Kong Polytechnic University, the doctoral researcher successfully completed a qualitative subject, and one of her academic supervisors, who is a qualitative researcher, helped to improve her interview skills through practice prior to the commencement of the interviews. The whole study was designed and implemented with the support and guidance of the two academic supervisors. The research team was therefore capable for managing both the quantitative and qualitative study in the project.

### **5.6.2 Study quality assurance for the phase one cross-sectional survey**

To minimize the potential risks of bias, several strategies were proposed to maintain the study quality of the cross-sectional survey as follows.

#### **(1) Choosing scales with good psychometric properties and an appropriate number of items**



For a cross-sectional study, many scales are usually used to measure the outcomes, and the reliability of the study findings is closely associated with the validity and reliability of the scales. In this study, all the instruments used were scales with well-established psychometric properties, which ensured the reliability and validity of the study findings. For the PNPC-sv questionnaire, there was no Chinese version, and a validation study was conducted first to examine its validity and reliability within the Chinese culture before the final implementation of this scale in this study (the psychometric properties of the PNPC-sv questionnaire will be presented in Chapter Six). The majority of the selected scales were specific to the issues that were measured, which promoted the accuracy of the findings. For example, the PNPC-sv questionnaire was particularly designed to assess the palliative care needs of cancer patients at an advanced stage, and the CQOLC is a specific scale used for quality of life assessment in relation to the informal caregivers of cancer patients. To minimize the nonresponse rate and missing data, the number of items in the scales was considered when choosing the scales. Moreover, the researcher and the research assistants were required to check the scales immediately after the participants completed the questionnaire booklets. If there were any missing data or scribbled answers, the participants were asked to complete their answers.

## **(2) Providing standard training for the research assistants**

To ensure consistency among the research assistants and the researcher, the doctoral researcher (WT) visited the study sites and provided face-to-face training to the two research assistants prior to the commencement of the survey. The training programme included the research aims and objectives, the study procedures, purpose of and instructions for each scale, how to introduce and guide the participants in filling out the scales, how to interpret the terms in the scales, how to provide a neutral interpretation if the participants felt confused about terms or items in the scale, how to provide assistance to elderly participants or participants with vision problems (e.g., read aloud word by word), and how to communicate with the participants in a friendly manner and establish a good relationship with them. During the study process, the

researcher kept in contact with the research assistants and had regular video meetings with them to ensure the quality of the study's implementation.

### **(3) Double-checking the data**

As this was a cross-sectional survey with a large sample size, a huge amount of data was managed and analysed. To minimize mistakes, all data were double-checked by the researcher and another student helper before conducting data cleaning.

### **5.6.3 Study quality assurance for the phase two semi-structured interviews**

The rigor and trustworthiness of the semi-structured interviews were maintained by the following four indicators: credibility, transferability, dependability, and confirmability (Anney, 2014; Lincoln & Guba, 1985).

Credibility refers to the truth of the data and findings (interpretation and representation) (Anney, 2014). In this study, several strategies were used to ensure the credibility of the qualitative part:

- (1) Ensure participants' honesty in contributing data (Shenton, 2004): The participation of all participants was on a voluntary basis, and only those who were really willing to take part in the study and express their views freely were included. Moreover, all the participants were those who had taken part in the survey.
- (2) Build trust and rapport between the doctoral researcher and the interviewees (Anney, 2014): Before the qualitative interviews were conducted, a cross-sectional survey was conducted first in the study hospitals and the researcher stayed in the study hospital for 10 months. During this period, the researcher built trust and rapport with the participants.
- (3) Frequent debriefing (Anney, 2014): This was performed between the doctoral researcher and her two supervisors. During the process of data collection, the doctoral researcher reported the study's progress to her two supervisors regularly by email

communication and face-to-face meetings to timely recognize her own biases and preferences.

- (4) Member checking (Anney, 2014): This was used to ensure that the findings were true to the informants' expressed meanings. Several participants were invited to read the transcripts of the dialogues in which they participated to check whether the words matched what they actually intended to express. The identified categories and sub-categories were sent back to some of the participants to check whether these categories really indicated their perceptions and experiences.
- (5) Separate coding (Anney, 2014): Some transcripts were coded independently by the doctoral researcher and two other experienced qualitative researchers with PhD degrees (LXL and CHL). The majority of the codes were agreed upon easily. For any disagreement, consistency was achieved through discussion among the doctoral researcher, the two qualitative researchers, and the supervisors of the doctoral researcher. After finalizing the coding structure, the doctoral researcher completed the rest of the coding and the results were discussed among the doctoral researcher and her two supervisors until agreement was achieved.

In relation to the extracted categories and representative quotes that were listed in the qualitative study results section, two bilingual translators (English and Mandarin Chinese, WT and TJY) translated the quotes (forward and backward translation) to ensure the equivalence of the participants' descriptions between the different languages (English and Mandarin Chinese). A third party was involved when inconsistency existed between the two bilingual translators.

Transferability is the external validity of a study, which refers to the degree to which the findings can be transferred to other situations (Anney, 2014). Positivists have stated that it is impossible to demonstrate the transfer of qualitative findings and conclusions to other situations and populations as qualitative studies are specific to a small number of participants within a particular environment (Shenton, 2004). While some have argued that although each case may be unique, it is also an example of a broader group (Denscombe, 1998; Stake, 1994,

pp. 236-247). In this study, transferability was ensured by providing thick descriptions of the research context and findings, and sufficient and representative extracts (i.e., vivid quotes from the participants) were used to support the identified categories and sub-categories. A detailed description of this study intended to help readers determine how far the results and conclusions could be transferred to other situations. As Li (2004, p. 305) has suggested, a detailed description to 'enable judgments about how well the research context fits other contexts, thick descriptive data, i.e. a rich and extensive set of details concerning methodology and context, should be included in the research report.'

Dependability refers to 'the stability of findings over time' (Bitsch, 2005, p. 86). In this study, dependability was ensured by taking the following measures. First, the qualitative part in this thesis was reported in detail based on the Standards for Reporting Qualitative Research (SRQR) (O'Brien, Harris, Beckman, Reed, & Cook, 2014). Moreover, some transcripts were analysed by more than two researchers separately and the results were compared to achieve consistency. Details of this strategy (i.e., separate coding approaches among different researchers) was elaborated in the credibility section above. The code-recode strategy (Anney, 2014) was also used in this study. The doctoral researcher code-recoded the data twice, with an interval period between each coding, to see whether the results from the two codings were similar. A comparison of the results from the two codings was conducted among the doctoral researcher and her two supervisors. Finally, to ensure dependability, the study design and study process were reported in detail in this thesis to enable a future researcher to develop a thorough understanding of the study and to repeat the work. The concept of confirmability is 'the qualitative investigator's comparable concern to objectivity' (Shenton, 2004, p. 72). In this study, the coding data, sub-categories, and categories were shared with the participants and experts in oncology and qualitative methodology to ensure that the results were not based on the doctoral researcher's preferences but were the real thoughts and views of the participants (Shenton, 2004).

#### **5.6.4 Ethical considerations**

Ethical approvals of this project were obtained from the Research Committees of The Hong Kong Polytechnic University and the three study hospitals (the Affiliated Hospital of Southwest Medical University, the Affiliated Hospital of North Sichuan Medical College, and the Fifth Affiliated Hospital of Zunyi Medical University) before the implementation of this study (see **Appendix XII**). As this study involved human subjects, the following ethical principles were considered and followed during the whole study process (Beauchamp & Childress, 2009; World Medical Association, 2001).

### **The Principle of Autonomy**

All study participants were clearly informed of the following issues: (1) why the study was being done; (2) the full study procedure; and (3) the potential risks and benefits of the study. Based on their personal values and beliefs (Beauchamp & Childress, 2009), the participants had the right to decide whether to participate in the study or not. An information sheet (see **Appendix XIII**) was provided for every potential participant, and a written informed consent form (see **Appendix I**) was obtained from every eligible person who agreed to participate after the risks and benefits of the study had been fully explained both verbally and in writing. The contact number of the researcher was provided to the participants for any further inquiry. Participation in the study was on a voluntary basis, and all potential participants were informed and assured that they had the right to refuse to participate in or withdraw from the study at any time and that it would not result in any negative effects regarding their care, treatment, and other healthcare services.

### **The Principle of Confidentiality**

All potential participants were informed and assured that any information they provided would be used for research purposes only. Researchers must not use or disclose information gained from the participants without the confider's authorization (Beauchamp & Childress, 2009). To ensure confidentiality and anonymity in this study, every document collected from the participants was coded with a number rather than the participants' name or clear identifiers, and all data were only accessible to the researcher and her two academic supervisors. Hard

copies of the study data (e.g., questionnaires, etc.) were kept by the researcher in a locked cabinet, and the electronic copies (e.g., audio data from the interviews) were stored in an encrypted computer file. All the data will be destroyed five years after the study.

### **The Principle of Non-maleficence and Beneficence**

Non-maleficence means do no harm to the participants (Beauchamp & Childress, 2009). Researchers cannot conduct any action that may put the participants at risk (Andersson et al., 2010). Beneficence means ‘all forms of action intended to benefit other person[s]’ (Beauchamp & Childress, 2009, p. 197). This study intended to learn about palliative care needs using a cross-sectional survey and interviews. Potential risks to the participants were minimal. There was only a small risk that the patients would feel sad when they were talking about their unhappy experiences in the interviews. For these cases, some psychological support was provided for free. If the interviewee felt extremely uneasy or sad, the interview was stopped (which did not happen in this study). Because this study involved no interventions, no biomedical procedures, and no drugs, there was no possibility of physical harm. This study added new knowledge in this area, providing evidence for improving current healthcare services in terms of better meeting the needs of advanced cancer patients and their informal caregivers.

### **5.7 Summary of this chapter**

This chapter presented the whole research methodology of this doctoral research project. This study employed a multimethod research design (a quantitatively driven project followed by a qualitative project [QUAN→qual]). Phase One was a cross-sectional survey and Phase Two was a follow-up qualitative descriptive study using semi-structured interviews. Before reporting the study findings of the cross-sectional survey and the semi-structured interviews, a preparatory study examining the psychometric properties of the Chinese version of the PNPC-sv questionnaire will be presented first in the next chapter, including the background, study design, results, and discussion.

**Chapter Six: Preparatory Study: Psychometric Properties of the PNPC-sv  
Questionnaire, Chinese Version**

## **6.1 Introduction**

The PNPC-sv is a scale that was specifically designed for measuring the palliative care needs of advanced cancer patients, and it was selected and used in this current study to measure the palliative care needs of Chinese advanced cancer patients (rationales of selection are presented in Section 5.4.5.2.1). However, there is no Chinese version of the PNPC-sv. Before using the PNPC-sv in this study, a psychometric assessment study was conducted first to examine the validity, reliability, and clinical feasibility of the PNPC-sv for Chinese patients with advanced cancer. Details of this preparatory study are presented in this current chapter. The background, methods, results, and discussion of this preparatory study will be reported in this chapter in Section 6.2 to Section 6.6. It should be noted that this validation study has already been published in an international peer-reviewed journal (Wang, Molassiotis, Chung, & Tan, 2019). In order to fit into the whole structure and organization of this doctoral thesis, the major contents, text citations, and reference list of the published validation study have been slightly modified by the doctoral researcher. According to the publisher, this published validation paper is ‘an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited’ (Source: <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0450-5>).

## **6.2 Background**

Experiences and symptom distress of cancer patients vary across their illness trajectory (Waller et al., 2012a). Cancer patients at an advanced stage usually encounter more difficulties in optimising their well-being than those at an early-stage, which subsequently contribute to a poor quality of life and an increasing demand of care needs (Sanson-Fisher et al., 2000; Waller et al., 2012a). Quality of life is the patients’ subjective view of their overall life satisfaction and their sense of well-being, which involves multidimensional components including physical, psychological, social, etc. (Chu, 2009). According to the definition proposed by the World Health Organization (World Health Organization, 2002), palliative care is an approach that aims to optimize patients’ well-being and improve quality of life through addressing their



multidimensional problems and needs. A recent systematic review conducted by our group highlighted that advanced cancer patients had a wide range of palliative care needs and their needs were somewhat context-bound (Wang et al., 2018b). Patients with unsolved problems and unmet needs experience poor health status and quality of life (Cheng, Wong, & Koh, 2016). Assessing patients' care needs in a given setting therefore is important for developing tailored palliative care services to overcome their problems and meet their needs. Healthcare services that are inconsistent with their care needs would increase healthcare cost and result in negative effects such as increasing patient's anxiety and decreasing quality of life (Wen & Gustafson, 2004).

Providing tailored palliative care services requires systematic and comprehensive assessment first, and such an assessment could be supported better by a valid and specific instrument (Wang et al., 2018a). Several instruments have been developed and used in advanced cancer patients, and have been critically evaluated in a recent systematic review conducted by our group (Wang et al., 2018b); not all the assessed instruments reported adequate evidence with regards to their psychometric properties (Wang et al., 2018b). Multidimensional instruments with well-documented psychometric properties were scant and the commonly used scales in current practice and research were the Supportive Care Needs Survey (SCNS), Problems and Needs in Palliative Care questionnaire (PNPC), and the Needs Assessment of Advanced Cancer Patients (NA-ACP) (Sanson-Fisher et al., 2000).

The SCNS is a generic tool rather than a specific one for patients at advanced stage. The two other instruments (PNPC and NA-ACP) were particularly designed for advanced cancer patients and cover the majority of the palliative care needs of advanced cancer patients (Osse et al., 2004; Rainbird et al., 2005). However, the NA-ACP has 132 items, which might overburden patients and contribute to missing data (Tan, 2017). Besides, patients might not want professional care support for each of the problems they experience (Steinert & Rosenberg, 1987). The PNPC questionnaire was designed considering this issue, and it assesses patients'

problems and to which extent they want care support to address their problems (needs for care) separately (Osse et al., 2004).

The PNPC questionnaire was first developed in 2004 through a series of rigorous procedures including in-depth interviews with patients, their life companions and health professionals, literature review, expert panel discussion, and repeated adjustment (Osse et al., 2004). The original language of the PNPC questionnaire was Dutch and it has been translated into English (Osse et al., 2004). The original version consisted of 90 items; thus, patients needed a long time to complete the entire questionnaire.

To improve its feasibility and utility, the PNPC-shorter version (PNPC-sv) with 33 items was subsequently developed in 2007 (Osse et al., 2007). Its psychometric properties have been examined, with adequate validity, reliability and feasibility (Osse et al., 2007). The PNPC-sv, as a simple and user-friendly instrument, has been translated and utilized in both research and clinical practice in some countries (Effendy et al., 2015a; Khan et al., 2012). Due to the absence of such an instrument in China, the aims of this study were to translate the PNPC-sv questionnaire into Mandarin Chinese and determine its reliability, validity and feasibility in a heterogeneous group of Chinese patients with advanced cancer.

## **6.3 Methods**

### **6.3.1 Study design**

This was a validation study using a forward- and backward- translation procedure, a panel of experts and a cross-sectional study design, from October 2017 to April 2018. A convenience sampling approach was used for subject recruitment. Ethical approvals were granted by the Human Subjects Ethics Sub-Committee at The Hong Kong Polytechnic University and the study hospitals. Written informed consent was required from each study participant.

### **6.3.2 Translation of the PNPC-sv questionnaire**

The original English version was translated into Mandarin Chinese following a forward- and backward-translation procedure (Sousa & Rojjanasrirat, 2011). Four independent translators

(two each for forward and backward translation) were included with the following inclusion criteria (Sousa & Rojjanasrirat, 2011): (1) were bilingual, including English and Mandarin Chinese; and (2) had different backgrounds, were knowledgeable about the terminology used in health science, and were familiar with colloquial phrases, idiomatic expressions, and health care slang and jargon in Mandarin Chinese.

#### **6.3.2.1 Forward translation**

The original English version of the PNPC-sv was translated into Mandarin Chinese by two translators separately. The first author and a nursing academic (who was bilingual in English and Mandarin Chinese, had a PhD degree in nursing, and has accumulated rich research experience in cancer and palliative care) compared the two translated Chinese versions from ambiguities and discrepancies of the words and sentences. Different translations were identified for five items (14, 19, 20, 27, and 28). Discussions among the researcher, nursing academic, and the two translators were conducted to reach an agreement.

#### **6.3.2.2 Backward translation**

The preliminary translated Chinese version of the PNPC-sv questionnaire was translated back into English by two other independent translators who were blind to the original English version. The equivalence of the original and back-translated English versions was assessed and compared by a panel, consisting of the researcher, all four translators and the nursing academic. Different opinions were raised regarding items 20, 27, and 28 (item 20—‘Finding others not receptive to talking about the disease’; item 27—‘Difficulties to be engaged usefully’; and item 28—‘Difficulties to be avail for others’). Discussions were conducted among the panel and further revisions were made to reach agreement.

#### **6.3.3 Readability and clarity test of the translated version**

As recommended by Koller et al. (2007), 10 adult (>18 years old) Chinese advanced cancer patients (stage III or stage IV) with different background (e.g., education level, age, and occupation) were included using a purposive sampling approach. After they completed the entire questionnaire, participants were asked six questions regarding the readability and clarity

of the PNPC-sv to determine if the items in the questionnaire were easy to read and understand and if any of the items have particular ambiguous, discrepant and sensitive expressions. Those six questions were designed based on previous studies (Kakehi et al., 2002; Tan, Suen, & Molassiotis, 2016) and group discussions among the researchers: Q1) 'Is the instrument useful to record your problems and needs that you experienced during your cancer trajectory? [0-10 numerical rating scale [NRS] from 0 (totally useless) to 10 (totally useful)]'; Q2) 'Is the instrument easy for you to complete? [0-10 NRS scale from 0 (extremely difficult) to 10 (extremely easy)]'; Q3) 'Are there any difficulties in understanding any of the items? (yes /no, no=0, yes=1)? If yes, please specify.'; Q4) 'Are there any sensitive items or words that make you not want to fill out the instrument? (yes /no, no=0, yes=1)? If yes, please specify.'; Q5) 'How long did it take you to complete the instrument (minutes)?'; and Q6) 'Do you have any other comments and recommendations? Please specify'.

Participants reported that the PNPC-sv Mandarin Chinese version can comprehensively assess their existing problems, with the score of Q1 rating from 7 to 10 (mean: 8.5). The PNPC-sv was also regarded as a scale easy to understand (Q2 mean: 8.5), and the average time for completing the questionnaire was 11.4 minutes. No patient complained about sensitive and/or abstract words or items. The completion rate was high, without any missing data in any item. This translated version was confirmed with satisfactory readability and clarity and was further used in the next study phase to examine its psychometric properties.

#### **6.3.4 Sample and sample size calculation**

Eligible patients were recruited from three tertiary hospitals in China (participants of the phase one cross-sectional survey as per Chapter 5 were recruited from two of the tertiary hospitals) based on the following inclusion criteria: (1) a confirmed diagnosis of cancer at advanced stage (stage III or stage IV); (2) aged above 18 years; (3) able to communicate in Chinese Mandarin; (4) agreed to participate in this study and willing to sign the informed consent; and (5) emotionally, cognitively, and physically capable of study participation.

Cengiz et al. (2015) proposed that the sample size for estimating the reliability of an instrument should be five to 10 times larger than the total items of the scale. The PNPC-sv has 33 items, the sample size therefore should be at least 165 patients. Hobart et al. (2012) suggested that 20 and 80 subjects were the minimal sample size for the reliability and validity estimation, respectively. Considering the above recommendations, 165 was used as the estimated sample size of this study. By considering additional 8% of missing data, the sample size was finally determined as 178.

### **6.3.5 Data collection procedures**

The content validity of the translated version of the PNPC-sv was evaluated through a panel of six experts specialized in cancer care and/or palliative care using the Content Validity Assessment Form (see **Appendix XIV**). Half of the experts had more than 15 years of clinical or research experience. Three were professors or associated professors working in universities or tertiary hospitals, while the other three were lecturers or senior lecturers with more than five years of experience in cancer-related research. Four experts had a doctoral degree and two had a master's degree. The panel used a 4-point Likert scale ('4=very relevant', '3=quite relevant', '2=somewhat relevant' and '1=not relevant') to assess the cultural relevance and translation equivalence of each item. Oncologists or oncology nurses helped to screen and identify the patients who met the inclusion criteria at the study hospitals. Detailed information of the study purpose and procedures were elaborated by the researcher before inviting them to participate in this study. Patients who agreed with study participation were asked to sign a written consent. Each patient was then asked to complete a demographic questionnaire, the translated Chinese PNPC-sv questionnaire and the EORTC QLQ-C30. Participants completed all the questionnaires anonymously and they returned the questionnaires to the researchers immediately after completion. For any missing data or scribbled answer, the participants were asked for clarification. The PNPC-sv was self-administered, and the researchers provided assistance to patients who were unable to complete it on their own by reading the items as they were in the scale and not providing any further clarification.

### **6.3.6 Study questionnaires**

#### **6.3.6.1 Demographic questionnaire**

A demographic questionnaire specific for this validation study was designed. The items included age, gender, educational background, income level, place of residence, religion and marital status, and illness-related information including diagnosis, cancer stage and relevant treatments, etc.

#### **6.3.6.2 Problems and Needs in Palliative Care-short version (PNPC-sv)**

The PNPC-sv has 33 items and covers eight domains of problems and palliative care needs of advanced cancer patients including daily activities (three items), physical (nine items), autonomy (four items), social (five items), psychological (five items), spiritual (four items), financial (two items) and information (one item) issues (Osse et al., 2007). The PNPC-sv consists of the Problem part and the Need for Care part (Osse et al., 2007). In each item, the patients were asked two questions (Osse et al., 2007): (1) ‘Do you experience the item to be a problem?’, which belongs to the Problem part with the answer of ‘yes’, ‘somewhat’, and ‘no’; and (2) ‘Do you need (extra) professional attention for the item?’, which belongs to the Need for Care part with the answer of ‘yes, more’, ‘as much as now’, and ‘no’. In terms of the PNPC-sv scoring system for the psychometric assessment purpose, the scoring method of the original questionnaire (Osse et al., 2007) and the recommendations from the researcher who developed the PNPC-sv were adapted (‘yes’=2, ‘somewhat’/‘as much as now’=1, and ‘no’=0). Higher scores indicate more problems and stronger care needs. The psychometric properties of the Problem part and the Need for Care part were determined separately.

#### **6.3.6.3 European Organisation for Research and Treatment of Cancer Quality-of-Life Questionnaire Core 30 (EORTC QLQ-C30)**

As with the original version of the PNPC-sv, the QLQ-C30 was used to test the concurrent validity of the PNPC-sv Mandarin Chinese version (see **Appendix XV**). This scale is a self-administered QoL scale which was specifically designed for cancer patients (Aaronson et al., 1993). It consists of 30 items, with five scales assessing functional status (physical, role,

emotional, cognitive, and social), three symptom scales (pain, fatigue, and nausea, and vomiting), a global health status/QoL scale, and some single items measuring other symptoms which are frequently reported by cancer patients, and one item regarding financial difficulties (Aaronson et al., 1993). Higher scores for each sub-scale indicate poorer QoL. While for the global health status /QoL scale, higher score represents better QoL. Satisfactory psychometric properties of the QLQ-C30 have been reported in Chinese cancer patients (Wan et al., 2008).

### **6.3.7 Psychometric assessment**

#### **6.3.7.1 Validity**

Content validity, face validity, concurrent validity and construct validity were examined. A panel of six experts identified the content validity through a 4-point Likert scale. Face validity was examined by asking patients and experts several questions regarding the feasibility, usability and clarity of the PNPC-sv. Concurrent validity is ‘how well a test correlates with another test that has already had its validity estimated’ (Newman & Newman, 1994, p. 53), which was measured by exploring the relationships between the PNPC-sv and the QLQ-C30. Sub-scales in the PNPC-sv that do not have corresponding dimensions in the QLQ-C30 were not included in the concurrent validity test (Osse et al., 2007). The total scores and sub-scores of the PNPC-sv and the QLQ-C30 were hypothesized to be significantly correlated with each other. For construct validity, confirmatory factor analysis was performed to evaluate the fitness of original model of the PNPC-sv to the present data. Besides, the construct validity was also evaluated using contrasted group analysis, which is an approach used for identifying differences between known groups to demonstrate different traits on a construct of measurement (Terwee et al., 2007). Based on previous studies (Fitch, 1994; Wang et al., 2018b), differences in the total scores and sub-scores of the PNPC-sv were compared between patient subgroups with different gender, age, marital status, educational level, living place, and cancer stage. It was hypothesized that female patients would have higher scores in the psychological, physical and ADL sub-scales; single patients would demonstrate higher scores in the psychological sub-scale; scores of financial problems and needs would be higher among

patients with lower education and those living in countryside; elderly patients would report higher scores in terms of ADL and physical sub-scales, but lower financial scores; and the scores of physical and psychological sub-scale would be higher among stage IV cancer patients (Fitch, 1994; Wang et al., 2018b).

### **6.3.7.2 Reliability and acceptability**

Internal consistency reliability of the PNPC-sv Mandarin Chinese version was measured by Cronbach's alpha (Frost et al., 2007). Item-to-total correlations were examined to test how well each item score correlates with the overall PNPC-sv score (Bohrstedt, 1969). Test-retest reliability was not measured given that problems and palliative care needs of advanced cancer patients are not stable as they usually experience rapid progression or deterioration (Waller et al., 2012a). Completion rate and the six questions (as mentioned before) were used to determine its acceptability and feasibility.

### **6.3.8 Data analysis**

Data analysis was conducted using the IBM SPSS 22.0 and the IBM SPSS Amos 24.0. All statistical tests were two-tailed and the significance level was set as  $P < 0.05$ . Descriptive statistics were used to present the demographic characteristics of the patients. The content validity index (CVI) was adopted to measure content validity of the scale. CVI for each PNPC-sv item was examined by the proportion of items which were rated as 'very relevant' or 'quite relevant' (Lynn, 1986; Rubio, Berg-Weger, Tebb, Lee, & Rauch, 2003; Waltz, & Bausell, 1981) by the expert panel. The item was regarded as content valid when at least five out of six experts rating it as 'very relevant' or 'quite relevant' (Lynn, 1986). The average CVI across items was used to present the content validity of the entire PNPC-sv scale, and a CVI of 0.83 or above was viewed as a satisfactory agreement level (Lynn, 1986; Rubio et al., 2003). Structural Equation Modelling was used to evaluate the relationships between structural paths and factors. The goodness-of-fit indicators including chi-squared ( $\chi^2$ ) divided by degrees of freedom ( $\chi^2/df$ ), Root-Mean-Square Error of Approximation (RMSEA), the Comparative Fit Index (CFI), the Tucker-Lewis index (TLI), and the Root Mean square Residual (RMR) were



employed to assess the fit of the original model to this sample data (Schreiber, Nora, Stage, Barlow, & King, 2006). The criteria for a good fit were  $1.0 < \chi^2/df < 3.0$ ,  $RMSEA \leq 0.08$ ,  $CFI \geq 0.90$ ,  $TLI \geq 0.90$ , and  $RMR \leq 0.05$  (Arpaci & Baloğlu, 2016). If the model did not fit the data adequately, items with a factor loading of 0.4 or below could be considered for removal (Malakouti, Fatollahi, Mirabzadeh, Salavati, & Zandi, 2006), but whether it should be deleted or not would finally be determined based on both the statistical and judgmental criteria for scale-purification (Wieland, Durach, Kembro, & Treiblmaier, 2017) (details are elaborated in the discussion section). The normality of each independent variable (demographic characteristics) was explored by using the Kolmogorov-Smirnov tests. A Mann-Whitney U test was finally utilized for the contrasted group analysis because all the variables violated the assumption of normal distribution. For concurrent validity, Spearman's correlations were used to explore the relationships between the PNPC-sv and the QLQ-C30. A correlation coefficient of 0.40 or above was regarded as substantial for conceptually related scales (Kaasa et al., 1995; Lim, Seubsman, & Sleigh, 2008). Reliability was tested using Cronbach's alpha and item-to-total correlations. Alpha values and values of item-to-total correlations were regarded as acceptable when they reached 0.65 and 0.40 or above, respectively (DeVellis, 2003).

## **6.4 Results**

### **6.4.1 Psychometric properties assessed by expert panel**

#### **6.4.1.1 Content validity and face validity**

A panel of six experts were invited and two rounds of content validity assessment were performed. In round one, some comments and suggestions were provided for items 10, 17 and 29. For example, three experts suggested changing the 'sexual dysfunction' (item 10) to '...affecting sexual life', which could make this expression less sensitive within the conservative Chinese culture (Tan, 2017). With considering those suggestions and comments, item 10 was revised. In the second-round, all six experts agreed that the PNPC-sv is specifically designed for measuring problems and palliative care needs of advanced cancer

patients and all items are culturally appropriate. A CVI of 1.0 was achieved at both the item-level and the scale-level.

Patients further reported that the PNPC-sv is a useful instrument to assess their problems and needs and the mean score was 7.99 (SD=1.48). Almost all of the participants reported that the items were not particularly sensitive and easy to understand. Only one patient reported the item 16 ('experiencing loss of control over one's life') was a little difficult to understand, and item 10 ('affecting sexual life') and item 29 ('difficulties concerning the meaning of death') were reported somewhat sensitive by three and one patient, respectively.

#### **6.4.2 Psychometric properties assessed via the patients**

##### **6.4.2.1 Demographic and clinical characteristics of the patients**

Of the 178 patients who participated in the study, 174 completed all the questionnaires. Regarding recruitment, 96.6% of the patients were recruited from inpatient settings. More than 60% of the patients were male and younger than 60 years old, 75.9% had a middle school education or below, and most of the patients were married (94.8%) and employed (80.5%). Almost a third of (31%) of the participants had lung cancer, while a smaller proportion had: nasopharyngeal (17.2%); colorectal (16.7%); cervical (12.1%) or other gynecological cancers (6.3%). Most (60%) had advanced cancer (stage IV) (see **Table 6.1**).

**Table 6.1** Demographic and clinical characteristics of the study sample (N=174)

<b>Demographic and Clinical Characteristics</b>		<b>N(%)</b>
<b>Age (year)</b>	<60	109(62.6%)
	≥60	65(37.4%)
<b>Gender</b>	Female	69(39.7%)
	Male	105(60.3%)
<b>In/outpatient</b>	Inpatient	168(96.6%)
	Outpatient	6(3.4%)
<b>Education level</b>	Middle school education or below	132(75.9%)
	High school education or above	42(24.1%)
<b>Marital status</b>	Single	9(5.2%)
	Married	165(94.8%)
<b>Employment status</b>	Technical staff	24(13.8%)
	Manual worker	57(32.8%)
	Housewife	10(5.7%)
	Clerical/admin	17(9.8%)
	Self-employed	32(18.4%)
	Unemployment	8(4.6%)
	Retired	26(14.9%)
<b>Religion</b>	Non/Not Indicated	145(83.3%)
	Buddhism	26(14.9%)
	Taoism	3(1.8%)
<b>Location of living place</b>	Countryside	80(46.0%)
	City	94(54.0%)
<b>Living status</b>	Living alone	3(1.7%)
	Living with family	171(98.3%)
<b>Types of cancer</b>	Lung cancer	54(31.0%)
	Nasopharynx cancer	30(17.2%)
	Colorectal cancer	29(16.7%)
	Cervical cancer	21(12.1%)
	Gynecological cancer	11(6.3%)
	Liver cancer	5(2.9%)
	Breast cancer	4(2.3%)
	Oesophageal cancer	3(1.7%)
	Oral cancer	6(3.4%)
Others	11(6.4%)	
<b>Stage of cancer</b>	III	70(40.2%)
	IV	104(59.8%)

#### 6.4.2.2 Acceptability and descriptive analysis of the scale

The acceptability of the PNPC-sv questionnaire was satisfactory with the completion rate of 97.6%. The majority of the patients reported the PNPC-sv is easy to understand. The average time to complete the questionnaire was 11 minutes. Percentages of each PNPC-sv item reported to be either a problem or somewhat a problem by the patients ranged from 7.5% to 83.9%, with financial problems were the most prominent issue (69.5% to 83.9%). For the

indicated problems, 10.3% of the patients had the need for professional attention and support. (see **Table 6.2**)

#### 6.4.2.3 Reliability

Cronbach’s alpha coefficient for the total scale of Problem part and Need for Care part was 0.88 and 0.91, respectively. Cronbach’s alpha coefficients for all the sub-scales within the Problem part ranged from 0.58-0.79, while they were 0.69-0.85 for the sub-scales within the Need for Care part (see **Table 6.2**). The majority of the item-to-total correlations were above 0.40.

**Table 6.2** Cronbach’s alpha reliability: Total scale and sub-scales

PNPC-sv Dimensions	No. of Items	PNPC Problem Part		PNPC Need for Care Part	
		Range in percentage of ‘somewhat’ and ‘yes’ (%)	Cronbach’s alpha	Range in percentage of ‘as much as now’ and ‘yes’	Cronbach’s alpha
<b>ADL</b>	3	30.5-42.0	0.75	27-29.3	0.81
<b>Physical</b>	9	20.1-54.0	0.61	13.2-54.3	0.72
<b>Autonomy</b>	4	25.1-52.3	0.79	27-45.4	0.84
<b>Social</b>	5	7.5-23.6	0.75	10.3-20.1	0.79
<b>Psychological</b>	5	30.5-49.4	0.78	23-42.5	0.85
<b>Spiritual</b>	4	19.5-38.5	0.68	19.5-27.6	0.80
<b>Financial</b>	2	69.5-83.9	0.58	63.2-82.8	0.69
<b>Information</b>	1	42.5	NA	43.1	NA
<b>Total scale</b>			0.88		0.91

Note: NA=not applicable

#### 6.4.2.4 Construct validity

The goodness of fit indexes for the Problem part were  $\chi^2=700.8$ ,  $\chi^2/df=1.58$ , RMSEA=0.06, CFI=0.83, TLI=0.81, and RMR=0.04. For the Need for Care part, the corresponding indexes were  $\chi^2=907.354$ ,  $\chi^2/df=2.05$ , RMSEA=0.07, CFI=0.81, TLI=0.79, and RMR=0.03. The CFI and TLI in both the Problem part and Need for Care part were slightly below the cut-off values of 0.90. The factor loading ranged from 0.12 to 0.79 for Problem part and from 0.23 to 0.87 for Need for Care part. The items with factor loading less than 0.4 were all in the physical factor including item 8—‘Itch’, item 9—‘Sexual dysfunction’, item 10—‘Prickling or numb sensation’, and item 11—‘(Nightly) Sweating or hot flushes’. Considering that all these four

symptoms were not uncommon theoretically and clinically in advanced cancer patients, the four items were not deleted after a group discussion with clinicians and researchers in cancer care to maintain its clinical value.

#### **6.4.2.5 Contrasted groups validity**

Female participants reported higher scores regarding global and some sub-scores including ADL, psychological, and spiritual domains ( $p<0.05$ ) for both the Problem part and needs-for-care part (see **Table 6.3**). Higher scores were presented in older patients regarding ADL, physical, social problems and the global score of the Problem part ( $p<0.05$ ). Younger patients demonstrated more financial problems ( $p<0.05$ ). Similar results were detected for the needs-for-care part, with older patients having higher needs scores for ADL, physical, and social support ( $p<0.05$ ), and older patients reported lower score for financial needs ( $p<0.05$ ) (see **Table 6.4**). Patients who were living in countryside had higher scores for the financial needs ( $p<0.001$ ). Except for psychological needs ( $p<0.05$ ), no significant differences were detected in the marital status of patients. Single patients had lower scores of psychological needs ( $p=0.045$ ). In terms of the educational level, patients with middle school education or below reported higher scores of financial problems ( $p<0.01$ ) and financial needs ( $p<0.001$ ). Stage IV cancer patients had higher scores regarding the autonomic and social problems ( $p<0.05$ ) as well as higher global score of the Problem part ( $p<0.05$ ) than patients with stage III cancer. Similar trend was detected in the Need for Care part.

**Table 6.3** Differences in total and sub-scores of the PNPC-sv between female and male subjects

Dimensions	Female		Male		Z Value	P Value
	n	Mean Rank	n	Mean Rank		
<b>Problem Part</b>						
ADL	69	99.63	105	79.53	-2.685	<b>0.007<sup>a</sup></b>
Physical	69	92.66	105	84.11	-1.100	0.271
Autonomy	69	91.93	105	84.59	-0.962	0.336
Social	69	87.04	105	87.80	-0.113	0.910
Psychological	69	101.54	105	78.28	-3.017	<b>0.003<sup>a</sup></b>
Spiritual	69	98.29	105	80.41	-2.400	<b>0.016<sup>a</sup></b>
Financial	69	87.67	105	87.39	-0.038	0.970
Information	69	94.79	105	82.71	-1.746	0.081
Global Problem Score	69	98.28	105	80.27	-2.338	<b>0.019<sup>a</sup></b>
<b>Need for Care Part</b>						
ADL	69	99.26	105	79.77	-2.728	<b>0.006<sup>a</sup></b>
Physical	69	91.50	105	84.87	-0.857	0.392
Autonomy	69	93.17	105	83.78	-1.265	0.206
Social	69	84.64	105	89.38	-0.731	0.465
Psychological	69	100.11	105	79.21	-2.776	<b>0.006<sup>a</sup></b>
Spiritual	69	97.03	105	81.24	-2.230	<b>0.026<sup>a</sup></b>
Financial	69	88.44	105	86.88	-0.211	0.833
Information	69	92.75	105	84.05	-1.255	0.210
Global Problem Score	69	97.28	105	81.07	-2.079	<b>0.038<sup>a</sup></b>

**Note:** a=Statistic reached a level of statistical significance.

**Table 6.4** Differences in total and sub-scores of the PNPC-sv between different age groups

Dimensions	<60ys		≥60ys		Z Value	P Value
	n	Mean Rank	n	Mean Rank		
<b>Problem Part</b>						
ADL	109	81.14	65	98.17	-2.250	<b>0.024<sup>a</sup></b>
Physical	109	80.78	65	98.77	-2.288	<b>0.022<sup>a</sup></b>
Autonomy	109	83.53	65	94.16	-1.379	0.168
Social	109	81.06	65	98.30	-2.507	<b>0.012<sup>a</sup></b>
Psychological	109	84.99	65	91.71	-.862	0.389
Spiritual	109	83.89	65	93.55	-1.281	0.200
Financial	109	94.87	65	75.15	-2.699	<b>0.007<sup>a</sup></b>
Information	109	83.94	65	93.47	-1.362	0.173
Global Problem Score	109	81.55	65	97.48	-2.020	<b>0.043<sup>a</sup></b>
<b>Need for Care Part</b>						
ADL	109	81.83	65	97.00	-2.099	<b>0.036<sup>a</sup></b>
Physical	109	79.51	65	100.90	-2.734	<b>0.006<sup>a</sup></b>
Autonomy	109	84.68	65	92.23	-1.006	0.314
Social	109	80.79	65	98.75	-2.743	<b>0.006<sup>a</sup></b>
Psychological	109	83.94	65	93.48	-1.253	0.210
Spiritual	109	84.82	65	92.00	-1.003	0.316
Financial	109	93.45	65	77.52	-2.130	<b>0.033<sup>a</sup></b>
Information	109	83.72	65	93.85	-1.444	0.149
Global Problem Score	109	81.77	65	97.11	-1.945	0.052

**Note:** a=Statistic reached a level of statistical significance.

### 6.4.2.6 Concurrent validity

Significant positive correlations were found between PNPC-sv and QLQ-C30 in terms of the majority of the sub-scale scores, with the correlation coefficients ranging from 0.19 to 0.56 in the Problem part and from 0.24 to 0.60 in the Need for Care part. Significant negative correlations were identified between the total score of PNPC-sv and the score of global health status of QLQ-C30, with the correlation coefficient of -0.48 and -0.42 for the Problem part and Need for Care part, respectively. Correlations identified between the Problem part of PNPC-sv and QLQ-C30 were better than that between the Need for Care part of PNPC-sv and QLQ-C30 for the majority of the sub-scales (see **Table 6.5**).

**Table 6.5** Correlations between the PNPC-sv and the EORCT QLQ-C30

PNPC-sv Dimensions	QLQ-C30 Dimensions Expected to Correlate	PNPC Problem Part	PNPC Need for Care Part
		Spearman's Correlation	Spearman's Correlation
ADL	Physical Functioning	0.563**	0.597**
Physical	Fatigue	0.509**	0.588**
	Nausea and Vomiting	0.200**	0.129
	Pain	0.581**	0.519**
	Dyspnoea	0.509**	0.337**
	Insomnia	0.437**	0.358**
	Appetite Loss	0.196**	0.250**
Financial	Financial Difficulties	0.363**	0.477**
Social	Social Functioning	0.188*	0.243**
Psychological	Emotional Functioning	0.527**	0.499**
Global Scores	Global Health Status	-0.484**	-0.419**

**Note:** This table shows Spearman's rho correlations of sum scores of proposed PNPC-sv dimensions with corresponding dimensions of the EORTC QLQ-C30. \*\*: The correlations are significant at 0.01. \*: Significant at 0.05.

## 6.5 Discussion

The PNPC-sv is currently the only scale designed to evaluate both the problems of advanced cancer patients and to which extent they need care support to address their problems (palliative care needs). The PNPC-sv was initially developed in Dutch (Osse et al., 2004), and it was subsequently translated into English (Osse et al., 2007) and Indonesian (Effendy et al., 2015a).



The psychometric properties of the Indonesian version were not reported (Effendy et al., 2015a). This paper presents the first validation study of the PNPC-sv Mandarin Chinese version in advanced cancer patients. Conceptual and cultural equivalence between the original and the Mandarin Chinese version of the PNPC-sv were well maintained through a forward and backward translation approach, which enables the Mandarin Chinese version of the PNPC-sv to be culturally relevant to Chinese advanced cancer patients (World Health Organization, Process of translation and adaptation of instruments). Excellent content validity was identified with the CVI value being higher than 0.83 (Lynn, 1986; Rubio et al., 2003). Face validity was documented, as patients reported that the PNPC-sv questionnaire can comprehensively cover and assess their existing problems and palliative care needs. Usability and clarity of this tool were well supported by the responses of both the panel experts and the patients. Given patients completing the questionnaire within a relatively short time and the good completion rate, the PNPC-sv was proved to be a convenient and user-friendly tool. Such a convenient instrument will produce less burden on patients and minimizes the risk of missing data.

Concurrent validity of the PNPC-sv was adequate with moderate or strong correlations identified in majority of the sub-scales, which was similar to the original version (Osse et al., 2007). The significant negative associations between the total scores of the PNPC-sv and global health status of the QLQ-C30 supported that patients who had more problems and care needs experienced poorer health status and QoL (Cheng et al, 2016). Statistically significant correlations were also observed between the majority of the sub-scales of PNPC-sv (problem and Need for Care part) and QLQ-C30, confirming that the PNPC-sv and the QLQ-C30 are conceptually related. As expected, the correlations of QLQ-C30 were statistically stronger regarding the Problem part than the Need for Care part and weak correlations were identified for a few sub-scales. Such findings were similar to the psychometric assessment results of the original version (Osse et al., 2007). A possible explanation might be the difference in the focus of the PNPC-sv and the QLQ-C30. The QLQ-C30 scale mainly assesses patients' quality of life through capturing the problems they experienced, while patients' needs for professional care are not its focus. Compared with the psychometric assessment study of the original

version of the PNPC-sv, significant correlations between the PNPC-sv and the QLQ-C30 were observed in more sub-scales in this study, which may be partially attributed to a larger sample size in the current study.

Factor analysis has been regarded as one of the commonly utilised methods in psychological measures development and evaluation. In this study, the value of CFI and TLI were slightly lower than the recommended cut-off points (0.90), which might indicate that the original model did not well fit this sample data adequate. However, the CFI and TLI value were close to the threshold of 0.90. Meanwhile, according to the critical value of 0.80 proposed by Kline (Kline, 2010), the results may indicate that the overall fit of the instrument model was basically acceptable. Some also argued that ‘if the vast majority of the indexes indicate a good fit, then there is probably a good fit’ (Schreiber et al., 2006, p. 327). In this study, three out of five fit indexes meet the critical criteria, which might, to some extent, indicate a potentially acceptable fit. Removing items with low or complex factor loadings is a commonly used approach when the hypothesized model does not fit the data adequate (Litzelman, Stratos, Marriott, & Skeff, 1998). However, researchers should ‘ensure that judgmental and statistical criteria are combined before making a scale purification decision’ (Wieland et al., 2017, p. 325). The application of judgmental criteria mainly relies on theoretical and practical knowledge of the domain experts (Wieland et al., 2017). Judgmental assessment ensures that ‘a scale covers the entirety of all relevant aspects that need to be measured’ (Wieland et al., 2017, p. 325). Thus, whether the items with low factor loading can be definitely deleted should be determined based on not only the statistical results but also researchers’ professional and practical knowledge and concerns. In this study, the PNPC-sv was a clinical practice-focused instrument which aims at examining problems and to which extent the available care can address the problems in general advanced cancer patients. Keeping these items in the scale therefore would maintain the clinical value of this instrument and help clinicians comprehensively identify patients’ physical problems and needs. All the physical symptoms mentioned in the items were not uncommon in advanced cancer patients, and they were ‘regarded as relevant from a theoretical perspective’ (Cambra-Fierro & Polo-Redondo, 2008, p. 216). According to a general rule of

thumb, the sufficient sample size for confirmatory factor analysis should be 300 to 500 subjects (Gonzalez & Griffin, 2011; Sousa & Rojjanasrirat, 2011), while the sample size in this study was significantly fewer than the recommended sample size. In such a relatively small sample size, a mixed sample with more than 10 types of cancer were included, which might be a possible reason to contribute to the low factor loadings as those symptoms were particularly related to specific cancer types or cancer treatments. Thus, the currently study results can only be interpreted as preliminary given the mixed study sample with various types of cancer and a relatively small sample size.

Construct validity of the PNPC-sv was well demonstrated given contrasted groups analysis clearly indicated that patients with different gender, age, living place and cancer stage presented different problems and care needs in some specific PNPC-sv domains. Female patients reported more ADL, psychological and spiritual problems and needs, and the results were consistent with previous studies (Hasegawa et al., 2016; Morasso et al., 1999). Living in rural or urban areas has been deemed as an influencing factor for palliative care needs of advanced cancer patients (Fitch, 1994), which was also verified in this study. The results of elderly patients having more physical issues and fewer financial issues were consistent with some previous studies (Morasso et al., 1999; Osse et al., 2005), although opposite results were identified in some other studies, with elderly patients reporting fewer physical issues (Houts et al., 1988; Teunissen et al., 2006). Patients with stage IV cancer generally showed more problems and higher needs, which was in line with only one previous studies (Hwang et al., 2004). It might be because the predictive value of age and cancer stage on problems and care needs are not as strong as the gender factor, and this study adopted non-parametric tests which are less powerful than parametric tests. The factors of age and cancer stage are worthy of further exploration. Different from previous studies, statistical differences were detected in only one sub-scale of the PNPC-sv among patients of different educational level and marital status, and the considerably uneven sample size between groups may partially contribute to this. Reliability was adequate and it was similar to the original version, which indicates that the Mandarin Chinese PNPC-sv is internally reliable. Acceptable internal consistency

indicated that items of each domain of the PNPC-sv measure the same construct and conceptually fit together (DeVon et al., 2007).

There were some limitations of this study. Although the patients of this study were recruited from three study sites, the convenience sampling method used for subject recruitment may limit the generalizability of the study findings. A mixed sample with various types of cancer diagnosis in this study contributed to significantly heterogeneity of the study participants, and results from the factor analysis should be prudently interpreted. Future research is needed to further examine the psychometric properties of the PNPV-sv, particular its internal structure, in new and larger patient samples.

## **6.6 Summary of this chapter**

This chapter presented the preparatory study in terms of the psychometric assessment of the PNPC-sv (Chinese version) in a group of Chinese patients with different advanced cancer diagnosis. A total of 174 advanced cancer patients participated and completed the study. High content and face validity were determined after the two rounds of assessment with the expert panel and the patients. Contrasted groups analysis clearly discriminated the differences on some specific needs in patients with different gender, age and cancer stages. Satisfactory concurrent validity of the PNPC-sv (Chinese version) was identified when tested against the EORTC QLQ-C30. The internal consistency and item-to-total correlations also proved to be adequate and acceptable. The findings of the preparatory study showed that the Mandarin Chinese version of the PNPC-sv is a valid, reliable and user-friendly instrument for measuring problems and palliative care needs of patients with advanced cancer in Mainland China. The PNPC-sv (Chinese version) was therefore used in the cross-sectional survey to assess the palliative care needs of Chinese advanced cancer patients. The findings of this doctoral research project, including the results from both the cross-sectional survey and the semi-structured interviews, will be presented in the following chapters.

## **Chapter Seven: Results of the Cross-sectional Survey**

## **7.1 Introduction**

This chapter, which consists of eleven sections divided among three parts, will present the study results from the cross-sectional survey. These results will address the first six research objectives of the doctoral research project that were listed in Chapter 5, page 113. This first section provides a general introduction of this chapter. Section 7.2 will describe the recruitment of subjects and response rate. Part One (Sections 7.3 to 7.6) will present the results from the patients with advanced cancer who participated in the study. Demographic and clinical characteristics, physical distress, anxiety and depression, social support, coping strategies, and quality of life of the patients will be described in Section 7.3, while Section 7.4 will report the problems and palliative care needs of patients with advanced cancer. Univariate analysis (categorical variables) and Pearson's correlation analysis (continuous variables) were used to explore the relationships between the potential predictors of needs and the palliative care needs of patients, and the results will be reported in Section 7.5. The significant predictors of the palliative care needs of patients with advanced cancer were examined using stepwise regression analysis, and Section 7.6 will show the results. Part Two (Sections 7.7 to 7.10) will show the results relating to the informal caregivers who participated in the study, including demographic and clinical characteristics (Section 7.7), the levels of their care needs (Section 7.8), the relationship between the potential predictors of needs and their care needs (section 7.9), and the significant predictors of caregivers' needs (Section 7.10). Part Three (Section 7.11) will report the correlations between the needs of the patients and their informal caregivers. Section 7.12 will summarize the chapter.

## **7.2 Recruitment of subjects and response rate**

The participants in this study were recruited from two tertiary hospitals in Mainland China. Participant recruitment was conducted during a ten-month period, from April 2018 to January 2019. Patients and their informal caregivers were recruited in dyads. 477 eligible patient and informal caregiver dyads were approached; however, 49 dyads declined to participate for the following reasons: the patients or informal caregivers had no interest in this study (n=20), the patients or informal caregivers complained about the number of questionnaires (n=19); and

some families would not allow the patients to participate (n=10). Ultimately, 428 patient and informal caregiver dyads provided written informed consent and participated in the survey, yielding a response rate of 89.7%. Of the 428 received questionnaires, nine were subsequently excluded because the percentage of missing data exceeded 50% and many important questions had not been answered (these patients absented themselves for physical examinations during the period in which their questionnaires were being completed). Thus, a total of 419 patient and informal caregiver dyads completed all the required questionnaires, and they constituted the final sample of participants. The results of patients and caregivers will be reported separately in two parts as follows before the presentation of the relationships between the needs of patients and caregivers.

## **Part One: Patient Needs Assessment Survey Results**

### **7.3 Characteristics of patients with advanced cancer**

#### **7.3.1 Demographic and clinical characteristics**

The mean age of the patients was  $56.2 \pm 1.0$  years, ranging from 19 to 88 years old. The majority of the participants (343/419, 81.9%) had only a primary school education or less, and a small number (76/419, 18.1%) had received a higher level of education. The majority of the patients (402/419, 95.9%) were married, and only 17 patients (17/419, 4.1%) were single. A majority (357/419, 85.2%) indicated no religious beliefs. Nearly half of the patients (207/419, 49.4%) reported that their family income was less than 3,000 Chinese Yuan per month. More than half (235/419, 56.1%) of the patients came from the countryside. More than one-third (148/419, 35.3%) were lung cancer patients, and 66.1% (277/419) of the patients had stage IV cancer and the rest had stage III. About two-thirds of the patients (286/419, 68.3%) reported that they had received cancer-related surgery after their diagnosis. The majority of the patients (342/419, 81.6%) were receiving curative-intent treatment at that time, with 16.2% patients (n=68) receiving both chemotherapy and radiotherapy, 55.8% (n=234) receiving chemotherapy only, 5.0% (n=21) receiving radiotherapy only, and 4.5% (n=19) receiving chemotherapy/radiotherapy combined with targeted therapy. One-fifth of the patients (85/419, 20.3%) reported that, apart from the cancer, they had one or more complications (chronic diseases, e.g.,

chronic obstructive pulmonary disease, heart disease, etc.). Details of the demographic and clinical characteristics of the patients are presented in **Table 7.1** below:

**Table 7.1** Demographic and clinical characteristics of the patients (N=419)

Variables		Mean±SD/Percentage
Age (yrs.)		56.2±1.0
Gender	Male	237(56.6%)
	Female	182(43.4%)
In/outpatient	Inpatients	411(98.1%)
	Outpatients	8(1.9%)
Education	No formal education	66(15.8%)
	Primary education <sup>#</sup>	277(66.1%)
	Higher education <sup>##</sup>	76(18.1%)
Marital status	Married	402(95.9%)
	Single	17(4.1%)
Religion	No	357(85.2%)
	Yes	62(14.8%)
Family income per month	≤3000 CNY	207(49.4%)
	3000-6000 CNY	146(34.8%)
	6000-10,000 CNY	42(10.0%)
	>10,000 CNY	24(5.8%)
Living place	Rural	235(56.1%)
	City	184(43.9%)
Types of cancer	Respiratory system	148(35.3%)
	Digestive system	98(23.4%)
	Reproductive system	63(15.0%)
	Head and neck cancer	83(19.8%)
	Others	27(6.5%)
Length of time since diagnosis	≤1 month	48(11.5%)
	1-3 months (including 3)	77(18.4%)
	3-6 months (including 6)	84(20.0%)
	6-12 months (including 12)	97(23.2%)
	>12months	113(26.9%)
Stage	III	142(33.9%)
	IV	277(66.1%)
Surgery	Yes	286(68.3%)
	No	133(31.7%)
Current treatments	Chemotherapy + radiotherapy	68(16.2%)
	Chemotherapy only	234(55.8%)
	Radiotherapy only	21(5.0%)
	Chemotherapy/radiotherapy + targeted therapy	19(4.5%)
	Symptoms relieving	40(9.5%)
	Follow-up*	22(5.3%)
	No treatment**	15(3.6%)
Complications	Yes	85(20.3%)
	No	334(79.7%)

**Note:** \* Follow-up: patients who had already completed either chemotherapy or radiotherapy at that time and were at the stage of follow-up. \*\* No treatment: patients who were just diagnosed with advanced cancer at that time and did not receive any treatment. # Primary education: patients who had received primary school and middle school education; ## Higher education: patients who had received high school education or above.



### 7.3.2 Characteristics of physical distress

The physical distress of the patients with advanced cancer was assessed using the Edmonton Symptom Assessment Scale (ESAS); the Cronbach's alpha was 0.861 in this sample. Each item (symptom) of the ESAS was assessed with a 0 to 10 visual numerical scale (VNS), and the higher the score the greater the severity of the symptom. According to the mean scores of each symptom, the top three symptoms rated by the patients with advanced cancer were fatigue ( $4.4\pm 3.0$ ), poor appetite ( $4.6\pm 2.9$ ), and well-being ( $4.8\pm 1.7$ ). Details of the physical distress of the patients are listed in **Table 7.2** below:

**Table 7.2** Symptoms experienced by patients with advanced cancer (N=419, M $\pm$ SD)

Item	Minimum Score	Maximum Score	Mean $\pm$ SD
Item 1-Pain	0	10	4.2 $\pm$ 3.0
Item 2-Fatigue	0	10	4.4 $\pm$ 3.0
Item 3-Nausea	0	10	3.6 $\pm$ 2.9
Item 4-Depression	0	10	3.7 $\pm$ 2.6
Item 5-Anxiety	0	10	3.7 $\pm$ 2.8
Item 6-Drowsiness	0	10	4.1 $\pm$ 2.9
Item 7-Shortness of breath	0	10	2.9 $\pm$ 2.9
Item 8-Appetite	0	10	4.6 $\pm$ 2.9
Item 9-Sleep	0	10	4.2 $\pm$ 3.0
Item 10-Well-being	0	10	4.8 $\pm$ 1.7

### 7.3.3 Characteristics of emotional status

The emotional status of the patients with advanced cancer was evaluated via the Hospital Anxiety and Depression Scale (HADS). The ranges of possible scores are from 0 to 21 for the sub-scales of anxiety and depression. Total scores of 8 to 10 indicate borderline cases, and total scores of 11 or above indicate a clinical case of anxiety and depression. In this study, the Cronbach's alpha was 0.85 for the sub-scale of anxiety and 0.88 for the sub-scale of depression. The actual scores ranged from 0 to 19 for both the anxiety and depression sub-scales, with a mean score of 7.1 (SD=4.1) for anxiety and 6.9 (SD=4.6) for depression. Some of the patients with advanced cancer showed symptoms of clinical anxiety (21.7%, n=91) and depression (23.2%, n=97), and some patients had borderline cases of anxiety (29.1%, n=122) and depression (24.6%, n=103).

### 7.3.4 Characteristics of social support

The Medical Outcomes Study-Social Support Survey (MOS-SSS) was used to measure the status of received social support for the patients with advanced cancer. Higher scores indicate better social support, and all the scale scores were transformed to a 0 to 100 scale using the recommended formula. The Cronbach's alpha of the MOS-SSS in this study was 0.91. The highest score was for the sub-scale of tangible support, with a mean and standard deviation of  $77.7 \pm 12.6$ . The lowest score was for the positive social interaction sub-scale ( $60.5 \pm 18.8$ ). The ranges of the scores, the mean scores of each sub-scale, and the overall scale, are shown in

**Table 7.3.**

**Table 7.3** Social support for patients with advanced cancer (N=419, M $\pm$ SD)

Domains	Number of Items	Minimum	Maximum	Mean $\pm$ SD
Tangible support	4	31.3	100	77.7 $\pm$ 12.6
Informational and emotional support	8	15.6	100	65.1 $\pm$ 12.9
Positive social interaction	4	0	100	60.5 $\pm$ 18.8
Affectionate support	3	8.3	100	71.5 $\pm$ 14.3
<b>Total Score</b>	19	26.3	100	67.8 $\pm$ 11.8

### 7.3.5 Characteristics of coping strategies

The Brief Coping Orientation to Problems Experienced (Brief-COPE) scale was employed to evaluate the coping strategies of the patients, and the Cronbach's alpha was 0.86 in this sample. Since the number of items (N) in the domains varied, the mean of each sub-scale (M $\pm$ SD) divided by N was calculated to compare the relative contributions of the domains with the total score. The results showed that problem-focused coping ( $3.1 \pm 0.6$ ) was the most commonly used coping strategy for patients with advanced cancer. The least frequently used coping strategy was maladaptive coping ( $2.2 \pm 0.4$ ). The details are outlined in **Table 7.4** below:

**Table 7.4** Coping strategies of patients with advanced cancer (N=419, M $\pm$ SD)

Domains	Number of Items (N)	Minimum	Maximum	Mean $\pm$ SD	(M $\pm$ SD)/N
Problem-focused coping	6	9	24	18.4 $\pm$ 3.5	3.1 $\pm$ 0.6
Emotion-focused coping	6	8	24	14.1 $\pm$ 2.6	2.4 $\pm$ 0.4
Adaptive coping	4	6	16	11.1 $\pm$ 2.0	2.8 $\pm$ 0.5
Maladaptive coping	12	16	43	26.1 $\pm$ 4.5	2.2 $\pm$ 0.4

### 7.3.6 Characteristics of quality of life

The EORTC Quality-of-Life Questionnaire Core 15-Palliative Care (QLQ-C15-PAL) was utilized to assess the quality of life of the patients. Except for global health status, a high score represented a poor quality of life. In this survey, the Cronbach's alpha of the QLQ-C15-PAL was 0.78. Since the number of items (N) in the domains varied, the mean of each sub-scale ( $M \pm SD$ ) divided by N was calculated to compare the relative contributions of domains with the total score. The mean score of each sub-scale is presented in **Table 7.5** below:

**Table 7.5** Quality of life of patients with advanced cancer (N=419,  $M \pm SD$ )

Domains	Number of Items (N)	Raw Scores				Transformed Scores
		Minimum	Maximum	Mean $\pm$ SD	( $M \pm SD$ )/N	Mean $\pm$ SD
Physical Functioning	3	3	12	5.1 $\pm$ 2.3	1.7 $\pm$ 0.8	76.5 $\pm$ 25.9
Emotional Functioning	2	2	8	4.2 $\pm$ 1.6	2.1 $\pm$ 0.8	62.6 $\pm$ 27.4
Fatigue	2	2	8	4.9 $\pm$ 1.8	2.5 $\pm$ 0.9	48.7 $\pm$ 30.3
Nausea and Vomiting	1	1	4	2.2 $\pm$ 1.0	2.2 $\pm$ 1.0	40.9 $\pm$ 32.6
Pain	2	2	8	4.5 $\pm$ 1.9	2.3 $\pm$ 0.9	41.8 $\pm$ 31.5
Dyspnoea	1	1	4	1.8 $\pm$ 0.9	1.8 $\pm$ 0.9	28.2 $\pm$ 31.1
Insomnia	1	1	4	2.3 $\pm$ 1.0	2.3 $\pm$ 1.0	43.3 $\pm$ 34.8
Appetite Loss	1	1	4	2.5 $\pm$ 1.0	2.5 $\pm$ 1.0	48.4 $\pm$ 33.3
Constipation	1	1	4	2.0 $\pm$ 1.0	2.0 $\pm$ 1.0	33.5 $\pm$ 33.7
Global Health Status	1	1	7	4.3 $\pm$ 1.2	4.3 $\pm$ 1.2	54.6 $\pm$ 20.6

### 7.4 Problems and palliative care needs of patients with advanced cancer

#### 7.4.1 Percentages of problems and palliative care needs of patients with advanced cancer

The palliative care needs of patients with advanced cancer were assessed using the Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv). This instrument included two parts, the Problem part and the Need for Care part. The Cronbach's alpha for each part was 0.88 (Problem part) and 0.94 (Need for Care part) in this sample. The patients were asked to indicate the level of problems they experienced and the extent to which they needed professional attention using a 3-point Likert scale, where 1='yes', 2='somewhat', and 3='no' (Problem part) and 1='yes, more', 2='as much as now', and 3='no' (Need for Care part). For the Problem part, those who answered 'somewhat' and 'yes' were grouped together and

classified as 'having the problem'. For the Need for Care part, the answer of 'yes, more' and 'as much as now' were grouped together and classified as 'need for professional attention for the problem'. For the Problem part, as shown in **Table 7.6**, the top five problems reported by the patients were 'extra expenditures because of the disease' (92.6%, Financial Problems), 'loss of income because of the disease' (87.4%, Financial Problems), 'insufficient information' (80.7%, Information), 'pain' (69.9%, Physical Symptoms), and 'fatigue' (68.5%, Physical Symptoms). The five problems with the lowest frequency of occurrence included 'problems in relationship with life companion' (11.9%, Social Issues), 'difficulties in talking about the disease with life companion' (22.0%, Social Issues), 'Itch' (26.0%, Physical Symptoms), 'sexual dysfunction' (24.9%, Physical Symptoms), and 'difficulties in finding someone to talk to (confidant)' (27.2%, Social Issues).

For the Need for Care part, patients needed professional attention/support for the following problems: 'extra expenditures because of the disease' (88.3%, Financial Needs), 'loss of income because of the disease' (85.2%, Financial needs), 'insufficient information' (82.3%, Need for Information), 'pain' (69.7%, Physical Symptoms), and 'fear of physical suffering' (64.9%, Psychological Issues). The items on which the least number of respondents reported 'yes, more' and 'as much as now' were 'difficulties in finding someone to talk to (confidant)' (34.6%, Social Issues), 'difficulties in talking about the disease with life companion' (33.2%, Social Issues), 'Itch' (32.5%, Physical Symptoms), 'problems in relationship with life companion' (27.7%, Social Issues), and 'sexual dysfunction' (23.7%, Physical Symptoms). Details of the percentages of problems and palliative care needs of patients are listed in **Table 7.6** below:

**Table 7.6** Responses of the patients with advanced cancer to their problems and palliative care needs (N=419, %)

Is this a problem? (Problem Part)				Item	Do you want professional attention for this? (Need for Care Part)			
Yes (1)	Somewhat (2)	No (3)	(1)+(2)		Yes, more (1)	As much as now (2)	No (3)	(1)+(2)
<b>Daily Activities</b>								
33(7.9%)	90(21.5%)	296(70.6%)	<b>29.4%</b>	Body care, washing, dressing, or toilet	24(5.7%)	156(37.2%)	239(57.0%)	<b>42.9%</b>
56(13.4%)	104(24.8%)	259(61.8%)	<b>38.2%</b>	Personal transportation (cycling, driving a car, using public transportation, etc.)	34(8.1%)	167(39.9%)	218(52.0%)	<b>48.0%</b>
57(13.6%)	85(20.3%)	277(66.1%)	<b>33.9%</b>	Doing light housework (tidying up, etc.)	48(11.5%)	133(31.7%)	238(56.8%)	<b>43.2%</b>
<b>Physical Symptoms</b>								
155(37.0%)	138(32.9%)	126(30.1%)	<b>69.9%</b>	Pain	135(32.2%)	157(37.5%)	127(30.3%)	<b>69.7%</b>
146(34.8%)	141(33.7%)	132(31.5%)	<b>68.5%</b>	Fatigue	157(37.5%)	111(26.5%)	151(36.0%)	<b>64.0%</b>
141(33.7%)	136(32.5%)	142(33.8%)	<b>66.2%</b>	Sleeping problems	172(41.1%)	88(21.0%)	159(37.9%)	<b>62.1%</b>
80(19.1%)	122(29.1%)	217(51.8%)	<b>48.2%</b>	Shortness of breath	110(26.3%)	106(25.3%)	203(48.4%)	<b>51.6%</b>
84(20.0%)	100(23.9%)	235(56.1%)	<b>43.9%</b>	Cough	101(24.1%)	108(25.8%)	210(50.1%)	<b>49.9%</b>
42(10.0%)	67(16.0%)	310(74.0%)	<b>26.0%</b>	Itch	42(10.0%)	94(22.4%)	283(67.5%)	<b>32.5%</b>
27(6.5%)	76(18.4%)	311(75.1%)	<b>24.9%</b>	Sexual dysfunction	21(5.1%)	77(18.6%)	316(76.3%)	<b>23.7%</b>
77(18.4%)	87(20.8%)	255(60.9%)	<b>39.1%</b>	Prickling or numb sensation	85(20.3%)	95(22.7%)	239(57.0%)	<b>43.0%</b>
104(24.8%)	87(20.8%)	228(54.4%)	<b>45.6%</b>	(Nightly) Sweating or hot flushes	120(28.6%)	79(18.9%)	220(52.5%)	<b>47.5%</b>
<b>Autonomy</b>								
68(16.2%)	130(31.0%)	221(52.7%)	<b>47.3%</b>	Difficulties in continuing the usual activities	102(24.3%)	115(27.4%)	202(48.2%)	<b>51.8%</b>
75(17.9%)	124(29.6%)	220(52.5%)	<b>47.5%</b>	Difficulty to give tasks out of hands	105(25.1%)	105(25.1%)	209(49.9%)	<b>50.1%</b>
106(25.3%)	124(29.6%)	189(45.1%)	<b>54.9%</b>	Being dependent of others	110(26.3%)	112(26.7%)	197(47.0%)	<b>53.0%</b>
91(21.7%)	93(22.2%)	235(56.1%)	<b>43.9%</b>	Experiencing loss of control over one's life	118(28.2%)	69(16.5%)	232(55.4%)	<b>44.6%</b>
<b>Social Issues</b>								
3(0.7%)	47(11.2%)	369(88.1%)	<b>11.9%</b>	Problems in the relationship with life companion	12(2.9%)	104(24.8%)	303(72.3%)	<b>27.7%</b>
26(6.2%)	66(15.8%)	327(78.0%)	<b>22.0%</b>	Difficulties in talking about the disease with life companion	32(7.6%)	107(25.5%)	280(66.8%)	<b>33.2%</b>
101(24.1%)	95(22.7%)	223(53.2%)	<b>46.8%</b>	Finding it difficult to talk about the disease, because of not receptive to talking about the disease	67(16.0%)	113(27.0%)	239(57.0%)	<b>43.0%</b>

74(17.7%)	108(25.8%)	237(56.6%)	<b>43.4%</b>	Finding others not receptive to talking about the disease	72(17.2%)	102(24.3%)	245(58.5%)	<b>51.5%</b>
44(10.5%)	70(16.7%)	305(72.8%)	<b>27.2%</b>	Difficulties in finding someone to talk to (confidant)	64(15.3%)	81(19.3%)	274(65.4%)	<b>34.6%</b>
<b>Psychological Issues</b>								
116(27.7%)	146(34.8%)	157(37.5%)	<b>62.6%</b>	Depressed mood	122(29.1%)	139(33.2%)	158(37.7%)	<b>62.3%</b>
117(27.9%)	138(32.9%)	164(39.1%)	<b>60.9%</b>	Fear of physical suffering	151(36.0%)	121(28.9%)	147(35.1%)	<b>64.9%</b>
131(31.3%)	120(28.6%)	168(40.1%)	<b>59.9%</b>	Fear of metastases	156(37.2%)	106(25.3%)	157(37.5%)	<b>62.5%</b>
67(16.0%)	121(28.9%)	231(55.1%)	<b>44.9%</b>	Difficulty coping with the unpredictability of the future	100(23.9%)	100(23.9%)	219(52.3%)	<b>47.7%</b>
123(29.4%)	93(22.2%)	203(48.4%)	<b>51.6%</b>	Difficulties to show emotions	150(35.8%)	82(19.6%)	187(44.6%)	<b>55.4%</b>
<b>Spiritual Issues</b>								
93(22.2%)	107(25.5%)	219(52.3%)	<b>47.7%</b>	Difficulties to be engaged usefully	131(31.3%)	97(23.2%)	191(45.6%)	<b>54.4%</b>
102(24.3%)	131(31.3%)	186(44.4%)	<b>55.6%</b>	Difficulties to be avail for others	118(28.2%)	108(25.8%)	193(46.1%)	<b>53.9%</b>
88(21.4%)	116(28.2%)	208(50.5%)	<b>49.5%</b>	Difficulties concerning the meaning of death	105(25.5%)	78(18.9%)	229(55.6%)	<b>44.4%</b>
147(35.1%)	87(20.8%)	185(44.2%)	<b>55.8%</b>	Difficulties to accept the disease	173(41.3%)	56(13.4%)	190(45.3%)	<b>54.7%</b>
<b>Financial Problems</b>								
313(74.7%)	75(17.9%)	31(7.4%)	<b>92.6%</b>	Extra expenditures because of the disease	337(80.4%)	33(7.9%)	49(11.7%)	<b>88.3%</b>
321(76.6%)	45(10.7%)	53(12.6%)	<b>87.4%</b>	Loss of income because of the disease	330(78.8%)	27(6.4%)	62(14.8%)	<b>85.2%</b>
<b>Need for Information</b>								
280(66.8%)	58(13.8%)	81(19.3%)	<b>80.7%</b>	Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help, alternative healing methods, etc.	315(75.2%)	30(7.2%)	74(17.7%)	<b>82.3%</b>

#### 7.4.2 Problems and unmet palliative care needs of patients with advanced cancer

For the Problem part, the answer of ‘somewhat’ and ‘yes’ were accumulated and classified as ‘having the problem’. For the Need for Care part, patients who rated ‘yes, more’ were classified as ‘unmet need’ (i.e., the need was not met). Financial problems (87.3% to 92.6%) and information problems (80.6%) were the most reported problems. Likewise, financial and information needs were rated as the top two unmet care needs of patients with advanced cancer, with percentages of 78.8% to 80.4% and 75.2%, respectively. The mean scores and the percentage ranges for each domain are reported in **Table 7.7** below:

**Table 7.7** Problems and unmet palliative care needs of patients with advanced cancer

Domains	PNPC-sv Problem part		PNPC-sv Need for Care part	
	Mean±SD	Problem Part* (%)	Mean±SD	Need for Care Part**(%)
ADL	1.4±1.8	29.4%-38.2%	1.6±1.8	5.7%-11.5%
Physical	6.4±3.5	24.5%-69.9%	6.9±4.4	5.0%-41.1%
Autonomy	2.7±2.7	43.9%-54.9%	3.0±3.0	24.3%-28.2%
Social	2.1±2.0	11.9%-46.8%	2.4±2.6	2.9%-17.2%
Psychological	4.1±2.9	44.9%-62.5%	4.5±3.3	23.9%-37.2%
Spiritual	3.1±2.4	47.7%-55.9%	3.3±2.8	25.1%-41.3%
Financial	3.3±1.2	87.3%-92.6%	3.3±1.3	78.8%-80.4%
Information	1.5±0.8	80.6%	1.6±0.8	75.2%

**Note:** \* Problem part=‘Is this a problem?’: accumulated categories: Yes + Somewhat; \*\* Need for Care part=‘Do you want attention for this?’: categories: Yes, more.

#### 7.5 Relationship between various independent variables and palliative care needs of patients

The normality of the data was determined using skewness and kurtosis. In this study, as both the absolute skew value and kurtosis value were less than 2 and 7, respectively, the data was determined to be normal distribution, and a parametric test was employed. An independent t-test and one-way ANOVA were conducted to explore the association between demographic characteristics (categorical variables) and the problems and palliative care needs of patients with advanced cancer. Pearson correlation analysis (continuous variables) was used to explore the correlations between physical distress, anxiety and depression, social support, coping strategies, quality of life, and the problems and palliative care needs of patients.

## **7.5.1 Associations between demographic characteristics (categorical variables) and problems and palliative care needs**

### **7.5.1.1 Gender**

Female patients had more psychological problems than male patients ( $p=0.006$ ). No significant differences were identified in any other domains of the problems and palliative care needs.

The detailed results are shown in **Table 7.8**.

### **7.5.1.2 Marital status**

As is shown in **Table 7.9**, no significant differences were identified in terms of the problems experienced by married patients and singles. For the Need for Care part, significant differences were identified in the domains of ADL ( $p=0.008$ ) and autonomy ( $p=0.005$ ).

### **7.5.1.3 Living place**

Patients who lived in rural areas recorded higher scores in the financial ( $p=0.000$ ) and information domains ( $p=0.002$ ) and the global score in the Problem part ( $p=0.024$ ). Regarding the Need for Care part, those who lived in rural areas recorded higher scores in the domains of physical, social, financial, and information needs, as well as the global need score ( $p<0.05$ ).

The results are presented in **Table 7.10**.

### **7.5.1.4 Religion**

No significant differences were identified in either the Problem part or the Need for Care part ( $p>0.05$ ).

### **7.5.1.5 Stage**

As shown in **Table 7.11**, patients at stage IV reported higher sub-scores in the domains of ADL ( $p=0.028$ ) and psychological ( $p=0.001$ ), as well as the global score ( $p=0.019$ ), in the Problems part compared with patients at stage III. No significant differences were identified in any domain in the Need for Care part ( $p>0.05$ ).

### **7.5.1.6 Surgery or not**

A significant difference was identified in the information domain ( $p<0.023$ ) in the Problem part. For the Need for Care part, significant differences were detected in the domains of



physical, social, spiritual, and information and the global score ( $p<0.05$ ). Details are listed in **Table 7.12**.

#### **7.5.1.7 Complications**

As shown in **Table 7.13**, patients with complications reported higher scores in the physical, psychological, and information domains and the global score in the Problem part compared with patients without complications ( $p<0.05$ ). Statistical differences were detected in the same domains in the Need for Care part ( $p<0.01$ ).

#### **7.5.1.8 Education level**

Patients with a higher level of education had fewer problems regarding the physical, social, spiritual, financial, and information domains, as well as a lower global score, than those with a primary education or no formal education ( $p<0.05$ ). Regarding the Need for Care part, patients with a higher level of education reported less physical, autonomy, social, and spiritual needs ( $p<0.05$ ). **Table 7.14** shows the details.

#### **7.5.1.9 Length of time since diagnosis**

Significant differences were detected in many domains in the Problem part, including physical, autonomy, social, and psychological problems ( $p<0.05$ ), while for the Need for Care part, only needs in the autonomy domain showed statistical differences among patients with different lengths of time since diagnosis ( $p=0.014$ ). Details are displayed in **Table 7.15**.

#### **7.5.1.10 Monthly family income**

As shown in **Table 7.16**, except for the ADL and psychological domains in the Problem part, significant differences were detected in all the other domains in both the Problem part and the Need for Care part ( $p<0.01$ ).

#### **7.5.1.11 Types of cancer**

Significant differences were identified in the spiritual domain ( $p=0.044$ ) in the Problem part. For the Need for Care part, significant differences were detected in the social and spiritual domains as well as the global score, with a  $p$  value less than 0.05. The details are shown in **Table 7.17**.

### 7.5.1.12 Received treatment therapy

Patients receiving different treatments reported different ADL and autonomy problems ( $p=0.000$ ). Significant differences were detected in all of the Need for Care domains and the global score ( $p<0.05$ ). Detailed information is highlighted in **Table 7.18**.

### 7.5.1.13 C-Education (informal caregivers' education level)

Apart from the financial domain ( $F=5.451$ ,  $p=0.005$ ) in the Problem part, no significant differences were identified in any other domains regarding the education level of the informal caregivers.

### 7.5.1.14 C-Gender (informal caregivers' gender)

No significant differences were identified in either the Problem part or the Need for Care part ( $p>0.05$ ).

Variables that showed statistical significance ( $p<0.05$ ) in the univariate analysis (as shown in Table 7.8-7.18) were included in the regression analysis for each domain of the PNPC-sv and the global score of the PNPC-sv (both Problem part and Need for Care part). Details of the variables included in the regression model for analysis were listed as follows:

<b>Problem part</b>	
ADL	cancer stage, treatment therapy
Physical	education level, complications, length of time since diagnosis, income
Autonomy	length of time since diagnosis, income, treatment therapy
Social	education level, length of time since diagnosis, income
Psychological	gender, cancer stage, complications, length of time since diagnosis
Spiritual	education level, income, cancer type
Financial	living place, education level, income
Information	living place, surgery or not, complications, education level, income
Global score	living place, cancer stage, complications, education level, length of time since diagnosis, income, treatment therapy
<b>Need for Care part</b>	
ADL	marital status, income, treatment therapy
Physical	complications, surgery or not, education level, income, treatment therapy
Autonomy	marital status, education level, length of time since diagnosis, income, treatment therapy
Social	living place, surgery or not, education level, income, cancer type, treatment therapy
Psychological	complications, income, treatment therapy
Spiritual	surgery or not, education level, income, cancer type, treatment therapy
Financial	living place, education level, income, treatment therapy
Information	living place, surgery or not, complications, income, treatment therapy
Global score	living place, surgery or not, complications, education level, income, cancer type, treatment therapy

**Table 7.8** Differences in total and sub-scores of the PNPC-sv between female and male patients (N=419, M±SD)

Gender	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
Female (n=182)	1.4±1.8	6.5±3.5	2.7±2.6	2.3±2.1	4.6±2.9	3.1±2.3	3.4±1.1	1.5±0.8	25.6±11.2
Male (n=237)	1.3±1.8	6.3±3.6	2.8±2.7	2.0±1.9	3.8±2.9	3.12±.5	3.2±1.2	1.5±0.8	23.9±11.5
<i>t</i>	0.653	0.719	-0.292	1.690	2.774	0.160	1.906	0.192	1.517
<i>p</i>	0.514	0.472	0.771	0.092	0.006	0.873	0.057	0.847	0.130
<b>Need for Care Part</b>									
Female (n=182)	1.5±1.7	6.4±4.2	2.8±2.9	2.3±2.4	4.8±3.1	3.2±2.5	3.5±1.2	1.6±0.8	26.0±13.7
Male (n=237)	1.7±1.8	6.9±4.6	3.2±3.1	2.5±2.7	4.4±3.3	3.4±3.0	3.2±1.3	1.6±0.8	27.0±16.6
<i>t</i>	-1.184	-1.341	-1.505	-0.532	1.093	-0.691	1.838	-0.214	-0.668
<i>p</i>	0.237	0.181	0.133	0.595	0.275	0.490	0.067	0.831	0.504

**Table 7.9** Differences in total and sub-scores of the PNPC-sv between patients by marital status (N=419, M±SD)

Married/ Single	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
Single (n=17)	1.2±1.6	5.8±4.1	2.1±2.6	2.3±2.3	3.4±3.1	3.2±3.1	3.2±1.1	1.5±0.9	22.7±13.7
Married (n=402)	1.4±1.8	6.4±3.5	2.8±2.7	2.1±2.0	4.2±2.9	3.1±2.4	3.3±1.2	1.5±0.8	24.7±11.3
<i>t</i>	-0.297	-0.716	-1.079	0.396	-1.011	0.113	-0.281	-0.023	-0.716
<i>p</i>	0.767	0.474	0.281	0.692	0.313	0.911	0.779	0.982	0.474
<b>Need for Care Part</b>									
Single (n=17)	0.8±1.1	4.8±4.5	1.5±2.0	1.8±1.9	3.6±3.4	2.7±2.9	3.2±1.4	1.5±0.9	19.8±13.9
Married (n=402)	1.6±1.8	6.8±4.4	3.1±3.0	2.4±2.6	4.6±3.2	3.4±2.8	3.3±1.3	1.6±0.8	26.8±15.4
<i>t</i>	-2.961	-1.789	3.155	-1.012	-1.243	-1.011	-0.300	-0.568	-1.837
<i>p</i>	0.008	0.074	0.005	0.312	0.215	0.313	0.764	0.570	0.067

**Table 7.10** Differences in total and sub-scores of the PNPC-sv between patients by geographic origin (N=419, M±SD)

Living Place	Mean ± SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
Rural (n=235)	1.4±1.8	6.6±3.5	2.8±2.7	2.3±2.1	4.2±2.9	3.3±2.3	3.6±0.9	1.6±0.7	25.7±11.0
City (n=184)	1.3±1.8	6.0±3.5	2.6±2.7	1.9±1.9	4.1±3.0	2.9±2.5	3.0±1.4	1.3±0.8	23.2±11.6
<i>t</i>	0.749	1.604	0.713	1.936	0.232	1.488	5.136	3.114	2.26
<i>p</i>	0.455	0.109	0.476	0.054	0.817	0.138	0.000	0.002	0.024
<b>Need for Care Part</b>									
Rural (n=235)	1.6±1.7	7.1±4.5	3.2±3.1	2.6±2.6	4.7±3.2	3.5±2.8	3.7±0.9	1.7±0.7	28.1±15.4
City (n=184)	1.5±1.8	6.1±4.2	2.8±2.9	2.1±2.6	4.4±3.2	3.1±2.7	2.9±1.5	1.5±0.8	24.4±15.2
<i>t</i>	0.634	2.244	1.473	2.154	0.907	1.533	5.684	2.363	2.441
<i>p</i>	0.527	0.025	0.142	0.032	0.365	0.126	0.000	0.019	0.015

**Table 7.11** Differences in total and sub-scores of the PNPC-sv between stage III and stage IV patients (N=419, M±SD)

Cancer Stage	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
Stage III (n=142)	1.1±1.4	6.0±3.4	2.5±2.4	2.1±2.0	3.5±2.6	2.9±2.4	3.3±1.1	1.5±0.8	22.8±10.9
Stage IV (n=277)	1.5±2.0	6.6±3.6	2.9±2.8	2.1±2.0	4.4±3.0	3.3±2.4	3.4±1.2	1.5±0.8	25.5±11.5
<i>t</i>	-2.201	-1.521	-1.513	-0.047	-3.217	-1.569	-0.838	-0.057	-2.358
<i>p</i>	0.028	0.129	0.131	0.963	0.001	0.117	0.403	0.955	0.019
<b>Need for Care Part</b>									
Stage III (n=142)	1.5±1.6	6.5±4.5	2.9±2.9	2.4±2.5	4.1±3.2	3.2±2.9	3.3±1.3	1.5±0.8	25.5±15.9
Stage IV (n=277)	1.7±1.8	6.8±4.4	3.1±3.1	2.4±2.6	4.8±3.3	3.4±2.7	3.3±1.3	1.6±0.8	27.0±15.2
<i>t</i>	-1.00	-0.487	-0.845	0.110	-1.906	-0.709	-0.035	-.623	-0.959
<i>p</i>	0.318	0.627	0.399	0.913	0.057	0.479	0.972	0.534	0.338

**Table 7.12** Differences in total and sub-scores of the PNPC-sv for the variable of surgery (N=419, M±SD)

Surgery or Not	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
Yes (n=133)	1.4±1.9	6.3±3.7	2.8±2.8	2.1±2.2	4.3±3.0	2.9±2.3	3.3±1.2	1.3±0.9	24.4±11.9
No (n=286)	1.3±1.7	6.4±3.5	2.7±2.6	2.1±1.9	4.0±2.9	3.2±2.5	3.3±1.1	1.5±0.8	24.7±11.1
<i>t</i>	0.566	-0.161	0.025	-0.246	0.823	-1.328	-0.143	-2.296	-0.252
<i>p</i>	0.572	0.872	0.980	0.806	0.411	0.185	0.886	0.023	0.801
<b>Need for Care Part</b>									
Yes (n=133)	1.4±1.8	6.0±4.0	2.7±2.8	1.8±2.1	4.2±3.3	2.8±2.5	3.2±1.4	1.4±0.8	23.4±13.3
No (n=286)	1.7±1.8	7.0±4.6	3.2±3.1	2.7±2.7	4.7±3.2	3.6±2.8	3.4±1.2	1.6±0.7	27.9±16.1
<i>t</i>	-1.614	-2.273	-1.867	-3.765	-1.582	-3.116	-1.186	-2.407	-3.039
<i>p</i>	0.107	0.024	0.063	0.000	0.114	0.002	0.236	0.017	0.003

**Table 7.13** Differences in total and sub-scores of the PNPC-sv for the variable of complications (N=419, M±SD)

Complications	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
Yes (n=85)	1.7±2.1	7.0±3.4	3.1±2.8	2.3±2.0	4.8±3.2	3.5±2.7	3.2±1.3	1.7±0.6	27.2±12.2
No (n=334)	1.3±1.7	6.2±3.6	2.7±2.6	2.1±2.0	4.0±2.9	3.0±2.4	3.3±1.1	1.4±0.8	23.9±11.0
<i>t</i>	1.46	1.995	1.473	0.913	2.118	1.473	-0.920	2.764	2.390
<i>p</i>	0.145	0.047	0.142	0.362	0.036	0.143	0.359	0.006	0.017
<b>Need for Care Part</b>									
Yes (n=85)	1.9±1.9	7.8±4.5	3.6±3.	2.7±2.9	5.5±3.3	3.7±2.9	3.3±1.4	1.8±0.6	30.4±16.0
No (n=334)	1.5±1.7	6.4±4.3	2.9±3.0	2.3±2.5	4.3±3.2	3.2±2.7	3.3±1.2	1.5±0.8	25.5±15.1
<i>t</i>	1.832	2.684	1.942	1.308	3.104	1.542	-.453	3.697	2.626
<i>p</i>	0.068	0.008	0.053	0.192	0.002	0.124	0.651	0.000	0.009

**Table 7.14** Differences in total and sub-scores of the PNPC-sv among patients with different education levels (N=419, M±SD)

Education Level	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
No formal education (n=66)	1.3±1.7	7.2±3.4	3.2±2.6	2.5±2.2	4.2±2.7	3.6±2.3	3.3±1.2	1.6±0.8	26.8±10.7
Primary education (n=277)	1.3±1.8	6.4±3.5	2.6±2.7	2.2±2.0	4.3±3.0	3.2±2.5	3.5±1.0	1.5±0.8	25.0±11.3
Higher education (n=76)	1.5±1.8	5.5±3.7	3.0±2.8	1.5±1.6	3.4±2.7	2.3±2.1	2.8±1.4	1.3±0.9	21.2±11.7
F	0.292	4.603	1.844	4.781	2.910	5.478	10.548	4.022	4.913
p	0.747	0.011	0.160	0.009	0.056	0.004	0.000	0.019	0.008
<b>Need for Care Part</b>									
No formal education (n=66)	2.0±1.8	8.3±4.6	3.9±3.0	3.3±2.7	5.2±3.2	4.3±2.8	3.4±1.3	1.6±0.7	31.9±16.4
Primary education (n=277)	1.5±1.8	6.5±4.3	2.8±3.0	2.3±2.6	4.6±3.3	3.3±2.8	3.5±1.2	1.6±0.8	26.0±14.9
Higher education (n=76)	1.6±1.6	5.8±4.3	3.2±3.1	2.0±2.5	4.0±3.2	2.8±2.7	2.8±1.5	1.5±0.8	23.7±15.6
F	1.740	6.313	3.994	5.300	2.450	5.039	6.945	1.107	5.623
p	0.177	0.002	0.019	0.005	0.088	0.007	0.001	0.332	0.004

**Table 7.15** Differences in total and sub-scores of the PNPc-sv by length of time since diagnosis (N=419, M±SD)

Time Since Diagnosis	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
≤1 month (n=48)	1.2±1.8	6.0±3.8	2.4±2.8	1.7±1.7	4.0±3.0	2.9±2.4	3.4±1.2	1.5±0.8	23.1±11.7
1-3 months (including 3) (n=77)	1.2±1.9	5.4±3.4	2.2±2.3	1.7±1.7	4.0±3.1	2.8±2.8	3.1±1.2	1.5±0.8	21.8±11.5
3-6 months (including 6) (n=84)	1.2±1.4	6.1±3.6	2.2±2.5	2.0±2.0	3.6±2.8	2.9±2.4	3.3±1.1	1.4±0.8	22.6±11.6
6-12 months (including 12) (n=97)	1.5±1.9	6.7±3.1	3.3±2.8	2.4±2.0	3.9±2.9	3.3±2.4	3.3±1.3	1.6±0.7	25.9±9.9
≥12months (N=113)	1.6±1.9	7.0±3.7	3.2±2.8	2.4±2.3	5.0±2.8	3.4±2.2	3.4±1.0	1.4±0.9	27.5±11.5
F	1.219	3.028	4.112	2.510	3.362	1.098	.939	1.077	4.319
p	0.302	0.018	0.003	0.041	0.010	0.357	0.441	0.368	0.002
<b>Need for Care Part</b>									
≤1 month (n=48)	1.3±1.8	6.3±4.3	2.6±3.1	2.0±2.6	4.1±3.3	3.2±2.8	3.2±1.4	1.6±0.8	24.4±15.8
1-3 months (including 3) (n=77)	1.4±1.7	6.0±4.1	2.6±3.0	2.1±2.7	4.2±3.5	2.9±2.8	3.3±1.4	1.6±0.8	24.1±15.9
3-6 months (including 6) (n=84)	1.5±1.6	6.1±4.8	2.4±2.8	2.4±2.7	4.2±3.2	3.0±2.8	3.4±1.2	1.6±0.8	24.5±16.1
6-12 months (including 12) (n=97)	1.9±1.8	7.5±4.4	3.8±3.0	2.9±2.7	4.8±3.2	3.8±2.8	3.4±1.3	1.7±0.7	29.7±15.0
≥12months (N=113)	1.7±1.8	7.1±4.2	3.3±3.1	2.3±2.4	5.0±3.1	3.5±2.7	3.3±1.2	1.5±0.8	27.7±14.4
F	1.489	1.858	3.182	1.569	1.328	1.510	.256	1.133	2.311
p	0.205	0.117	0.014	0.182	0.259	0.198	0.906	0.340	0.057

**Table 7.16** Differences in total and sub-scores of the PNPC-sv by income level (N=419, M±SD)

Income	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
<3000CNY (n=207)	1.6±1.9	7.0±3.5	3.3±2.7	2.4±2.0	4.5±2.8	3.7±2.2	3.6±0.8	1.6±0.7	27.7±10.4
3000-6000CNY (n=146)	1.1±1.6	6.0±3.3	2.3±2.5	2.0±2.0	3.8±3.0	2.5±2.4	3.3±1.2	1.4±0.8	22.3±11.1
6000-10,000CNY (n=42)	1.4±2.0	5.3±3.7	2.1±2.6	1.5±1.7	3.7±3.3	2.4±2.4	2.4±1.5	1.2±0.9	20.0±11.8
>10,000CNY (n=24)	1.1±2.1	5.0±3.8	2.3±3.1	1.2±1.4	3.6±2.9	3.1±3.0	2.5±1.5	1.1±0.9	19.9±13.2
F	2.529	5.677	5.439	4.345	2.414	9.349	19.957	5.892	11.802
<i>p</i>	0.057	0.001	0.001	0.005	0.066	0.000	0.000	0.001	0.000
<b>Need for Care Part</b>									
<3000CNY (n=207)	2.1±1.8	8.0±4.5	3.9±3.1	3.1±2.7	5.3±3.1	4.2±2.8	3.8±0.7	1.7±0.6	32.0±15.0
3000-6000CNY (n=146)	1.2±1.6	6.0±4.0	2.3±2.8	2.0±2.4	4.0±3.2	2.6±2.5	3.3±1.3	1.5±0.8	23.0±13.7
6000-10,000CNY (n=42)	1.0±1.5	4.1±3.4	1.9±2.5	1.1±1.6	3.3±3.4	2.1±2.3	1.9±1.8	1.3±0.9	16.6±12.6
>10,000CNY (n=24)	0.8±1.6	4.3±3.9	2.0±2.8	1.1±1.8	3.4±3.0	2.8±3.0	2.0±1.6	1.1±0.9	17.6±14.7
F	11.024	16.269	12.754	11.987	8.928	13.592	45.622	7.848	22.936
<i>p</i>	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000



**Table 7.17** Differences in total and sub-scores of the PNPC-sv among patients with different cancers (N=419, M±SD)

Types of Cancer	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
Respiratory system (n=148)	1.3±1.9	6.7±3.5	2.9±2.7	2.2±1.9	4.3±3.1	3.4±2.5	3.2±1.3	1.6±0.8	25.6±11.1
Digestive system (n=98)	1.6±1.9	6.3±3.6	2.7±2.7	2.2±2.2	3.9±2.9	2.7±2.3	3.3±1.1	1.4±0.9	24.1±11.8
Reproductive system (n=63)	1.4±1.8	5.7±3.2	2.3±2.3	2.1±1.9	4.1±2.5	2.6±2.1	3.5±1.0	1.4±0.8	23.2±10.4
Head and neck cancer (n=83)	1.1±1.5	5.9±3.7	2.6±2.7	1.8±1.9	3.8±2.9	3.3±2.7	3.4±1.0	1.5±0.7	23.4±11.4
Others (n=27)	1.7±2.0	7.5±3.6	3.5±3.3	2.3±2.4	4.6±3.5	3.7±2.2	3.2±1.3	1.4±0.8	28.0±12.8
F	1.042	2.010	1.094	0.685	0.799	2.473	1.364	1.087	1.339
<i>p</i>	0.385	0.092	0.359	0.603	0.526	0.044	0.245	0.362	0.255
<b>Need for Care Part</b>									
Respiratory system (n=148)	1.5±1.8	7.1±4.4	3.2±3.1	2.5±2.8	4.7±3.3	3.5±2.8	3.3±1.3	1.6±0.7	27.4±15.9
Digestive system (n=98)	1.6±1.7	6.4±4.2	2.9±2.9	2.2±2.3	4.1±3.1	2.8±2.6	3.1±1.3	1.4±0.8	24.5±14.1
Reproductive system (n=63)	1.6±1.8	5.6±4.0	2.1±2.5	1.9±1.9	3.9±2.8	2.6±2.4	3.5±1.2	1.5±0.8	22.8±12.3
Head and neck cancer (n=83)	1.9±1.8	7.2±4.9	3.5±3.3	3.1±2.9	5.1±3.4	4.0±3.1	3.6±1.1	1.7±0.7	30.0±17.5
Others (n=27)	1.5±1.7	6.3±4.4	3.3±3.4	2.0±2.3	4.8±3.6	3.9±2.4	3.2±1.4	1.6±0.8	26.5±15.0
F	0.599	1.702	2.117	2.482	1.637	3.744	1.760	2.207	2.558
<i>p</i>	0.663	0.149	0.078	0.043	0.164	0.005	0.136	0.068	0.038

**Table 7.18** Differences in total and sub-scores of the PNPc-sv among patients receiving different treatments (N=419, M±SD)

Therapy	Mean±SD								
	ADL	Physical	Autonomy	Social	Psychological	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>									
No treatment (n=15)	0.3±0.8	6.2±3.7	1.3±2.4	1.8±1.8	3.0±3.1	2.6±2.1	3.3±1.4	1.9±0.5	20.3±9.2
Chemotherapy + radiotherapy (n=68)	1.8±1.6	7.0±3.7	3.6±2.6	2.5±1.9	4.3±2.4	3.4±2.0	3.6±0.8	1.6±0.7	27.8±9.5
Chemotherapy only (n=234)	1.2±1.6	6.1±3.3	2.5±2.6	2.0±2.0	3.9±2.9	2.9±2.4	3.3±1.2	1.4±0.8	23.3±11.0
Radiotherapy only (n=21)	1.3±1.8	7.1±3.7	3.1±3.0	1.5±1.6	4.0±2.9	3.0±2.8	3.3±1.3	1.7±0.6	24.9±12.6
Targeted therapy (n=19)	1.6±2.2	6.2±4.3	2.3±3.0	2.5±2.2	4.2±3.8	3.4±2.8	3.7±0.8	1.4±0.9	25.2±14.2
Symptoms relieving (n=40)	2.3±2.7	6.9±3.7	4.0±2.8	1.9±2.3	5.0±3.3	4.2±2.9	3.0±1.5	1.3±0.9	28.5±13.1
Follow-up (n=22)	0.8±1.6	5.5±3.5	1.6±2.3	3.0±2.4	5.1±3.3	2.9±2.6	3.1±1.4	1.4±0.9	23.4±11.6
F	4.520	1.081	4.641	1.969	1.473	1.933	1.838	1.655	2.686
p	0.000	0.373	0.000	0.069	0.186	0.074	0.090	0.131	0.014
<b>Need for Care Part</b>									
No treatment (n=15)	0.5±1.2	5.7±4.1	1.3±2.8	1.6±1.8	3.1±3.1	2.0±1.8	2.9±1.8	1.9±0.5	19.1±12.7
Chemotherapy + radiotherapy (n=68)	2.5±1.7	8.6±4.3	4.5±3.0	3.7±2.7	5.8±2.6	4.3±2.7	3.8±0.8	1.7±0.7	34.9±13.9
Chemotherapy only (n=234)	1.4±1.7	6.2±4.2	2.7±2.9	2.1±2.5	4.1±3.2	3.0±2.7	3.3±1.3	1.5±0.8	24.4±14.9
Radiotherapy only (n=21)	2.0±1.7	8.3±4.6	4.1±3.1	2.6±3.0	4.9±2.9	4.2±3.0	3.6±1.0	2.0±0.0	31.8±15.1
Targeted therapy (n=19)	1.1±1.4	5.8±4.4	2.1±2.4	2.1±2.5	4.3±4.0	3.2±2.7	3.6±0.9	1.4±0.9	23.4±14.1
Symptoms relieving (n=40)	2.2±2.1	7.6±4.7	4.0±3.2	2.4±3.0	5.6±3.5	4.0±3.2	3.2±1.5	1.5±0.8	30.5±17.4
Follow-up (n=22)	0.6±0.9	3.7±3.4	1.2±2.0	2.0±2.1	4.2±3.7	2.4±2.7	2.6±1.7	1.3±0.9	17.9±11.4
F	7.907	5.844	7.091	3.948	3.630	3.714	3.1±39	2.621	7.399
p	0.000	0.000	0.000	0.001	0.002	0.001	0.005	0.017	0.000

## **7.5.2 Correlations between patients' age, ESAS, HADS, MOS-SSS, Brief-COPE, QoL, and PNPC-sv**

### **7.5.2.1 Correlations regarding the Problem part of the PNPC-sv**

**Table 7.19** displays the results of the correlations between the age of the patients, their ESAS, HADS, MOS-SSS, Brief-COPE, and QoL scores, and the Problem part of the PNPC-sv. Apart from age and maladaptive coping, significant correlations were identified between the global scores in the Problem part of the PNPC-sv and the physical distress, anxiety and depression, social support, coping strategies, and quality of life scores of the patients, with the correlation coefficients ranging from -0.194 to 0.625. The absolute values of the majority of the Pearson correlation coefficients were above 0.3, indicating moderate correlations or above. Social support (all sub-scales), coping strategies (problem-focused coping, emotion-focused coping, and adaptive coping), and the global health status of QoL were negatively correlated to the global scores in the Problem part of the PNPC-sv. In terms of the sub-scores of the PNPC-sv, patients' greater physical distress, anxiety and depression, and poorer quality of life were significantly related to higher levels of problems; patients having more social support and using more problem-focused, emotion-focused, and adaptive coping strategies and having a better global health status, were significantly related to lower levels of problems.

**Table 7.19** Correlations between the patients' age, ESAS, HADS, MOS-SSS, Brief-COPE, QoL, and the PNPC-sv (Problem part)

Age/ESAS/HADS/MOS-SSS/Brief-COPE/QoL		Domains of the PNPC-sv (Problem Part)								
		ADL	Physical	Autonomy	Social	Psycho-logical	Spiritual	Financial	Information	Global Score
<b>Age</b>	Age of patients	-0.008	0.024	0.026	0.042	0.016	-0.002	-0.162**	0.059	0.011
<b>HADS</b>	Anxiety	0.305**	0.393**	0.477**	0.317**	0.522**	0.494**	0.214**	0.224**	0.618**
	Depression	0.348**	0.386**	0.492**	0.266**	0.471**	0.490**	0.144**	0.159**	0.592**
<b>ESAS</b>	Item 1-Pain	0.384**	0.502**	0.439**	0.162**	0.227**	0.244**	0.126*	0.122*	0.482**
	Item 2-Fatigue	0.240**	0.464**	0.436**	0.209**	0.334**	0.370**	0.200**	0.146**	0.519**
	Item 3-Nausea	0.190**	0.294**	0.284**	0.114*	0.211**	0.211**	0.252**	0.025	0.336**
	Item 4-Depression	0.263**	0.435**	0.437**	0.355**	0.592**	0.465**	0.179**	0.161**	0.625**
	Item 5-Anxiety	0.259**	0.465**	0.448**	0.320**	0.531**	0.424**	0.225**	0.122*	0.608**
	Item 6-Drowsiness	0.275**	0.376**	0.353**	0.197**	0.242**	0.257**	0.081	0.111*	0.413**
	Item 7-Shortness of breath	0.261**	0.451**	0.401**	0.052	0.198**	0.254**	0.108*	0.136**	0.412**
	Item -Appetite	0.321**	0.345**	0.377**	0.053	0.260**	0.291**	0.138**	0.099*	0.408**
	Item 9-Sleep	0.167**	0.475**	0.313**	0.108*	0.297**	0.245**	0.108*	0.034	0.410**
	Item 10-Well-being	0.312**	0.470**	0.491**	0.171**	0.385**	0.340**	0.142**	0.082	0.535**
<b>MOS-SSS</b>	Tangible support	-0.072	-0.093	-0.123*	-0.249**	-0.106*	-0.124*	-0.172**	-0.132**	-0.194**
	Informational and emotional support	-0.075	-0.137**	-0.129**	-0.298**	-0.188**	-0.218**	-0.131**	-0.130**	-0.255**
	Positive social interaction	-0.067	-0.180**	-0.115*	-0.292**	-0.198**	-0.224**	-0.123*	-0.123*	-0.265**
	Affectionate support	-0.184**	-0.176**	-0.255**	-0.213**	-0.181**	-0.302**	-0.144**	-0.197**	-0.322**
	Total	-0.116*	-0.198**	-0.199**	-0.351**	-0.218**	-0.309**	-0.162**	-0.191**	-0.338**
<b>Brief-COPE</b>	Problem-focused coping	-0.285**	-0.224**	-0.305**	-0.078	-0.104*	-0.221**	-0.092	-0.182**	-0.297**
	Emotion-focused coping	-0.168**	-0.157**	-0.224**	-0.158**	-0.104*	-0.180**	-0.101*	-0.177**	-0.245**
	Adaptive coping	-0.254**	-0.319**	-0.348**	-0.210**	-0.202**	-0.321**	-0.129**	-0.138**	-0.403**

	Maladaptive coping	-0.135**	-0.041	-0.171**	0.133**	0.109*	0.006	0.027	0.019	-0.018
<b>EORCT QLQ- C15</b>	Physical functioning	0.688**	0.384**	0.638**	0.092	0.249**	0.256**	0.041	0.139**	0.529**
	Emotional functioning	0.279**	0.423**	0.411**	0.323**	0.465**	0.436**	0.182**	0.191**	0.576**
	Fatigue	0.279**	0.480**	0.426**	0.201**	0.327**	0.362**	0.142**	0.102*	0.514**
	Nausea and vomiting	0.167**	0.309**	0.210**	0.066	0.173**	0.175**	0.191**	0.012	0.287**
	Pain	0.366**	0.492**	0.403**	0.137**	0.264**	0.256**	0.107*	0.103*	0.472**
	Dyspnoea	0.227**	0.470**	0.379**	-0.005	0.182**	0.227**	0.038	0.104*	0.378**
	Insomnia	0.169**	0.453**	0.273**	0.102*	0.264**	0.277**	0.067	0.088	0.391**
	Appetite loss	0.210**	0.306**	0.285**	0.046	0.216**	0.248**	0.101*	0.043	0.326**
	Constipation	0.167**	0.249**	0.236**	-0.006	0.082	0.150**	0.054	0.077	0.223**
Global health status	-0.415**	-0.399**	-0.483**	-0.172**	-0.327**	-0.388**	-0.130**	-0.178**	-0.528**	

**Note:** \*\* = Correlation is significant at the 0.01 level (two-tailed); \* = Correlation is significant at the 0.05 level (two-tailed).

### 7.5.2.2 Correlations regarding the Need for Care part of the PNPC-sv

**Table 7.20** shows the results of the correlations between the age of patients, their ESAS, HADS, MOS-SSS, Brief-COPE, and QOL scores, and the Need for Care part of the PNPC-sv. The patients' age was negatively correlated to their physical and autonomy needs. Moderate correlations between the ESAS, HADS, MOS-SSS, Brief-COPE, QOL, and the global need scores were detected, and the absolute values of the majority of the Pearson correlation coefficients were above 0.3. Higher levels of physical distress, anxiety and depression, and poorer quality of life were significantly related to higher levels of palliative care needs. For the correlations between social support, coping strategies, and palliative care needs, negative correlations were detected. Furthermore, patients who received more social support and used more problem-focused, emotion-focused, and adaptive coping strategies were significantly related to lower levels of palliative care needs.

**Table 7.20** Correlations between patients' age, ESAS, HADS, MOS-SSS, Brief-COPE, QoL, and the PNPC-sv (Need for Care part)

Age/ESAS/HADS/MOS-SSS/Brief-COPE/QoL		Domains of the PNPC-sv (Need for Care Part)								
		ADL	Physical	Autonomy	Social	Psycho-logical	Spiritual	Financial	Information	Global Score
<b>Age</b>	Age of patients	0.091	0.125*	0.103*	0.071	0.054	0.049	-0.092	0.080	0.095
<b>HADS</b>	Anxiety	0.477**	0.547**	0.534**	0.465**	0.647**	0.557**	0.356**	0.290**	0.675**
	Depression	0.518**	0.559**	0.552**	0.459**	0.604**	0.568**	0.338**	0.250**	0.675**
<b>ESAS</b>	Item 1-Pain	0.400**	0.559**	0.450**	0.306**	0.372**	0.334**	0.237**	0.206**	0.514**
	Item 2-Fatigue	0.324**	0.448**	0.441**	0.275**	0.441**	0.388**	0.294**	0.189**	0.495**
	Item 3-Nausea	0.233**	0.371**	0.348**	0.207**	0.286**	0.268**	0.308**	0.040	0.372**
	Item 4-Depression	0.329**	0.462**	0.433**	0.406**	0.622**	0.479**	0.342**	0.227**	0.580**
	Item 5-Anxiety	0.360**	0.504**	0.463**	0.378**	0.577**	0.465**	0.367**	0.188**	0.585**
	Item 6-Drowsiness	0.355**	0.356**	0.364**	0.251**	0.308**	0.289**	0.158**	0.162**	0.394**
	Item 7-Shortness of breath	0.376**	0.530**	0.444**	0.310**	0.360**	0.347**	0.175**	0.139**	0.494**
	Item -Appetite	0.362**	0.413**	0.429**	0.254**	0.365**	0.362**	0.266**	0.146**	0.458**
	Item 9-Sleep	0.272**	0.483**	0.319**	0.212**	0.348**	0.264**	0.147**	0.085	0.405**
Item 10-Well-being	0.326**	0.427**	0.421**	0.245**	0.414**	0.328**	0.246**	0.106*	0.455**	
<b>MOS-SSS</b>	Tangible support	-0.207**	-0.210**	-0.179**	-0.358**	-0.210**	-0.215**	-0.202**	-0.107*	-0.284*
	Informational and emotional support	-0.095	-0.142**	-0.130**	-0.254**	-0.239**	-0.216**	-0.192**	-0.103*	-0.230**
	Positive social interaction	-0.037	-0.080	-0.096*	-0.164**	-0.186**	-0.150**	-0.179**	-0.109*	-0.160**
	Affectionate support	-0.378**	-0.0373**	-0.378**	-0.461**	-0.364**	-0.426**	-0.238**	-0.219**	-0.486**
	Total	-0.174**	-0.210**	-0.204**	-0.340**	-0.289**	-0.279**	-0.239**	-0.150**	-0.316**
<b>Brief-COPE</b>	Problem-focused coping	-0.531**	-0.508**	-0.457**	-0.470**	-0.368**	-0.446**	-0.275**	-0.244**	-0.568**
	Emotion-focused coping	-0.339**	-0.316**	-0.317**	-0.326**	-0.264**	-0.315**	-0.231**	-0.203**	-0.388**
	Adaptive coping	-0.450**	-0.505**	-0.441**	-0.411**	-0.363**	-0.452**	-0.281**	-0.221**	-0.544**
	Maladaptive coping	-0.312**	-0.271**	-0.313**	-0.215**	-0.086	-0.172**	-0.093	-0.041	-0.269**
	Physical functioning	0.673**	0.500**	0.605**	0.292**	0.399**	0.367**	0.175**	0.225**	0.564**

<b>EORCT QLQ-C15</b>	Emotional functioning	0.394**	0.534**	0.455**	0.431**	0.606**	0.507**	0.316**	0.271**	0.619**
	Fatigue	0.240**	0.377**	0.349**	0.154**	0.339**	0.300**	0.180**	0.133**	0.377**
	Nausea and vomiting	0.166**	0.341**	0.237**	0.121*	0.241**	0.201**	0.231**	0.014	0.290**
	Pain	0.374**	0.516**	0.416**	0.264**	0.377**	0.306**	0.212**	0.184**	0.478**
	Dyspnoea	0.327**	0.493**	0.392**	0.217**	0.288**	0.266**	0.088	0.129**	0.414**
	Insomnia	0.275**	0.485**	0.310**	0.181**	0.330**	0.300**	0.143**	0.139**	0.404**
	Appetite loss	0.214**	0.320**	0.303**	0.147**	0.276**	0.252**	0.194**	0.097*	0.325**
	Constipation	0.278**	0.329**	0.271**	0.171**	0.176**	0.229**	0.091	0.125*	0.300**
	Global health status	-0.468**	-0.495**	-0.468**	-0.366**	-0.475**	-0.452**	-0.275**	-0.248**	-0.565**

**Note:** \*\* = Correlation is significant at the 0.01 level (two-tailed); \* = Correlation is significant at the 0.05 level (two-tailed).



### 7.5.3 Correlations between caregivers' HADS, MOS-SSS, Brief-COPE, QoL, and PNPC-sv

**Table 7.21** shows the results of the correlations between the caregivers' HADS, MOS-SSS, Brief-COPE, QoL, and PNPC-sv. The caregivers' anxiety and depression were positively correlated to the sub-scores and global score of the Problem part of the PNPC-sv ( $r < 0.3$ ). The caregivers' higher levels of social support were weakly correlated to the patients' lower levels of psychological, spiritual, and information problems. No significant correlations were identified between the maladaptive coping strategies of the informal caregivers and the Problem part of the PNPC-sv. However, the problem-focused, emotion-focused, and adaptive coping strategies of the caregivers were negatively related to the majority of the sub-scales in the PNPC-sv. The informal caregivers' higher levels of quality of life were related to fewer problems in patients. Regarding the Need for Care part, similar trends were identified, and the correlation coefficients were stronger than those in the Problem part, as detailed in **Table 7.21** below:

**Table 7.21** Correlations between caregivers' HADS, MOS-SSS, Brief-COPE, QoL, and the PNPC-sv

HADS/MOS-SSS/Brief-COPE/QoL		Domains of the PNPC-sv								
		ADL	Physical	Autonomy	Social	Psycho-logical	Spiritual	Financial	Information	Global Score
<b>Problem Part</b>										
<b>C-HADS</b>	C-Anxiety	0.105*	0.164**	0.134**	0.216**	0.241**	0.236**	0.099*	0.177**	0.273**
	C-Depression	0.146**	0.179**	0.178**	0.193**	0.221**	0.249**	0.068	0.128**	0.282**
<b>C-MOS-SSS</b>	Tangible support	0.012	-0.080	0.047	-0.105*	-0.103*	-0.081	0.022	-0.032	-0.074
	Informational and emotional support	0.073	-0.045	0.064	-0.101*	-0.102*	-0.096*	0.039	-0.123*	-0.057
	Positive social interaction	0.023	-0.077	0.017	-0.091	-0.132**	-0.095	-0.022	-0.121*	-0.097*
	Affectionate support	-0.025	-0.045	0.025	-0.082	-0.119*	-0.147**	0.010	-0.101*	-0.107*
	Total	0.036	-0.066	0.039	-0.107*	-0.123*	-0.111*	0.019	-0.108*	-0.086
<b>C-Brief-COPE</b>	Problem-focused coping	-0.130**	-0.144**	-0.151**	-0.035	-0.067	-0.148**	-0.011	-0.108*	-0.165**
	Emotion-focused coping	-0.091	-0.113*	-0.105*	-0.064	-0.149**	-0.150**	-0.051	-0.047	-0.165**
	Adaptive coping	-0.153**	-0.160**	-0.120*	-0.092	-0.125*	-0.163**	-0.181**	-0.085	-0.210**
	Maladaptive coping	0.018	0.029	0.048	0.025	-0.064	-0.001	-0.012	0.049	0.013
<b>C-QOL</b>	Burden	0.088	0.178**	0.160**	0.098*	0.179**	0.216**	0.113*	0.170**	0.241**
	Disruptiveness	0.154**	0.138**	0.218**	0.051	0.197**	0.278**	0.088	0.152**	0.258**
	Positive adaption	0.021	-0.002	0.027	0.026	0.082	0.116*	0.004	-0.026	0.058
	Financial concern	-0.012	0.031	0.054	0.041	0.130**	0.177**	0.270**	0.107*	0.135**
	Total	0.109*	0.153**	0.189**	0.090	0.209**	0.262**	0.127**	0.151**	0.259**
<b>Need or Care Part</b>										
<b>C-HADS</b>	C-Anxiety	0.142**	0.191**	0.187**	0.271**	0.296**	0.248**	0.148**	0.238**	0.281**
	C-Depression	0.219**	0.272**	0.250**	0.302**	0.312**	0.290**	0.132**	0.212**	0.341**
<b>C-MOS-SSS</b>	Tangible support	0.014	-0.043	0.041	-0.047	-0.103*	-0.064	-0.015	-0.059	-0.048
	Informational and emotional support	0.076	-0.007	0.052	-0.052	-0.072	-0.038	0.008	-0.131**	-0.020
	Positive social interaction	0.034	-0.027	0.034	-0.026	-0.092	-0.029	-0.017	-0.133**	-0.034

	Affectionate support	-0.089	-0.072	-0.057	-0.108*	-0.121*	-0.108*	-0.020	-0.117*	-0.112*
	Total	0.029	-0.033	0.031	-0.060	-0.101*	-0.059	-0.008	-0.125*	-0.049
<b>C-Brief- COPE</b>	Problem-focused coping	-0.297**	-0.309**	-0.291**	-0.285**	-0.220**	-0.260**	-0.131**	-0.202**	-0.342**
	Emotion-focused coping	-0.152**	-0.170**	-0.174**	-0.154**	-0.180**	-0.180**	-0.099*	-0.093	-0.209**
	Adaptive coping	-0.222**	-0.215**	-0.188**	-0.210**	-0.188**	-0.228**	-0.219**	-0.155**	-0.266**
	Maladaptive coping	-0.001	0.056	0.042	0.112*	0.045	0.066	0.012	0.054	0.068
<b>C-QOL</b>	Burden	0.200**	0.298**	0.262**	0.305**	0.320**	0.322**	0.196**	0.242**	0.365**
	Disruptiveness	0.364**	0.410**	0.399**	0.374**	0.406**	0.455**	0.239**	0.252**	0.500**
	Positive adaption	0.040	0.013	0.051	0.096*	0.129**	0.106*	-0.049	-0.050	0.074
	Financial concern	0.038	0.099*	0.095	0.088	0.151**	0.193**	0.258**	0.133**	0.161**
	Total	0.240**	0.310**	0.303**	0.314**	0.357**	0.370**	0.198**	0.220**	0.398**

**Note:** \*\* = Correlation is significant at the 0.01 level (two-tailed); \* = Correlation is significant at the 0.05 level (two-tailed).

## 7.6 Predictors of the problems and palliative care needs of patients

Stepwise multiple linear regression analysis was used to explore significant correlates of each domain and the global score of the PNPC-sv, including the Problem part and Need for Care part. Variables that showed statistical significance (cut-off point  $p < 0.05$ ) in the univariate analysis (as shown in Table 7.8-7.18) and correlation analysis (Table 7.19-7.21) were included in the regression analysis, using the stepwise variable-selection method with entrance and removal levels of  $p \leq 0.05$  and  $p \geq 0.10$ , respectively.

### 7.6.1 Predictors of ADL problems and needs

The results in **Table 7.22** show that the significant predictors of ADL problem were patients' global health status, total score of the patients' symptom distress, and received treatment therapy at that moment, accounting for 21.1% (adjusted  $R^2 = 0.211$ ) of the observed variance. The patients' global health status, use of coping strategies, total score of symptom distress, depression, marital status, and their informal caregivers' overall quality of life, anxiety, and coping strategies were detected as significant predictors of the ADL needs of the patients. These identified variables accounted for 43.5% (adjusted  $R^2 = 0.435$ ) of the observed dependent variable.

**Table 7.22** Stepwise multiple linear regression for variables predicting ADL problem and needs

PNPC -sv Do- mains	Variables	Unstandardized Coefficients		Stan. $\beta$	<i>t</i>	<i>p</i>	$R^2$	Adjusted $R^2$
		B	Std. Error					
<b>Problem part</b>								
ADL	P*QoL QLQ-C15 global health status	-0.353	0.085	-0.241	-4.126	0.000	0.217	0.211
	P Symptoms ESAS total score	0.021	0.005	0.237	4.091	0.000		
	P Therapy <sup>1</sup> Symptoms relieving	0.802	0.270	0.131	2.970	0.003		
<b>Need for Care part</b>								
ADL	P Symptoms ESAS total score	0.017	0.005	0.193	3.318	0.001	0.449	0.435
	P Brief-Coping Problem-focused coping	-0.091	0.027	-0.181	-3.423	0.001		
	Maladaptive coping	-0.053	0.016	-0.135	-3.212	0.001		

P QoL QLQ-C15 global health status	-0.155	0.073	-0.109	-2.136	0.033
P Depression	0.056	0.022	0.144	2.480	0.014
P Marital status	0.656	0.330	0.074	1.988	0.047
P Therapy <sup>1</sup> Chemo + radiotherapy	0.397	0.183	0.083	2.171	0.031
C** QoL CQOLC total score	0.015	0.005	0.159	3.039	0.003
C Coping Problem-focused coping	-0.052	0.021	-0.100	-2.517	0.012
C Anxiety	-0.044	0.022	-0.106	-2.013	0.045

**Note:** 1 = reference variable: no treatment; P\* = patients; C\*\* = informal caregivers.

### 7.6.2 Predictors of physical problems and needs

Three predictors of physical problems were identified, including patients' overall symptom distress, length of time since diagnosis, and use of coping strategies. The results indicated that those three variables accounted for 41.4% (adjusted  $R^2=0.414$ ) of the variance (see **Table 7.23**). For the physical needs of patients, a total of eight independent variables were entered into the regression (see **Table 7.23**), among which, the patients' overall symptom distress was the most significant positive predictor of physical needs, with the highest Beta coefficient ( $\beta=0.551$ ) at a statistically significant level ( $p=0.000$ ). The other seven identified predictors were age, coping strategies in relation to adaptive coping and maladaptive coping, received therapy, income level, caregivers' overall quality of life, and caregivers' problem-focused coping, accounting for 59.5% of the physical needs of the patients.

**Table 7.23** Stepwise multiple linear regression for variables predicting physical problem and needs

PNPC- sv Domains	Variables	Unstandardized Coefficients		Stan. $\beta$	<i>t</i>	<i>p</i>	$R^2$	Adj. $R^2$
		B	Std. Error					
<b>Problem Part</b>								
<b>Physical</b>	P* Symptoms ESAS total score	0.112	0.008	0.634	14.599	0.000	0.420	0.414
	P Length of time diagnosis <sup>2</sup> 1-3 months	-0.752	0.343	-0.083	-2.191	0.029		
	P Coping							

	Problem-focused coping	0.214	0.055	0.212	3.919	0.000		
	Adaptive coping	-0.340	0.092	-0.194	-3.696	.000		
<b>Need for Care</b>								
<b>Physical</b>	P symptoms ESAS total score	0.121	0.008	0.551	15.420	0.000	0.603	0.595
	P Coping Adaptive coping	-0.336	0.083	-0.154	-4.058	0.000		
	Maladaptive coping	-0.087	0.033	-0.089	-2.639	0.009		
	P Age	0.045	0.013	0.112	3.565	0.000		
	P Therapy <sup>1</sup> Follow-up	-1.420	0.621	-0.072	-2.287	0.023		
	P Income <sup>3</sup> <3000CNY	0.616	0.291	0.070	2.120	0.035		
	C** QoL CQOLC total score	0.029	0.008	0.125	3.806	0.000		
	C Coping Problem-focused coping	-0.107	0.044	0-0.082	-2.455	0.015		

**Note:** 1 = reference variable: no treatment; 2 = reference variable: length of time since diagnosis >12 months; 3 = reference variable: >10,000CNY; P\* = patients; C\*\* = informal caregivers.

### 7.6.3 Predictors of autonomy problems and needs

Regarding the autonomy problems of the patients, five independent variables were identified, and the details of the findings are shown in **Table 7.24**. Specifically, the regression results indicated that patients' overall symptom distress, global health status, treatment therapy, length of time since diagnosis, and use of coping strategies in relation to adaptive coping were significant in the prediction of autonomy problem ( $R^2= 39.7\%$ ). In terms of autonomy needs, a total of 10 independent variables were entered into the regression model (see **Table 7.24**). Overall, the patients' symptom distress was identified as the most significant positive predictor ( $\beta=0.411$ ,  $p=0.000$ ), followed by maladaptive coping, anxiety, age, time since diagnosis, income level, received therapy, and caregivers' anxiety, overall quality of life, and problem-focused coping. These 10 independent variables accounted for 52.7% of autonomy needs.

**Table 7.24** Stepwise multiple linear regression for variables predicting autonomy problem and needs

PNPC-sv Domains	Variables	Unstandardized Coefficients		Stan. $\beta$	<i>t</i>	<i>p</i>	$R^2$	Adj. $R^2$
		B	Std. Error					
<b>Problem Part</b>								
<b>Autonomy</b>	P* Symptoms ESAS total score	0.062	0.007	0.458	8.720	0.000	0.405	0.397
	P Therapy <sup>1</sup> Symptoms relieving	1.077	0.352	0.118	3.063	0.002		
	P QoL Global health status	-0.259	0.112	-0.119	-2.306	0.022		
	P Length of time diagnosis <sup>2</sup> 3-6 months	-0.751	0.263	-0.112	-2.859	0.004		
	1-3 months	-0.677	0.272	-0.098	-2.484	0.013		
	P Coping Adaptive coping	-0.134	0.057	-0.101	-2.356	0.019		
<b>Need for Care part</b>								
<b>Autonomy</b>	P Symptoms ESAS total score	0.062	0.007	0.411	8.455	0.000	0.538	0.527
	P Coping Maladaptive coping	-0.135	0.023	-0.202	-5.809	0.000		
	P Anxiety	0.124	0.035	0.168	3.494	0.001		
	P Age	0.026	0.009	0.096	2.815	0.005		
	P Length of time diagnosis <sup>2</sup> 6-12months	0.026	0.245	0.076	2.221	0.027		
	P Income <sup>3</sup> 3000-6000CNY	-0.482	0.220	-0.076	-2.191	0.029		
	P Therapy <sup>1</sup> Chemo + radiotherapy	0.570	0.288	0.070	1.979	0.049		
	C** QoL CQOLC total score	0.034	0.008	0.211	4.436	0.000		
	C Coping Problem-focused coping	-0.093	0.032	-0.103	-2.898	0.004		
	C Anxiety	-0.085	0.034	-0.119	-2.505	0.013		

**Note:** 1 = reference variable: no treatment; 2 = reference variable: length of time since diagnosis >12 months; 3 = reference variable: >10,000CNY; P\* = patients; C\*\* = informal caregivers.

#### 7.6.4 Predictors of social problems and needs

The identified predictors of social problem and needs are presented in **Table 7.25**. The patients' overall social support level was the most significant negative predictor ( $\beta=-0.270$ ,  $p=0.000$ ) of social problems. The other three predictors of social problems were patients' anxiety and maladaptive coping and caregivers' anxiety. These four predictors accounted for only 20.5% of the variance. For the patients' social needs, eight predictors were included in the regression model. The results indicated that the patients' overall social support level, coping strategies (problem-focused coping), anxiety, treatment therapy, overall symptom distress, and their caregivers' overall quality of life and coping in relation to problem-focused and maladaptive coping were significant predictors of the social needs of patients, and together these predictors accounted for 38.2% of the variance.

**Table 7.25** Stepwise multiple linear regression for variables predicting social problem and needs

PNPC Domains	Variables	Unstandardized Coefficients		Stan. $\beta$	$t$	$p$	$R^2$	Adj. $R^2$
		B	Std. Error					
<b>Problem Part</b>								
Social	P* Social support MOS-SSS total score	-0.046	0.008	-0.270	-5.887	0.000	0.212	0.205
	P Anxiety	0.108	0.023	0.221	4.745	0.000		
	P Coping Maladaptive coping	0.083	0.020	0.187	4.250	0.000		
	C** Anxiety	0.062	0.021	0.131	2.888	0.004		
<b>Need for Care Part</b>								
Social	P Coping Problem-focused coping	-0.143	0.036	-0.193	-4.022	0.000	0.393	0.382
	P Anxiety	0.095	0.036	0.150	2.660	0.008		
	P Social support MOS-SSS total score	-0.035	0.009	-0.158	-3.832	0.000		
	P Therapy <sup>1</sup> Chemo + radio	0.689	0.281	0.098	2.457	0.014		
	P Symptoms ESAS total score	0.017	0.007	0.132	2.374	0.018		
	C QoL CQOLC total score	0.021	0.006	0.151	3.606	0.000		
	C Coping Problem-focused coping Maladaptive coping	-0.104	0.033	-0.135	-3.157	0.002		
		0.053	0.023	0.095	2.274	0.023		

**Note:** 1 = reference variable: no treatment; P\* = patients; C\*\* = informal caregivers.



### 7.6.5 Predictors of psychological problems and needs

The results of the stepwise multiple linear regression analysis regarding psychological problems and needs are shown in **Table 7.26**. For psychological problem, 10 independent variables were finally detected, including patients' anxiety, use of coping strategies in relation to problem-focused and maladaptive coping, overall symptom distress, gender, overall social support level, time since diagnosis, number of complications, and caregivers' emotion-focused coping and anxiety. These independent variables explained 37.5% of the psychological problems. Among these 10 identified variables, patients' anxiety was the most significant positive predictor, with a  $\beta$  of 0.405. Regarding psychological needs, similar but less important predictors were identified compared with psychological problems. A total of seven predictors of psychological needs were identified, including patients' anxiety, overall symptom distress, number of complications, overall social support level, and caregivers' overall quality of life and their emotion-focused coping (adjusted  $R^2=51.4\%$ ). Among these, the most significant predictor of psychological needs was patients' anxiety level ( $\beta=0.377$ ,  $p=0.000$ ). Detailed information is listed in **Table 7.26** below:

**Table 7.26** Stepwise multiple linear regression for variables predicting psychological problems and needs

PNPC- sv Domains	Variables	Unstandardized Coefficients		Stan. $\beta$	<i>t</i>	<i>p</i>	$R^2$	Adj. $R^2$
		B	Std. Error					
<b>Problem Part</b>								
<b>Psycho- logical</b>	P* Anxiety	0.291	0.042	0.405	6.965	0.000	0.390	0.375
	P Coping Problem- focused coping	0.182	0.045	0.217	4.095	0.000		
	Maladaptive coping	0.060	0.030	0.092	2.023	0.044		
	P Symptoms ESAS total score	0.060	0.008	0.234	4.212	0.000		
	P Gender	-0.569	0.237	-0.096	-2.401	0.017		
	P Social support MOS-SSS total score	-0.021	0.010	-0.086	-2.075	0.039		

	P Length of time diagnosis <sup>2</sup> 6-12 months	-0.612	0.272	-0.088	-2.248	0.025		
	P Compli- cations	0.635	0.290	0.087	2.186	0.029		
	C** Coping Emotion- focused coping	-0.088	0.043	-0.081	-2.056	0.040		
	C Anxiety	0.079	0.028	0.114	2.772	0.006		
<b>Need for Care Part</b>								
<b>Psycho- logical</b>	P Anxiety	0.299	0.038	0.377	7.802	0.000	0.521	0.514
	P symptoms ESAS total score	0.045	0.008	0.274	5.732	0.000		
	P Compli- cations	0.574	0.282	0.071	2.036	0.042		
	P Social support MOS-SSS total score	-0.020	0.010	-0.073	-2.029	0.043		
	C QoL CQOLC total score	0.031	0.006	0.180	5.007	0.000		
	C Coping Emotion- focused coping	-0.092	0.041	-0.077	-2.229	0.026		

**Note:** 2 = reference variable: length of time since diagnosis >12 months; P\* = patients; C\*\* = informal caregivers.

### 7.6.6 Predictors of spiritual problems and needs

The predictors of spiritual problems and needs are presented in **Table 7.27**. The regression results showed that the patients' anxiety, overall symptom distress, monthly income level, overall social support level, coping strategies (problem-focused and adaptive coping), depression, and caregivers' quality of life were significant in the prediction of spiritual problems, with an adjusted  $R^2$  of 0.324. For spiritual needs, the following seven predictors were included: patients' depression, overall symptom distress, adaptive coping, monthly income level, and caregivers' quality of life, problem-focused coping, and depression. These variables together accounted for 45.1% of the variance for spiritual needs.

**Table 7.27** Stepwise multiple linear regression for variables predicting spiritual problems and needs

PNPC- sv Domains	Variables	Unstandardized Coefficients		Stan. $\beta$	<i>t</i>	<i>p</i>	<b>R<sup>2</sup></b>	<b>Adj. R<sup>2</sup></b>
		B	Std. Error					
<b>Problem Part</b>								
<b>Spiritual</b>	P* Anxiety	0.112	0.051	0.188	2.208	0.028	0.337	0.324
	P Symptoms ESAS total score	0.022	0.007	0.178	3.032	0.003		
	P Income <sup>3</sup> 3000-6000CNY	-0.626	0.210	-0.123	-2.986	0.003		
	P Social support MOS-SSS total score	-0.019	0.009	-0.093	-2.119	0.035		
	P Coping Problem- focused coping	0.158	0.041	0.228	3.832	0.000		
	Adaptive coping	-0.190	0.070	-0.158	-2.704	0.007		
	P Depression	0.095	0.048	0.178	1.987	0.048		
C** QoL CQOLC total score	0.014	0.006	0.108	2.544	0.011			
<b>Need for Care Part</b>								
<b>Spiritual</b>	P Depression	0.173	0.034	0.285	5.103	0.000	0.460	0.451
	P symptoms ESAS total score	0.030	0.007	0.217	4.174	0.000		
	P Coping Adaptive coping	-0.196	0.061	-0.143	-3.214	0.001		
	P Income <sup>3</sup> 3000-6000CNY	-0.557	0.215	-0.096	-2.587	0.010		
	C QoL CQOLC total score	0.042	0.007	0.282	5.715	0.000		
	C Coping Problem- focused coping	-0.085	0.033	-0.103	-2.600	0.010		
	C Depression	-0.078	0.033	-0.120	-2.349	0.019		

**Note:** 3 = reference variable: >10,000CNY; P\* = patients; C\*\* = informal caregivers.

### 7.6.7 Predictors of financial problems and needs

As shown in **Table 7.28**, several predictors were identified for financial problems. The patients' income level was the most significant positive predictor ( $\beta=0.299$ ,  $p=0.000$ ), followed by the patients' overall symptom distress, age, education level, living place, and caregivers' education level and adaptive coping. These factors together accounted for only 20.5% of the

financial problems, while for financial needs, the identified variables accounted for 35.7% of the variance, including patients' overall symptom distress, income level, treatment therapy, education level, and caregivers' adaptive and problem-focused coping. As with financial problems, the patients' monthly family income level was the most significant positive predictor ( $\beta=0.594$ ,  $p=0.000$ ) of financial needs.

**Table 7.28** Stepwise multiple linear regression for variables predicting financial problems and needs

PNPC Domains	Variables	Unstandardized Coefficients		Stan. $\beta$	t	P	R <sup>2</sup>	Adj. R <sup>2</sup>
		B	Std. Error					
<b>Problem part</b>								
<b>Financial</b>	P*Income <sup>3</sup> <3000CNY	0.691	0.173	0.299	4.004	0.000	0.221	0.205
	3000-6000CNY	0.482	0.163	0.199	2.959	0.003		
	P Symptoms ESAS total score	0.009	0.003	0.163	3.542	0.000		
	P Age	-0.016	0.005	-0.152	-3.477	0.001		
	P Education <sup>4</sup> Primary education	0.183	0.054	0.149	3.364	0.001		
	P Living place	-0.240	0.116	-0.103	-2.068	0.039		
	C** Education <sup>4</sup> Primary education	0.204	0.103	0.088	1.981	0.048		
C Coping Adaptive coping	-0.048	0.024	-0.090	-2.007	0.045			
<b>Need for Care part</b>								
<b>Financial</b>	P Symptoms ESAS total score	0.019	0.003	0.288	6.808	0.000	0.369	0.357
	P Income <sup>3</sup> <3000CNY	1.524	0.155	0.594	9.798	0.000		
	3000-6000CNY	1.202	0.158	0.447	7.619	0.000		
	P Therapy <sup>1</sup> Targeted therapy Follow-up	0.689 -0.473	0.245 0.229	0.112 -0.082	2.814 -2.061	0.005 0.040		

	P Education <sup>4</sup>	0.134	0.054	0.099	2.473	0.014		
	Primary education							
	C Coping Adaptive coping	-0.103	0.031	-0.174	-3.328	0.001		
	Problem-focused coping	0.048	0.020	0.127	2.406	0.017		

**Note:** 1 = reference variable: no treatment; 3 = reference variable: >10,000CNY; 4 = reference variable: higher education; P\* = patients; C\*\* = informal caregivers.

### 7.6.8 Predictors of information problems and needs

For information problems and needs, only a few predictors were identified through the regression analysis, and the detected factors accounted for less than 15% of the variance. More specifically, patients' anxiety, income level, and caregivers' anxiety were the predictors of information problems, accounting for only 7.2% of the information problems for the sample group. Regarding information needs, four independent variables in the regression model were patients' anxiety, number of complications, and caregivers' problem-focused coping and quality of life. However, they accounted for only 13.2% of the patients' information needs. Detailed information is shown in **Table 7.29** below:

**Table 7.29** Stepwise multiple linear regression for variables predicting information problems and needs

PNPC-sv Domains	Variables	Unstandardized Coefficients		Stan. $\beta$	<i>t</i>	<i>p</i>	$R^2$	Adj. $R^2$
		B	Std. Error					
<b>Problem Part</b>								
Infor- mation	P* Anxiety	0.031	0.010	0.162	3.218	0.001	0.078	0.072
	P Income <3000CN Y <sup>3</sup>	0.187	0.079	0.117	2.370	0.018		
	C** Anxiety	0.022	0.009	0.116	2.367	0.018		
<b>Need for Care Part</b>								
Infor- mation	P Anxiety	0.043	0.009	0.227	4.782	0.000	0.140	0.132
	P Compli- cations	0.185	0.090	0.096	2.067	0.039		
	C Coping	-0.034	0.011	-0.149	-3.225	0.001		

	Problem-focused coping							
	C QOL CQOLC total score	0.006	0.002	0.135	2.821	0.005		

**Note:** 3 = reference variable: >10,000CNY; P\* = patients; C\*\* = informal caregivers.

### 7.6.9 Predictors of overall problems and palliative care needs

**Table 7.30** presents the results regarding the predictors of overall problems and palliative care needs. The predictors of overall problems included the patients' symptom distress, anxiety, social support level, use of coping strategies in relation to problem-focused and adaptive coping, length of time since diagnosis, treatment therapy, and anxiety of their informal caregivers, accounting for 57.6% of the problems experienced for patients with advanced cancer. The findings showed that the patients' overall symptom distress, coping strategies regarding adaptive and maladaptive coping, anxiety, cancer type, treatment therapy, and caregivers' overall quality of life and problem-focused coping were significant variables in predicting the palliative care needs of patients with advanced cancer. All these predictors accounted for 70.2% of the variance (palliative care needs). The patients' overall symptom distress was the most significant positive predictor of both the problems and palliative care needs of patients with advanced cancer, with Beta coefficients of 0.507 and 0.411, respectively.

**Table 7.30** Stepwise multiple linear regression for variables predicting overall problems and needs

PNPC- sv Domains	Variables	Unstandardized Coefficients		Stan. $\beta$	<i>t</i>	<i>p</i>	$R^2$	Adj. $R^2$
		B	Std. Error					
<b>Problem Part</b>								
<b>Global Score</b>	P* Symptoms ESAS total score	0.289	0.026	0.507	11.086	0.000	0.585	0.576
	P Anxiety	0.633	0.131	0.229	4.818	0.000		
	P Social support MOS-SSS total score	-0.104	0.033	-0.108	-3.121	0.002		
	P Coping Problem-focused coping	0.728	0.151	0.225	4.809	0.000		
	Adaptive coping	-0.994	0.259	-0.177	-3.836	0.000		

	P Length of time diagnosis <sup>2</sup>							
	1-3 months	-3.052	0.970	-0.104	-3.147	0.002		
	3-6 months	-2.060	0.937	-0.073	-2.198	0.028		
	P Therapy <sup>1</sup> symptoms relieving	2.765	1.238	0.072	2.233	0.026		
	C** Anxiety	0.282	0.089	0.105	3.161	0.002		
<b>Need for Care Part</b>								
<b>Global Score</b>	P Symptoms ESAS total score	0.317	0.030	0.411	10.680	0.000	0.708	0.702
	P Coping Adaptive coping	-0.983	0.260	-0.129	-3.784	0.000		
	Maladaptive coping	-0.323	0.100	-0.095	-3.226	0.001		
	P Anxiety	0.850	0.149	0.226	5.706	0.000		
	P Income <sup>3</sup> <3000CNY	2.525	0.884	0.082	2.857	0.005		
	P Cancer type <sup>5</sup> Reproductive system	-2.551	1.167	-0.059	-2.186	0.029		
	P Therapy <sup>1</sup> Chemo + radio	2.343	1.156	0.056	2.027	0.043		
	C QoL CQOLC total score	0.150	0.024	0.181	6.363	0.000		
C Coping Problem-focused coping	-0.478	0.132	-0.105	-3.623	0.000			

**Note:** 1 = reference variable: no treatment; 2 = reference variable: length of time since diagnosis >12 months; 3 = reference variable: >10,000CNY; 5 = reference variable: other types of cancer; P\* = patients; C\*\* = informal caregivers.

## **Part Two: Caregiver Needs Assessment Survey Results**

### **7.7 Characteristics of informal caregivers**

#### **7.7.1 Demographic characteristics**

The informal caregivers were aged 18 to 78 years old, with a mean age of 45.6±13.8. More than half of the informal caregivers were female (229/419, 54.7%). Some 60.4% (n=253) had only a primary education or less. The majority of the informal caregivers (393/419, 93.8%) had no religious beliefs, and 66.1% of the informal caregivers (n=277) were unemployed. Nearly half of the informal caregivers (187/419, 44.5%) had taken care of the patients for one to six months, about one-third (139/419, 33.2%) had taken care of the patient more than six months, and the other 22.1% had taken care of the patient for less than one month. Of the informal caregivers, 191 (45.6%) reported that there were almost no other family members

sharing the care of the patient. For the relationship between the patients and the informal caregivers, about half (213/419, 50.8%) of the informal caregivers were couples or partners, 39.4% were children, and the rest were parents (2.9%) and other relatives or friends (6.9%). The details of the demographic characteristics of the informal caregivers are shown in Table 7.31 below:

**Table 7.31** Demographic characteristics of informal caregivers (N=419)

Variables		M±SD(%)
<b>Age (yrs.)</b>		45.6±13.8
<b>Marital status</b>	Married	368(87.8%)
	Single	51(12.2%)
<b>Gender</b>	Male	190(45.3%)
	Female	229(54.7%)
<b>Education</b>	No formal education	29(6.9%)
	Primary education	224(53.5%)
	Higher education	166(39.6%)
<b>Religion</b>	No	393(93.8%)
	Yes	26(6.1%)
<b>Working status</b>	Employed	132(33.9%)
	Unemployed	277(66.1%)
<b>Time length of caregiving</b>	≤1 month	93(22.2%)
	1-6 months	187(44.6%)
	≥6 months	139(33.2%)
<b>Other caregivers*</b>	No	191 (45.6%)
	Sometimes	89(21.2%)
	Regular	139(33.2%)
<b>Relationship with patient*</b> (You are the __ of the patient)	Couples/partners	213(50.8%)
	Parents	12(2.9%)
	Children	165(39.4%)
	Other relatives or friends	29(6.9%)

**Note:** \* = ‘Are there any other family members helping to take care of the patient?’

### 7.7.2 Characteristics of emotional status

The emotional status of the informal caregivers was evaluated using the Hospital Anxiety and Depression Scale (HADS). The Cronbach’s alphas of the anxiety and depression sub-scales in this sample were 0.86 and 0.86, respectively. The scores ranged from 0 to 21 for the anxiety sub-scale and from 0 to 18 for the depression sub-scale. The mean scores were 7.2 (SD=4.2) for anxiety and 6.4 (SD=4.2) for depression. Of the informal caregivers, 23.2% (n=97) exhibited symptoms of clinical anxiety and 18.1% (n=76) exhibited symptoms of clinical



depression, while 23.2% (n=97) and 24.1% (n=103) showed borderline cases of anxiety and depression, respectively.

### 7.7.3 Characteristics of social support

The social support of the informal caregivers was evaluated using the Medical Outcomes Study-Social Support Survey (MOS-SSS). Higher scores indicate more social support. The scores of all sub-scales were transformed to a 0 to 100 scale. The Cronbach's alpha of the MOS-SSS in the group of informal caregivers was 0.909. Affectionate support was rated highest (63.2±20.4), followed by tangible support (60.5±21.7), positive social interaction (57.4±21.0), and informational and emotional support (57.1±18.7). The mean score of the overall scale was 58.8 (SD=18.2).

### 7.7.4 Characteristics of coping strategies

The coping strategies used by the informal caregivers were evaluated by the Brief Coping Orientation to Problems Experienced (Brief-COPE) scale, and its Cronbach's alpha was 0.828 in this sample. As the item numbers (N) in each domain are different, the mean of each domain (M±SD) divided by N was calculated. The results were similar to those of the patients with advanced cancer, which was that problem-focused coping (3.1±0.6) was the most commonly used coping strategy for the informal caregivers. The least frequently used coping strategy was maladaptive coping (2.2±0.4). The coping strategies of the informal caregivers are presented in **Table 7.32** below:

**Table 7.32** Coping strategies of informal caregivers (N=419, M±SD)

Domains	Number of Items(N)	Minimum	Maximum	Mean±SD	(M±SD)/N
Problem-focused coping	6	6	24	18.3±3.4	3.1±0.6
Emotion-focused coping	6	6	24	13.9±2.7	2.3±0.5
Adaptive coping	4	4	16	11.5±2.2	2.9±0.6
Maladaptive coping	12	12	44	26.7±4.6	2.2±0.4

### 7.7.5 Characteristics of quality of life

The quality of life of the informal caregivers was explored utilizing the Caregiver Quality of Life Index-Cancer (CQOLC). The higher the score, the poorer the quality of life. The

Cronbach's alpha for the informal caregivers was 0.93. According to the results, 'financial concern' was reported as the highest rated domain, with a mean score of 2.7. 'Disruptiveness' was the lowest rated domain, with a mean score of 1.6 (SD=0.9). The details are shown in **Table 7.33** below:

**Table 7.33** Quality of life of informal caregivers (N=419, M±SD)

Domains	Number of Items (N)	Minimum	Maximum	Mean±SD	(M±SD)/N
Burden	11	0	40	19.6±8.0	1.8±0.7
Disruptiveness	6	0	24	9.8±5.3	1.6±0.9
Positive adaption	6	1	22	12.9±2.9	2.2±0.5
Financial concerns	3	0	12	8.0±2.8	2.7±0.9

### 7.8 Comprehensive needs of informal caregivers

The Comprehensive Needs Assessment Tool for Cancer Caregivers (CNAT-C) was adopted to assess the comprehensive needs of the informal caregivers, with a Cronbach's alpha of 0.942 in this study. The most frequently reported needs were related to the domains of 'health-care staff' (84.5%-95.0%), 'information' (66.3%-92.1%), and 'hospital facilities and services' (64.2%-90.5%). For the domain of 'health-care staff', the highest unmet need was 'nurses to promptly attend to patient discomfort and pain' (95.0%), and the lowest unmet need was 'being respected and treated as a person by my doctor' (84.5%). For information needs, 'information about tests and treatment' (92.1%) and 'information about caregiving-related stress management' (66.3%) were the highest and lowest unmet needs, respectively, reported by the informal caregivers. In terms of the domain of 'hospital facilities and services', the items with the lowest and highest percentages were 'a visiting nurse service for home' (64.2%), and 'a designated hospital staff member who would be able to provide counselling for any concerns, and guidance with the course of the treatment, from the point of diagnosis to the period after discharge' (90.5%), respectively. All the results of the unmet needs of the informal caregivers are shown in **Table 7.34** below:

**Table 7.34** Responses of the informal caregivers to their needs (N=419, %)

Item	Response Frequency: N(%)				Overall need expressed (1)+(2)+(3)
	No need	Low need (1)	Moderate need (2)	High need (3)	
<b>Health and psychological problems (Mean ± SD: 33.6±31.2)</b>					
1. My own health problems	208(49.6%)	57(13.6%)	80(19.1%)	74(17.7%)	50.4%
2. Concerns about the patient	127(30.3%)	78(18.6%)	120(28.6%)	94(22.4%)	69.7%
3. Depression	215(51.3%)	72(17.2%)	73(17.4%)	59(14.1%)	48.7%
4. Feelings of anger, irritability, or nervousness	223(53.2%)	73(17.4%)	71(16.9%)	52(12.4%)	46.8%
5. Loneliness or feelings of isolation	242(57.8%)	68(16.2%)	62(14.8%)	47(11.2%)	42.2%
6. Feelings of vague anxiety	205(48.9%)	82(19.6%)	81(19.3%)	51(12.2%)	51.1%
<b>Family/social support (Mean±SD: 34.3±28.0)</b>					
7. Help with patient over-dependence	146(34.8%)	83(19.8%)	134(32.0%)	56(13.4%)	65.2%
8. Help with patient lack of appreciation of the caregiving	150(35.8%)	108(25.8%)	114(27.2%)	47(11.2%)	64.2%
9. Help with difficulties in family relationships after cancer diagnosis	189(45.1%)	93(22.2%)	85(20.3%)	52(12.4%)	54.9%
10. Help with difficulties in interpersonal relationship after cancer diagnosis	198(47.3%)	82(19.6%)	99(23.6%)	40(9.5%)	52.7%
11. Help with my own relaxation and my personal life	222(53.0%)	89(21.2%)	75(17.9%)	33(7.9%)	47.0%
<b>Healthcare staff (Mean±SD: 71.3±27.2)</b>					
12. Being respected and treated as a person by my doctor	65(15.5%)	83(19.8%)	101(24.1%)	170(40.6%)	84.5%
13. Doctor to be clear, specific, and honest in his/her explanation	31(7.4%)	78(18.6%)	109(26.0%)	201(48.0%)	92.6%
14. Seeing doctor quickly and easily when in need	26(6.2%)	84(20.0%)	99(23.6%)	210(50.1%)	93.8%
15. Being involved in the decision-making process in choosing any tests or treatments that the patient receives	34(8.1%)	78(18.6%)	109(26.0%)	198(47.3%)	91.9%
16. Cooperation and communication among healthcare staff	31(7.4%)	73(17.4%)	110(26.3%)	205(48.9%)	92.6%
17. Sincere interest and empathy from my nurse	31(7.4%)	70(16.7%)	111(26.5%)	207(49.4%)	92.6%
18. Nurses to explain treatment or care that is being given to the patient	36(8.6%)	70(16.7%)	106(25.3%)	207(49.4%)	91.4%
19. Nurses to promptly attend to patient discomfort and pain	21(5.0%)	69(16.5%)	103(24.6%)	226(53.9%)	95.0%
<b>Information (Mean±SD: 59.5±23.9)</b>					
20. Information about the current status of a patient's illness and its future course	22(5.3%)	83(19.8%)	126(30.1%)	188(44.9%)	74.7%
21. Information about tests and treatment	33(7.9%)	55(13.1%)	171(40.8%)	160(38.2%)	92.1%
22. Information about caring for the patient (symptom management, diet, exercise, etc.)	60(14.3%)	97(23.2%)	110(26.3%)	152(36.3%)	85.7%
23. Guidelines or information about complementary and alternative medicine	96(22.9%)	103(24.6%)	107(25.5%)	113(27.0%)	77.1%

24. Information about hospitals or clinics and physicians who treat cancer	66(15.8%)	80(19.1%)	141(33.7%)	132(31.5%)	84.2%
25. Information about financial support for medical expenses, either from government and/or private organizations	36(8.6%)	61(14.6%)	103(24.6%)	219(52.3%)	91.4%
26. Help with communication with the patient and/or other family members	133(31.7%)	89(21.2%)	110(26.3%)	87(20.8%)	68.3%
27. Information about caregiving-related stress management	141(33.7%)	102(24.3%)	103(24.6%)	73(17.4%)	66.3%
<b>Religious/spiritual support (Mean±SD: 13.4±21.7)</b>					
28. Religious support	373(89.0%)	24(5.7%)	14(3.3%)	8(1.9%)	11.0%
29. Help in finding the meaning of my situation and coming to terms with it	278(66.3%)	48(11.5%)	66(15.8%)	27(6.4%)	33.7%
<b>Hospital facilities and services (Mean±SD: 51.5±26.8)</b>					
30. A designated hospital staff member who would be able to provide counselling for any concerns, and guidance with the course of the treatment, from the point of diagnosis to the period after discharge	40(9.5%)	75(17.9%)	141(33.7%)	163(38.9%)	90.5%
31. Guidance about hospital facilities and services	76(18.1%)	141(33.7%)	117(27.9%)	85(20.3%)	81.9%
32. Need for space reserved for caregivers	87(20.8%)	128(30.5%)	133(31.7%)	71(16.9%)	79.2%
33. A visiting nurse service for home	150(35.8%)	91(21.7%)	85(20.3%)	93(22.2%)	64.2%
34. Opportunity to share experiences or information with other caregivers	82(19.6%)	112(26.7%)	124(29.6%)	101(24.1%)	80.4%
35. Welfare services (e.g., psychological counselling) for caregivers	112(26.7%)	105(25.1%)	115(27.4%)	87(20.8%)	73.3%
<b>Practical support (Mean±SD: 44.6±31.0)</b>					
36. Transportation service for getting to and from the hospital	180(43.0%)	58(13.8%)	78(18.6%)	103(24.6%)	57.0%
37. Treatment near home	150(35.8%)	76(18.1%)	79(18.9%)	114(27.2%)	64.2%
38. Lodging near hospital where the patient is treated	225(53.7%)	58(13.8%)	56(13.4%)	80(19.1%)	46.3%
39. Help with the economic burden caused by cancer	54(12.9%)	57(13.6%)	77(18.4%)	231(55.1%)	87.1%
40. Someone to help me with housekeeping and/or child care	208(49.6%)	61(14.6%)	66(15.8%)	84(20.0%)	50.4%
41. Assisted care in hospital or at home	180(43.0%)	68(16.2%)	78(18.6%)	93(22.2%)	57.0%

## 7.9 Relationships between various independent variables and care needs of informal caregivers

Skewness and kurtosis were used to determine the normality of the data. In this study, both the absolute skew value and kurtosis values were less than 2 and 7, respectively, and the data was therefore determined as normal distribution, and a parametric test employed. The association between demographic characteristics (categorical variables) and the care needs of informal caregivers was explored through independent t-tests and one-way ANOVA. Pearson Correlation analysis was used to explore the correlations between the age, anxiety and depression, social support, coping strategies, quality of life and the needs of informal caregivers.

### 7.9.1 Associations between demographic characteristics (categorical variables) and care needs

#### 7.9.1.1 Gender

No significant difference was identified between male and female caregivers regarding their care needs ( $p>0.05$ ).

#### 7.9.1.2 Marital status

Informal caregivers who were single reported less health and psychological needs ( $p=0.010$ ) and less hospital facilities and service needs ( $p=0.039$ ). Details are presented in **Table 7.35** below:

**Table 7.35** Differences in total and sub-scores of the CNAT-C between single and married caregivers (N=419)

Marital Status	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
Single (n=51)	23.1±28.6	28.1±25.5	67.6±24.2	60.5±22.3	12.7±22.0	45.2±21.9	40.8±29.3	278.1±118.0
Married (n=368)	35.1±31.4	35.1±28.2	71.9±27.6	59.4±24.1	13.5±21.7	52.3±27.2	45.1±31.2	312.3±130.8
<i>t</i>	-2.582	-1.679	-1.056	0.329	-0.231	-2.107	-0.913	-1.770
<i>p</i>	0.010	0.094	0.292	0.742	0.817	0.039	0.362	0.077

### 7.9.1.3 Employment

Caregivers who had a job reported lower needs scores in terms of needs for hospital facilities and services ( $p=0.020$ ). The details are shown in **Table 7.36** below:

**Table 7.36** Differences in total and sub-scores of the CNAT-C on employment status of caregivers (N=419)

Employment	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
No (n=277)	33.8±31.7	33.8±28.8	72.7±25.7	60.6±23.6	13.5±23.1	53.7±26.6	44.7±30.2	312.7±125.7
Yes (n=142)	33.3±30.5	35.2±26.4	68.7±29.9	57.4±24.3	13.3±18.8	47.2±26.7	44.2±32.5	299.3±137.1
<b>t</b>	0.130	-0.475	1.409	1.299	0.096	2.339	0.149	0.994
<b>P</b>	0.896	0.635	0.160	0.195	0.924	0.020	0.882	0.321

### 7.9.1.4 Education

Significant differences were detected in the domains of health and psychological problems, healthcare staff, hospital facilities and services, and the total score ( $p<0.05$ ). Detailed information is shown in **Table 7.37** below:

**Table 7.37** Differences in total and sub-scores of the CNAT-C among subjects by education attainment (N=419)

Education	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
No formal education (n=29)	54.4±32.7	40.5±33.1	85.3±19.9	66.2±22.2	10.3±22.0	66.7±26.8	50.4±29.7	373.8±106.0
Primary education (n=224)	32.9±31.5	34.6±28.1	69.3±28.5	57.5±24.9	14.3±23.9	51.0±28.3	44.7±31.2	304.4±135.5
Higher education (n=166)	30.9±29.5	32.7±26.8	71.6±25.8	61.0±22.5	12.8±18.4	49.5±23.8	43.3±30.9	301.7±122.7
<b>F</b>	7.317	0.991	4.533	2.282	0.546	5.267	0.651	4.079
<b>p</b>	0.001	0.372	0.01	0.103	0.580	0.006	0.522	0.018

### 7.9.1.5 Length of caregiving time

As shown in **Table 7.38**, caregivers with differing lengths of caregiving time reported different needs in terms of the healthcare staff, information, and hospital facilities domains ( $p<0.05$ ).

**Table 7.38** Differences in total and sub-scores of the CNAT-C among subjects by length of caregiving time (N=419)

Length of Caregiving Time (months)	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
≤1 (n=93)	34.5±32.8	35.1±26.7	73.7±28.6	61.0±23.3	16.7±24.7	52.5±27.5	46.7±31.2	320.3±132.4
1-6 (n=187)	35.7±30.2	36.7±28.4	67.3±26.5	54.7±22.2	13.5±20.8	47.4±23.4	46.3±32.2	301.7±130.0
>6 (n=139)	30.2±31.4	30.4±28.0	75.2±26.5	65.0±25.2	11.0±20.7	56.2±29.8	40.7±29.0	308.7±127.7
F	1.304	2.076	3.902	7.810	1.891	4.489	1.603	0.638
p	0.273	0.127	0.021	0.000	0.152	0.012	0.202	0.529

### 7.9.1.6 Relationship between caregivers and patients

When the informal caregivers were couples/partners, they had lower information needs ( $p=0.045$ ). Higher scores of healthcare staff needs and the total score were identified for informal caregivers who were relatives or friends of the patients ( $p<0.05$ ). Details are shown in **Table 7.39** below:

**Table 7.39** Differences in total and sub-scores of the CNAT-C for subjects' relationship with patients (N=419)

Relationship	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
Couples/partners	35.5±31.7	34.6±28.7	72.8±28.0	59.6±24.5	13.9±22.8	54.1±28.2	46.8±31.4	317.4±132.6
Patients	31.9±30.8	32.2±34.6	74.7±33.3	70.1±21.9	9.7±19.4	50.0±27.0	23.6±18.5	292.3±122.9
Children	29.4±29.7	32.7±26.9	67.1±25.6	57.0±23.3	12.2±19.7	47.3±24.5	42.8±30.6	288.6±126.3
Other relatives or friends	44.4±34.1	40.9±26.1	83.0±23.5	68.2±20.4	17.8±25.6	56.1±26.0	47.1±31.7	357.7±113.9
F	2.436	0.747	3.444	2.699	0.717	2.368	2.475	3.127
p	0.064	0.525	0.017	0.045	0.543	0.070	0.061	0.026

### 7.9.1.7 Patients' cancer types

Caregivers who took care of a patient with head and neck cancers reported higher needs scores for the domain of health and psychological problems ( $p=0.000$ ), family/social support ( $p=0.000$ ), practical support ( $p=0.020$ ), and the total score ( $p=0.012$ ). The details are shown in **Table 7.40** below:

**Table 7.40** Differences in total and sub-scores of the CNAT-C by patients' cancer types (N=419)

Cancer Types	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
Respiratory system (n=148)	34.4±30.8	35.0±26.6	75.1±25.9	62.3±22.7	14.6±22.2	54.5±25.3	46.8±32.3	322.8±120.8
Digestive system (n=98)	28.3±26.1	29.7±28.0	73.9±27.0	58.2±24.2	11.6±20.2	49.7±27.8	38.4±28.4	289.7±132.3
Reproductive system(n=63)	21.1±26.1	23.8±24.9	67.5±28.8	55.4±26.2	15.6±23.7	48.9±28.6	39.1±26.9	271.3±131.7
Head and neck cancer (n=83)	47.1±35.5	44.8±28.2	66.4±24.7	59.7±21.3	13.5±22.6	51.6±23.3	52.1±32.7	335.1±119.0
Others (n=27)	36.6±33.6	38.3±31.1	65.7±34.8	58.2±29.6	8.0±16.3	46.9±35.3	44.4±31.8	298.2±168.1
F	7.627	6.266	2.203	1.070	0.871	0.945	2.940	3.244
p	0.000	0.000	0.068	0.371	0.481	0.438	0.020	0.012

### 7.9.1.8 Patients' treatment therapies

Statistical differences were detected among informal caregivers whose patients were receiving different treatments in the domains of health and psychological problems ( $p=0.000$ ), family and social support ( $p=0.001$ ), practical support ( $p=0.002$ ), and the total score ( $p=0.028$ ). The results are shown in **Table 7.41** below:

**Table 7.41** Differences in total and sub-scores of the CNAT-C regarding patients' treatments (N=419)

Treatment Therapies	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
No treatment (n=15)	24.1±33.4	24.0±23.6	79.2±25.5	66.9±21.4	8.9±16.5	51.5±28.3	31.1±22.6	285.7±110.0
Chemo + radiotherapy (n=68)	39.9±29.5	42.3±26.1	68.1±24.0	57.4±22.2	17.2±19.7	53.8±23.8	49.8±29.6	328.5±121.4
Chemotherapy only (n=234)	30.6±29.7	31.3±27.4	71.7±28.4	60.0±23.8	12.3±21.4	51.9±27.2	43.9±31.4	301.8±129.2
Radiotherapy only (n=21)	51.3±34.9	46.3±28.9	65.5±20.1	58.1±20.6	15.1±21.7	48.4±20.9	52.6±28.8	337.4±112.0
Targeted therapy (n=19)	16.7±19.2	28.1±28.5	67.8±35.5	56.4±30.8	20.2±33.6	42.7±29.3	31.0±30.3	262.7±168.1
Symptoms relieving (n=40)	46.9±34.8	44.2±31.0	76.4±23.1	61.7±23.1	15.8±24.7	52.6±26.7	55.1±32.3	352.7±121.3
Follow-up (n=22)	26.3±34.2	23.6±23.9	71.0±29.6	55.7±29.8	4.5±10.5	48.2±33.2	28.8±23.4	258.2±139.8
F	4.766	4.038	0.816	0.559	1.578	0.547	3.510	2.395
p	0.000	0.001	0.558	0.763	0.152	0.773	0.002	0.028



### 7.9.1.9 Patients' complications

When patients experienced complications, their caregivers required higher needs regarding health and psychological, family/social support, practical support, and the total need score ( $p < 0.01$ ). The results are shown in **Table 7.42** below:

**Table 7.42** Differences in total and sub-scores of the CNAT-C on the variable of patients' complications (N=419)

Complication	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
No (n=334)	30.4±30.3	32.5±28.4	71.1±27.9	58.5±24.2	12.6±21.9	50.8±27.3	42.4±30.8	298.3±131.3
Yes (n=85)	46.1±32.1	41.1±25.3	72.4±24.3	63.3±22.1	16.7±20.7	54.1±24.7	53.2±30.4	346.9±115.7
<i>t</i>	-4.201	-2.719	-0.407	-1.660	-1.553	-1.021	-2.905	-3.118
<i>p</i>	0.000	0.007	0.685	0.098	0.121	0.308	0.004	0.002

### 7.9.1.10 Patients' gender

As shown in **Table 7.43**, caregivers who took care of male patients rated higher scores on health and psychological, family/social support, healthcare staff, information domain, and the total score of the CNAT-C ( $p < 0.05$ ).

**Table 7.43** Differences in total and sub-scores of the CNAT-C on the variable of patients' gender (N=419)

Patients' Gender	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
Female (n=182)	29.1±30.9	30.6±28.2	67.8±28.1	56.0±25.4	13.8±22.5	48.6±28.2	41.2±29.7	287.1±140.8
Male (n=237)	37.1±31.2	37.0±27.5	74.1±26.2	62.2±22.3	13.1±21.1	53.7±25.5	47.1±31.7	324.3±118.2
<i>t</i>	-2.631	-2.342	-2.365	-2.630	0.349	-1.933	-1.948	-2.874
<i>p</i>	0.009	0.020	0.018	0.009	0.727	0.054	0.052	0.004

### 7.9.1.11 Patients' cancer stage

Caregivers who took care of stage III patients had higher scores in terms of healthcare staff compared with those who took care of stage IV patients ( $p = 0.041$ ). The details are shown in

**Table 7.44** below:

**Table 7.44** Differences in total and sub-scores of the CNAT-C by patients' cancer stage (N=419)

Stage	CNAT-C: Mean±SD							
	Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
Stage III (n=142)	31.5±28.1	34.9±27.9	75.1±25.4	61.7±22.6	14.8±20.8	53.6±24.4	43.5±30.4	315.1±118.4
Stage IV (n=277)	34.7±32.7	33.9±28.1	69.4±27.9	58.4±24.4	12.7±22.2	50.4±27.9	45.1±31.3	304.6±135.1
<i>t</i>	-1.043	0.328	2.050	1.354	0.934	1.187	-0.500	0.790
<i>p</i>	0.298	0.743	0.041	0.177	0.351	0.236	0.617	0.411

Variables that showed statistical significance ( $p < 0.05$ ) in the univariate analysis (as shown in Table 7.35-7.44) were included in the regression analysis for each domain of the CNAT-C and the global score of CNAT-C. Details of the variables that included in the regression model for analysis were listed as follows:

<b>Health and psychological problems</b>	marital status, education level, patients' cancer type, patients' treatment therapies, patients' complications, patients' gender
<b>Family/social support</b>	patients' cancer type, patients' treatment therapies, patients' complications, patients' gender
<b>Healthcare staff</b>	education level, length of caregiving time, caregivers' relationship with patients, patients' gender, patients' cancer stage
<b>Information</b>	length of caregiving time, caregivers' relationship with patients, patients' gender
<b>Religious/spiritual support</b>	none
<b>Hospital facilities and services</b>	marital status, caregivers' employment status, education level, length of caregiving time
<b>Practical support</b>	patients' cancer type, patients' treatment therapies, patients' complications
<b>Global score</b>	education level, caregivers' relationship with patients, patients' cancer type, patients' treatment therapies, patients' complications, patients' gender

### 7.9.2 Correlations between caregivers' age, HADS, MOS-SSS, Brief-COPE, QoL, and CNAT-C

**Table 7.45** shows the results of the correlations between caregivers' age, HADS, MOS-SSS, Brief-COPE, QoL, and CNAT-C. The caregivers' age was positively related to the need of health and psychological support, healthcare staff, hospital facilities and services, and the total score. Moderated positive correlations ( $r > 0.3$ ) were identified between anxiety and depression and the majority of the CNAT-C domains. For correlations between social support and the needs of caregivers, the findings indicated that the caregivers' levels of social support were negatively associated with their family/social support needs, but this data showed only weak correlations as all the correlation coefficients were less than 0.3. Weak correlations were

detected between the use of coping strategies and the needs of informal caregivers. The caregivers who used more maladaptive coping strategies were significantly related to higher levels of needs. The caregivers' use of problem-focused, emotional-focused, and adaptive coping strategies were negatively associated with health and psychological and family/social support needs but were positively related to healthcare staff related and information needs. In terms of the correlations between the caregivers' quality of life and needs, moderated correlations were identified in the majority of the needs domains, with coefficients above 0.3. Caregivers with a poorer quality of life were significantly related to higher levels of needs.

**Table 7.45** Correlations between caregivers' age, HADS, MOS-SSS, Brief-COPE, QoL, and CNAT-C

HADS/MOS-SSS/Brief-COPE/QOL		CNAT-C Domains							
		Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
<b>Age</b>	Age	0.140**	0.053	0.146**	0.094	0.049	0.212**	0.079	0.164**
<b>HADS</b>	Anxiety	0.487**	0.538**	0.137**	0.300**	0.222**	0.255**	0.421**	0.508**
	Depression	0.508**	0.554**	0.016	0.194**	0.189**	0.133**	0.410**	0.438**
<b>MOS-SSS</b>	Tangible support	-0.095	-0.168**	0.090	0.055	0.045	0.122*	0.001	0.003
	Informational and emotional support	-0.062	-0.107*	0.135**	0.115*	0.048	0.179**	0.073	0.074
	Positive social interaction	-0.088	-0.119*	0.011	-0.011	0.046	0.016	0.048	-0.024
	Affectionate support	-0.074	-0.122*	0.162**	0.127**	.015	0.152**	-0.014	0.044
	Total	-0.085	-0.139**	0.112*	0.083	0.046	0.139**	0.041	0.034
<b>Brief-COPE</b>	Problem-focused coping	-0.220**	-0.188**	0.321**	0.261**	-0.047	0.213**	-0.124*	0.028
	Emotion-focused coping	-0.096*	-0.059	0.232**	0.245**	0.151**	0.209**	0.016	0.130**
	Adaptive coping	-0.177**	-0.159**	0.259**	0.153**	-0.032	0.103*	-0.095	-0.001
	Maladaptive coping	0.201**	0.265**	0.204**	0.298**	0.181**	0.312**	0.309**	0.372**
<b>C-QoL#</b>	Burden	0.587**	0.571**	0.164**	0.320**	0.220**	0.371**	0.484**	0.587**
	Disruptiveness	0.557**	0.607**	0.021	0.215**	0.276**	0.234**	0.573**	0.541**
	Positive adaption	0.242**	0.230**	0.100*	0.208**	0.084	0.105*	0.238**	0.260**
	Financial concerns	0.380**	0.361**	0.211**	0.297**	0.102*	0.298**	0.383**	0.439**
	Total	0.598**	0.597**	0.157**	0.343**	0.239**	0.344**	0.558**	0.613**

**Note:** \*\* = Correlation is significant at the 0.01 level (two-tailed); \* = Correlation is significant at the 0.05 level (two-tailed); # = caregivers' quality of life.

### **7.9.3 Correlations between patients' HADS, ESAS, MOS-SSS, Brief-COPE, QoL, and caregivers' CNAT-C**

As shown in **Table 7.46**, weak correlations between the patients' HADS, ESAS, MOS-SSS, Brief-COPE, QOL, and the CNAT-C of the informal caregivers were detected, with the majority of the correlation coefficients below 0.3. The results indicated that the patients' anxiety and depression were positively correlated to the caregivers' needs regarding health and psychological, family/social support, practical support needs, and the total score of the CNAT-C. Similar findings were identified in terms of the correlations between the ESAS and the CNAT-C. Positive correlations were detected between the patients' symptom distress and the caregivers' health and psychological, family/social support, and practical support needs. For social support, the findings indicated that the patients' high levels of social support were negatively associated with the caregivers' needs regarding health and psychological support, family/social support, and the global need score. Apart from the domain of hospital facilities and services needs, correlations were identified between the patients' use of coping strategies and other caregivers' needs domains. The patients' quality of life was significantly related to the caregivers' health and psychological needs, family/social support needs, and practical support needs.

**Table 7.46** Correlations between patients' HADS, ESAS, MOS-SSS, Brief-COPE, QoL, and caregivers' CNAT-C

HADS/MOS-SSS/Brief-COPE/QoL		CNAT-C Domains							
		Health and Psychological Problems	Family/Social Support	Healthcare Staff	Information	Religious/Spiritual Support	Hospital Facilities and Services	Practical Support	Total Score
<b>HADS</b>	Anxiety	0.279**	0.325**	-0.040	-0.016	0.065	0.086	0.307**	0.228**
	Depression	0.285**	0.322**	-0.075	-0.041	0.095	0.039	0.304**	0.212**
<b>ESAS</b>	Item 1-Pain	0.211**	0.217**	-0.095	-0.014	0.043	0.043	0.181**	0.135**
	Item 2-Fatigue	0.281**	0.224**	0.049	0.117*	0.008	0.113*	0.220**	0.225**
	Item 3-Nausea	0.117*	0.111*	-0.049	-0.046	0.039	-0.001	0.157**	0.077
	Item 4-Depression	0.195**	0.248**	-0.046	-0.018	0.019	0.018	0.151**	0.130**
	Item 5-Anxiety	0.220**	0.223**	-0.047	-0.049	0.039	0.008	0.163**	0.129**
	Item 6-Drowsiness	0.101*	0.101*	-0.033	-0.017	-0.045	0.025	0.121*	0.063
	Item 7-Shortness of breath	0.222**	0.181**	-0.025	-0.015	0.101*	0.030	0.271**	0.172**
	Item -Appetite	0.118*	0.081	-0.121*	-0.101*	-0.041	-0.026	0.095	0.012
	Item 9-Sleep	0.150**	0.116*	-0.139**	-0.079	-0.007	-0.049	0.091	0.028
	Item 10-Feeling of well-being	0.089	0.078	-0.048	-0.027	-0.012	0.015	0.138**	0.057
<b>MOS-SSS</b>	Tangible support	-0.073	-0.100*	0.012	0.106*	-0.160**	-0.007	-0.113*	-0.073
	Informational and emotional support	-0.158**	-0.189**	-0.051	-0.036	-0.045	-0.067	-0.107*	-0.143**
	Positive social interaction	-0.118*	-0.168**	-0.056	-0.078	-0.047	-0.128**	-0.075	-0.143**
	Affectionate support	-0.308**	-0.272**	0.095	0.062	-0.149**	-0.019	-0.310**	-0.204**
	Total	-0.187**	-0.218**	-0.021	-0.007	-0.101*	-0.079	-0.159**	-0.169**
<b>Brief-COPE</b>	Problem-focused coping	-0.295**	-0.289**	0.178**	0.145**	-0.167**	0.021	-0.288**	-0.162**
	Emotion-focused coping	-0.262**	-0.269**	0.046	0.024	-0.084	-0.035	-0.216**	-0.180**
	Adaptive coping	-0.270**	-0.287**	0.169**	0.145**	-0.138**	0.041	-0.300**	-0.151**
	Maladaptive coping	-0.140**	-0.129**	0.119*	0.044	-0.065	0.074	-0.133**	-0.056

<b>Patients' QoL</b>	Physical functioning	0.231**	0.273**	-0.059	-0.021	0.100*	0.028	0.287**	0.189**
	Emotional functioning	0.300**	0.337**	-0.015	-0.005	0.051	0.088	0.262**	0.231**
	Fatigue	0.133**	0.135**	0.072	0.089	-0.066	0.112*	0.115*	0.132**
	Nausea and vomiting	0.040	0.037	-0.060	-0.039	0.022	0.009	0.061	0.018
	Pain	0.192**	0.191**	-0.082	0.007	-0.003	0.029	0.154**	0.114*
	Dyspnoea	0.180**	0.124*	0.005	0.015	0.050	0.058	0.182**	0.138**
	Insomnia	0.172**	0.193**	-0.099*	-0.045	0.008	-0.014	0.108*	0.078
	Appetite loss	0.067	0.000	-0.082	-0.085	-0.017	-0.032	0.018	-0.022
	Constipation	0.109*	0.110*	0.020	0.022	-0.008	0.129**	0.119*	0.112*
	Global health status	-0.222**	-0.224**	0.120*	0.035	-0.024	-0.019	-0.251**	-0.138**

**Note:** \*\* = Correlation is significant at the 0.01 level (two-tailed); \* = Correlation is significant at the 0.05 level (two-tailed).

### 7.10 Predictors of the care needs of caregivers

Significant correlates in each domain and the global score of the CNAT-C were examined through stepwise multiple linear regression. The variables that showed statistical significance (cut-off point  $p < 0.05$ ) in the univariate analysis and correlation analysis were included in the regression analysis, using the stepwise variable-selection method, with entrance and removal levels of  $p \leq 0.05$  and  $p \geq 0.10$ , respectively.

**Tables 7.47** presents the stepwise multiple linear regression analysis results. For the predictors of health and psychological need, eight independent variables were included in the regression including caregivers' overall quality of life, education level, depression, marital status, use of problem-coping strategies, patients' cancer types, and number of complications, of which the caregivers' overall quality of life was the most significant predictor of their health and psychological needs. Caregivers with a poor quality of life had higher health and psychological needs. These eight variables accounted for 46.6% of the observed variance.

For family/social support needs, the following six predictors were found: caregivers' overall quality of life, depression, use of maladaptive coping, patients' use of problem-focused coping, cancer type, and type of treatment therapy. The most significant predictor of this domain was the caregivers' overall quality of life. All the identified variables accounted for 44.7% of the variance. The significant predictors of needs regarding healthcare staff were caregivers' overall quality of life, use of problem-focused and adaptive coping, length of time engaged in caregiving, education level, and cancer stage of the patients. Caregivers' problem-focused coping strategy was the most significant factor, and all the factors together explained only 18.1% of the variance of needs in relation to healthcare staff.

In terms of the information needs of the informal caregivers, the most significant predictor was caregivers' own overall quality of life, followed by caregivers' use of coping strategies (problem-focused and maladaptive coping), length of time since diagnosis, anxiety, gender, and patients' adaptive coping strategies. These predictors together accounted for only 26.2% of the variance of information needs.



For religious/spiritual needs, three independent variables were identified, including caregivers' overall quality of life, caregivers' emotion-focused coping, and patients' problem-focused coping. However, the three factors accounted for only 9.7% of the religious/spiritual needs.

In terms of hospital facilities and services needs, several independent variables were examined—caregivers' age, overall quality of life, coping strategies, length of time since diagnosis, and the overall social support they received—which explained 23.5% of the variance.

With regard to the need for practical support, four predictors were detected, including caregivers' overall quality of life, depression, use of maladaptive coping, and patients' problem-focused coping, with an adjusted R<sup>2</sup> of 38.1%. Caregivers' overall quality of life was mostly related to their practical support needs.

Regarding the overall needs of the caregivers, seven predictors were identified, and six of the predictors were caregiver-related variables. They were caregivers' overall quality of life, use of maladaptive coping, age, relationship between caregivers and patients, anxiety, caregivers' education level, and patients' anxiety, which accounted for 45.0% of the overall needs of informal caregivers. Caregivers' overall quality of life was the most significant predictor of their overall needs, as reflected by the highest  $\beta$  at a statistically significant level ( $\beta=0.433$ ). Detailed information regarding the predictors of the needs of caregivers is shown in **Table 7.47** below:

**Table 7.47** Stepwise multiple linear regression for variables of predicting the needs of caregivers (N=419)

CNAT-C Domains	Variables	Unstandardized Coefficients		Stan. $\beta$	<i>t</i>	<i>p</i>	R <sup>2</sup>	Adj. R <sup>2</sup>
		B	Std. Error					
Health and Psychological Problems	C* QoL CQOLC total score	0.627	0.084	0.375	7.489	0.000	0.477	0.466
	C Education <sup>1</sup> No formal education	18.743	4.557	0.152	4.113	0.000		
	C Depression	1.399	0.365	0.190	3.837	0.000		
	C Marital status	9.635	3.472	.101	2.775	0.006		
	C Coping Problem-focused coping	-0.950	0.361	-0.102	-2.634	0.009		
	P** Coping Problem-focused coping	-1.421	0.355	-0.159	-4.002	00.000		

	Cancer type <sup>2</sup> Reproductive system	-8.251	3.237	-0.094	-2.549	0.011		
	Head and neck cancer	6.013	2.963	0.077	2.029	0.043		
	Complications	5.625	2.851	0.072	1.973	0.049		
Family/ Social Support	C QoL CQOLC total score	0.526	0.075	0.351	7.039	0.000	0.455	0.447
	C Depression	1.765	0.322	0.267	5.480	0.000		
	C Coping Maladaptive coping	0.595	0.230	0.099	2.586	0.010		
	P Coping Problem-focused coping	-1.272	0.304	-0.159	-4.187	0.000		
	Cancer types Reproductive system	-7.401	2.902	-0.095	-2.550	0.011		
	Therapy <sup>3</sup> Chemo + Radiotherapy	6.398	2.808	0.084	2.278	0.023		
Healthcare Staff	C Coping Problem-focused coping	1.977	0.474	0.245	4.168	0.000	0.193	0.181
	C QoL CQOLC total score	0.286	0.066	0.196	4.347	0.000		
	Stage	-9.513	2.593	-0.166	-3.668	0.000		
	Length of time caregiving <sup>4</sup> 1-6 months	-8.042	2.470	-0.147	-3.255	0.001		
	C Education <sup>1</sup> No formal education	11.674	4.817	0.109	2.423	0.016		
	C Coping Adaptive coping	1.530	0.735	0.122	2.081	0.038		
Information	C QoL CQOLC total score	0.329	0.077	0.257	4.264	0.000	0.274	0.262
	C Coping Problem-focused coping	1.509	0.325	0.213	4.635	0.000		
	Maladaptive coping	0.663	0.234	0.129	2.828	0.005		
	Length of time caregiving <sup>4</sup> 1-6 months	-6.681	2.065	-0.139	-3.235	0.001		
	P Coping Adaptive coping	1.493	0.544	0.126	2.742	0.006		
	C Gender	4.301	2.048	0.089	2.100	0.036		

	C Anxiety	0.688	0.332	0.122	2.070	0.039		
Religious/ Spiritual Support	C QoL CQOLC total score	0.247	0.055	0.212	4.491	0.000	0.103	0.097
	C Coping Emotion-focused coping	1.412	0.375	0.177	3.768	0.000		
	P Coping Problem-focused coping	-0.972	0.297	-0.157	-3.276	0.001		
Hospital Facilities and Services	C QoL CQOLC total score	0.450	0.066	0.314	6.824	0.000	0.246	0.235
	C Coping Problem-focused coping	0.981	0.389	0.123	2.522	0.012		
	Maladaptive coping	0.888	0.269	0.154	3.303	0.001		
	C Age	0.267	0.085	0.137	3.127	0.002		
	Length of time caregiving <sup>4</sup> 1-6 months	-7.728	2.340	-0.144	-3.303	0.001		
	C Social support MOS-SSS total score	0.159	0.071	0.108	2.231	0.026		
Practical Support	C QoL CQOLC total score	0.752	0.069	0.453	10.95 2	0.000	0.387	0.381
	P Coping Problem-focused coping	-1.159	0.414	-0.131	-2.798	0.005		
	C Copiong Maladaptive coping	1.216	0.269	.182	4.528	0.000		
	C Depression	0.886	0.323	0.130	2.745	0.006		
Total Score	C QoL CQOLC total score	3.004	0.360	0.433	8.343	0.000	0.459	0.450
	C Coping Maladaptive coping	5.433	1.067	0.195	5.091	0.000		
	C Anxiety	4.560	1.569	0.149	2.907	0.004		
	C Age	1.715	0.440	0.182	3.898	0.000		
	Relationship <sup>5</sup> Couple/Partner	-30.236	11.971	-0.117	-2.526	0.012		
	P Anxiety	3.065	1.195	0.097	2.564	0.011		
	C Education Primary education	-20.587	10.121	-0.079	-2.034	0.043		

**Note:** 1 = reference variable: higher education; 2 = reference variable: other types of cancer; 3 = reference variable: no treatment; 4 = reference variable: length of caregiving >6 months; 5 = reference variable: other relatives/friends; P \*\* = patients; C\* = informal caregivers.

**Part Three: Relationships between the needs of patients and the needs of informal caregivers**

**7.11 Correlations between the needs of patients and the needs of informal caregivers**

Pearson correlation analysis was used to preliminarily explore the correlations between the problems and needs of patients and those of their informal caregivers. For the Problem part of the PNPC-sv, weak correlations were identified between some domains of the PNPC-sv and the CNAT-C, with the correlation coefficients ranging from 0.096 to 0.281. **Table 7.48** below shows that as patients experienced more problems, their caregivers reported greater needs regarding health and psychological support, family/social support, practical support, and the overall needs score, and vice versa. In terms of the Need for Care part, the findings indicated that when patients had more unmet needs, their informal caregivers had more needs regarding health and psychological support, family/social support, religious/spiritual support, practical support, and the overall needs score, and vice versa. These results were similar to those of the Problem part, but the correlation coefficients (*r*) were much stronger, with the correlations (*r*) within a range of 0.108 to 0.469. More detailed information is presented in **Table 7.49** below:

**Table 7.48** Associations between the problems of patients and the needs of informal caregivers

CNAT-C	PNPC-sv (Problem Part)								
	ADL	Physical	Autonomy	Social	Psycho-logical	Spiritual	Financial	Infor-mation	Global Score
Health and Psychological Problems	0.150**	0.135**	0.201**	0.127**	0.135**	0.261**	0.076	0.183**	0.247**
Family/Social Support	0.184**	0.143**	0.230**	0.179**	0.174**	0.253**	0.105*	0.167**	0.281**
Healthcare Staff	-0.034	0.007	0.001	0.168**	0.135**	-0.009	0.072	0.094	0.073
Information	-0.013	0.046	0.032	0.134**	0.113*	0.009	0.135**	0.111*	0.096*
Religious/Spiritual Support	0.039	0.029	0.039	0.123*	0.052	.017	0.088	0.218**	0.088
Hospital Facilities and Services	.012	0.068	0.041	0.188**	0.081	0.050	0.174**	0.177**	0.128**
Practical Support	0.160**	0.125*	0.256**	0.126**	0.149**	0.252**	0.199**	0.240**	0.277**
Total Score	0.114*	0.122*	0.180**	0.219**	0.180**	0.191**	0.180**	0.250**	0.261**

**Note:** \*\* = Correlation is significant at the 0.01 level (two-tailed); \* = Correlation is significant at the 0.05 level (two-tailed).

**Table 7.49** Associations between the needs of patients and the needs of informal caregivers

CNAT-C	PNPC-sv (Need for Care part)								
	ADL	Physical	Autonomy	Social	Psycho-logical	Spiritual	Financial	Infor-mation	Global Score
<b>Health and Psychological Problems</b>	0.322**	0.344**	0.333**	0.385**	0.319**	0.395**	0.235**	0.284**	0.438**
<b>Family/Social Support</b>	0.299**	0.315**	0.338**	0.363**	0.329**	0.364**	0.253**	0.249**	0.420**
<b>Healthcare Staff</b>	- 0.132**	-0.125*	-0.063	-0.084	0.049	-0.060	-0.026	0.025	-0.079
<b>Information</b>	-0.077	-0.054	0.005	-0.027	0.064	-0.032	0.075	0.082	-0.010
<b>Religious/Spiritual Support</b>	0.092	0.124*	0.110*	0.186**	0.117*	0.087	0.147**	0.183**	0.161**
<b>Hospital Facilities and Services</b>	0.018	0.065	0.072	0.108*	0.113*	0.069	0.164**	0.162**	0.111*
<b>Practical Support</b>	0.361**	0.355**	0.392**	0.377**	0.335**	0.421**	0.297**	0.304**	0.469**
<b>Total Score</b>	0.205**	0.234**	0.268**	0.292**	0.293**	0.285**	0.249**	0.279**	0.340**

**Note:** \*\* = Correlation is significant at the 0.01 level (two-tailed); \* = Correlation is significant at the 0.05 level (two-tailed).

## 7.12 Summary of the cross-sectional survey results

A total of 428 patients with advanced cancer and informal caregiver dyads (428 patients and 428 informal caregivers) were recruited during a 10-month study period from two tertiary hospitals in China to participate in this survey, and 419 of them completed all the required questionnaires. The majority were hospital-based patients, and more than half were male, middle school educated or below, married, and stage IV cancer patients. The majority of the patients had been diagnosed with cancer for more than three months and were receiving curative-intent treatment at the time (e.g., chemotherapy and/or radiotherapy). Their informal caregivers were typically female, middle school educated or below, unemployed, and more than half of the caregivers and patients were couples or partners. The frequently experienced symptoms of patients with advanced cancer were loss of appetite, fatigue, pain, and sleep problems. Of the patients with advanced cancer, 21.7% and 23.2% were clinical cases of anxiety and depression, respectively. Moderate social

support was provided to the patients, with a mean score of 67.8 (on a scale from 0 to 100). The support typically received was tangible, and the least received support was positive social interaction. The most frequently used coping strategies were problem-focused coping, and those patients had a medium level of global health status/QoL.

For the informal caregivers, the proportions exhibiting clinical anxiety and depression were similar to those of the patients, namely, 23.2% with anxiety and 18.1% with depression. The informal caregivers received less social support than the patients, with a mean score of 58.8 (on a scale of 0 to 100). Affectionate support was the most commonly received support for the informal caregivers. Problem-focused coping was the most frequently used coping strategy adopted by the informal caregivers, and this matched that of the patients. Informal caregivers' quality of life was at a medium level, 'financial concerns' was the most often reported issue, and the least reported domain was 'disruptiveness' caused by taking care of the patients.

The top five palliative care needs of patients with advanced cancer were related to the financial ('extra expenditures because of the disease', 88.3%; 'loss of income because of the disease', 85.2%), information ('insufficient information', 82.3%), physical ('pain', 69.7%), and psychological ('fear of physical suffering', 64.9%) domains. The five least reported needs were related to the domains of social and physical.

With regards to the informal caregivers, the commonly reported needs were related to the domains of 'healthcare staff' ('nurses to promptly attend to patient discomfort and pain', 95.0%), 'information' ('information about tests and treatment', 92.1%), and 'hospital facilities and services' ('a designated hospital staff member who would be able to provide counselling for any concerns, and guidance with the course of the treatment, from the point of diagnosis to the period after discharge', 90.5%). Religious/spiritual support was the least reported need among the informal caregivers ('religious support', 11.0%). The results revealed that the information needs domain was a prominent unmet need for both patients with advanced cancer and their informal caregivers.

The results of the multiple stepwise regression analysis indicated that the patients' palliative care needs were predicted by various independent variables, including patient-related variables and caregiver-related variables. Patient-related variables included the patients' demographic characteristics (age, marital status, monthly family income level, education background), clinical characteristics (received treatment therapy, length of time since diagnosis, number of complications, cancer types), psychological status (anxiety, depression), physical status (overall symptom distress), social support, use of coping strategies, and quality of life (global health status). Caregivers-related variables included caregivers' psychological status (anxiety, depression), overall quality of life, and use of coping strategies. Four independent variables in relation to the patients' overall symptom distress, use of coping strategies, anxiety and depression, and caregivers' quality of life were the most influential in the prediction of their palliative care needs.

For the needs of the informal caregivers, several predictors were detected through multiple stepwise regression analysis. The results showed that the caregivers' needs were predicted by various caregiver-related and patient-related variables. Caregiver-related factors included caregivers' demographic characteristics (age, gender, marital status, education background, length of time engaged in caregiving, relationship between themselves and patients), overall quality of life, psychological status (anxiety, depression), use of coping strategies, and social support status. The following variables were patient-related: patients' cancer type, number of complications, received treatment therapy, anxiety, and the use of coping strategies. Caregivers' overall quality of life, use of coping strategies (particularly problem-focused coping), and anxiety and depression were three of the most significant predictors of their needs. Caregivers living with a poorer quality of life, using less problem-focused coping strategies, and having emotional problems were more likely to report more unmet needs.

Based on the quantitative results of both the patients and the informal caregivers, it was found that anxiety and depression, use of coping strategies, and caregivers' quality of life were three common and significant predictors of the needs of both patients and their informal caregivers. In addition, the quantitative results demonstrated that the information needs domain was reported as a prominent unmet need for both patients

with advanced cancer and their informal caregivers. However, the identified predictors could only partly account for the occurrence of their information needs, with 13.2% for patients and 28.2% for their informal caregivers. This suggested that the information needs of both the patients and their informal caregivers were worth further exploration through a qualitative approach. The following chapter will present the results of the qualitative interviews.



## **Chapter Eight: Results from the Qualitative Interviews**

## **8.1 Introduction**

This chapter will present the study findings from the qualitative interviews in four sections. This section (8.1) provides a general introduction of this chapter. The characteristics of the study participants and the extracted categories and sub-categories from the qualitative data will be presented in Section 8.2 and Section 8.3, respectively, while Section 8.4 will summarize this chapter.

## **8.2 Characteristics of the study participants**

Seventeen patients with advanced cancer participated in the qualitative study, with nine males and eight females. All the included patients were selected because they indicated that they ‘needed more information’ in the cross-sectional survey. Of the 17 patients, five were lung cancer patients, four were cervical cancer patients, and the rest were patients with nasopharyngeal carcinoma (n=2), oesophageal cancer (n=2), colorectal cancer (n=2), hepatic carcinoma (n=1), and ovarian cancer (n=1). The majority of the participants (n=15) were aged >40 years old and had only primary school education or below (n=11). Most of the participants (n=13) were cancer patients at stage IV and were still receiving active chemotherapy (n=10) at the time of the interviews. **Table 8.1** presents the characteristics of these patients.

Fifteen informal caregivers of advanced cancer patients were also included in the qualitative interviews. All the participants had also reported unmet information needs in the cross-sectional survey. More than half of the participants were female informal caregivers (n=8) and the majority of them (n=12) were taking care of patients with stage IV cancer at the time of the interviews. The majority of the participants (n=10) were aged >40 years old and had primary or middle school education (n=10). Of the 15 participants, seven were informal caregivers of lung cancer patients, three were informal caregivers of oesophageal cancer patients, and the rest were informal caregivers of patients with cervical cancer (n=1), hepatic carcinoma (n=1), breast cancer (n=1), gastric cancer (n=1), and colorectal cancer (n=1). The characteristics of these study participants are presented in **Table 8.2**.

All the patients and informal caregivers involved in the interviews were willing to elaborate on the information topics of their interest, and they were also willing to share their perceptions and experiences in relation to their unmet information needs. The majority of the participants said that they felt comfortable and relaxed during the interview process, and they appreciated the interview as it provided them with an opportunity to vent and a way for them to make contributions in terms of improvements to clinical services, particularly to the provision of information. One informal caregivers (C15) cried while narrating her experiences, but she said she enjoyed the interview and felt less stressed after reviewing and describing her experience. A majority of the informal caregivers said that they needed listeners and were happy to have a talk with nurses or doctors.

**Table 8.1** Characteristics of the advanced cancer patients participated in the interviews

<b>Patients</b>	<b>Gender</b>	<b>Age</b>	<b>Diagnosis</b>	<b>Cancer Stage</b>	<b>Education</b>	<b>Marital Status</b>	<b>Occupation</b>	<b>Religion</b>
P1	Male	56	Nasopharyngeal carcinoma	III	Illiterate	Married	Manual worker	No
P2	Male	51	Lung cancer	IV	Middle school	Married	Manual worker	No
P3	Female	55	Cervical cancer	IV	Primary school	Widowed	Manual worker	No
P4	Female	32	Cervical cancer	IV	High school	Divorced	Kindergarten teacher	No
P5	Female	36	Cervical cancer	III	High school	Married	Unemployed	No
P6	Male	48	Hepatic carcinoma	IV	Primary school	Married	Unemployed	No
P7	Male	60	Colorectal cancer	IV	High school	Married	Retired	No
P8	Female	45	Cervical cancer	III	Primary school	Married	Manual worker	No
P9	Female	43	Nasopharyngeal carcinoma	IV	Primary school	Married	Technician	No
P10	Male	63	Colorectal cancer	IV	Primary school	Married	Manual worker	No
P11	Female	43	Ovarian cancer	III	Primary school	Married	Self-employed	No
P12	Male	45	Lung cancer	IV	Primary school	Married	Manual worker	No
P13	Male	54	Oesophageal cancer	IV	Middle school	Married	Self-employed	No
P14	Male	63	Oesophageal cancer	IV	Primary school	Married	Manual worker	Buddhism
P15	Female	49	Lung cancer	IV	Primary school	Married	Manual worker	No
P16	Male	56	Lung cancer	IV	Middle school	Married	Unemployed	No
P17	Female	55	Lung cancer	IV	Primary school	Married	Manual worker	No

**Table 8.2** Characteristics of the informal caregivers participated in the interviews

Caregivers	Relationship with patients*	Gender	Age	Education	Marital Status	Occupation	Religion	Patient's Diagnosis	Patient's Cancer Stage
C1	Son	Male	34	Primary school	Married	Unemployed	No	Lung cancer	IV
C2	Husband	Male	53	Middle school	Married	Self-employed	No	Lung cancer	IV
C3	Wife	Female	49	Middle school	Married	Manual worker	No	Lung cancer	IV
C4	Son	Male	35	High school	Married	Self-employed	No	Lung cancer	IV
C5	Son	Male	36	Middle school	Married	Manual worker	No	Lung cancer	III
C6	Wife	Female	53	Primary school	Married	Unemployed	No	Oesophageal cancer	III
C7	Husband	Male	50	Primary school	Married	Unemployed	No	Cervical cancer	III
C8	Daughter	Female	33	High school	Married	Self-employed	No	Hepatic carcinoma	IV
C9	Wife	Female	46	Primary school	Married	Unemployed	No	Lung cancer	IV
C10	Wife	Female	52	Illiterate	Married	Manual worker	No	Oesophageal cancer	IV
C11	Wife	Female	70	Illiterate	Married	Manual worker	No	Oesophageal cancer	IV
C12	Wife	Female	70	Middle school	Married	Retired	No	Lung cancer	IV
C13	Husband	Male	73	Primary school	Married	Retired	No	Breast cancer	IV
C14	Son	Male	32	High school	Single	Unemployed	No	Gastric cancer	IV
C15	Wife	Female	57	Primary school	Married	Retired	Buddhism	Colorectal cancer	IV

**Note:** Relationship with patients means that the caregiver is the\_\_of the patient, for example, for C1, the caregiver is the son of the patient.

### 8.3 Qualitative results: Categories and sub-categories

An in-depth understanding of the unmet information needs of the patients and informal caregivers was obtained through qualitative interviews. Four categories were identified from the interview data for both the patients and the informal caregivers: (1) types of unmet information needs; (2) reasons for information needs being unmet; (3) preferences for provision of information; and (4) meaning and role of the information. Each category had two to four sub-categories, with similar sub-categories for the patients and the informal caregivers, but not entirely the same (see **Table 8.3** for the categories and sub-categories). In the following sections, a detailed introduction will be given for each of the categories and sub-categories. The quotations in the following sections are partial translations of the interview recordings, which were done by the doctoral researcher. Two other bilingual (English and Mandarin Chinese) researchers with a PhD degree checked the English translations to confirm that their meaning was consistent with the original Chinese.

**Table 8.3 Categories and sub-categories of the patients’ and informal caregivers’ unmet information needs**

Categories	Sub-categories	
	Patients	Informal Caregivers
<b>Types of unmet information needs</b>	Disease and treatment	Disease and treatment
	Daily life, particularly food therapy	Caregiving-related information
	Psychological and physical symptom management	Psychological adjustment
	Financial support	Financial support
<b>Reasons for information needs being unmet</b>	Patient factors	Caregiver factors
	Healthcare professional factors	Healthcare professional factors
	Family/social support	
<b>Preferences for provision of information</b>	Information provider	Information provider
	Information format	Information format
	Timing of information	Timing of information
<b>The meaning and role of the information</b>	Self-management	Being more prepared for caregiving role
	Decision-making	Decision-making and future planning
	Hope for and chance of survival	Hope for and chance of survival
	Psychological impact	Psychological impact

### **8.3.1 Category 1: Types of unmet information needs**

This category refers to the types of unmet information needs about which the patients and informal caregivers desired to learn more. Several similar unmet information needs were identified, along with a variety of other unmet information needs, as described in the following.

#### **8.3.1.1 Disease and treatment information**

Information on disease and treatment was the most commonly reported unmet information need for both patients and informal caregivers. Almost all the patients (15/17) and informal caregivers (15/15) expressed a desire to learn more about either the disease or its treatment.

##### Disease-related information

Regarding disease-related information, many patients and informal caregivers stated that they had inadequate information on disease conditions and progression, and they had a desire to learn more:

*“I know nothing about my disease, really nothing. I have stayed in hospital for more than one year, but I don’t know whether the disease has become better or not. Is there anything worse? I learn very little about all of this.”* (P11, Female, 43-year-old, Ovarian cancer, Stage III)

*“Little, I learnt very little information. Generally, when the patient felt unwell, I reported it to the doctor. Then the doctor came and asked something about the patient and suggested taking an electrocardiogram. However, the doctor didn’t give me any feedback after the examination and didn’t give us any medications. She didn’t tell me anything, so I don’t know the patient’s disease conditions at all.”* (C9, Wife, 46-year-old, Patient with lung cancer)

*“I want to know the conditions of my own disease. Are the conditions stable or anything worse? Is the tumour size bigger than before?”* (P17, Female, 55-year-old, Lung cancer, Stage IV)

*“For our family members, the thing that I mainly want to know is about his disease conditions. For example, if the disease is under control or not, or, if anything had become worse? Those are what I want to know.”* (C4, Son, 35-year-old, Patient with lung cancer)

Furthermore, some informal caregivers complained that they had learnt little about the patient’s condition, as the doctors usually did not tell them about the examination results.

*“Many reports of the examinations are delivered to the doctors directly so we cannot get the results reports. Thus, I can learn nothing unless the doctors tell us the results. We come from a faraway place to take medical examinations here, so no matter his conditions, good or bad, we hope the doctors can inform us initiatively while not I, an elderly person, have to ask the doctors every time. I am not a professional, so I don’t know the details of the examination items, for example, the blood test, I only know there was a blood test, but I didn’t know what was exactly tested. Sometimes, there are many examinations and I cannot remember all the items. We have spent a lot of money on examinations, so we want to know the results. Even though the results and his conditions are okay, I hope the doctor can tell me “his conditions are okay” and then I can go back home without worries.”* (C11, Wife, 70-year-old, Patient with oesophageal cancer)

Regarding cancer prognosis, only patients mentioned this unmet information need. They felt confused in terms of the prognosis and were wondering whether their cancer could be cured or not.

*“What I feel confused mostly is, whether my disease...some people said that it can be cured (laughing), but some others intentionally did not tell me the truth, which might mean it can’t be cured’.”* (P4, Female, 32-year-old, Cervical cancer, Stage IV)

*“I want to learn about my disease...like how long can I survive? Does the treatment make sense for my disease? Is it curable?”* (P11, Female, 43-year-old, Ovarian cancer, Stage III)



In addition to information about a patient's disease, information about cancer prevention was also a topic of information that informal caregivers wanted to learn about to prevent family members from ending up suffering from cancer. A young caregiver said:

*“[We want to learn information on cancer prevention] for ourselves, because he (the patient) has already suffered from cancer, and prevention no longer makes any sense for him. For us, as family members of a cancer patient, how can we prevent other family members, particularly his children, from suffering from the disease?”* (C8, Daughter, 33-year-old, Patient with hepatic carcinoma)

### Treatment-related information

Treatment-related information was the most commonly reported unmet information need for both patients and informal caregivers. They indicated that they could not obtain adequate treatment-related information from healthcare professionals:

*“Almost no, I can say I learn nothing [about the chemotherapy regimens]. This time, I was transferred to another doctor. I told the new doctor that I had serious vomiting, and I didn't want to continue. After that, the doctor suggested I use another regimen. But she only mentioned little about this, didn't tell me any details.”* (P3, Female, 55-year-old, Cervical cancer, Stage IV)

*“Currently, we learn very little information about continuing the treatment regimens. At least, we learn little from the doctors.”* (C6, Wife, 53-year-old, Patient with oesophageal cancer)

To “cure” the disease, reduce side effects, and/or the rate of recurrence, more than half of the patients and informal caregivers desired to obtain more information about therapeutic regimens:

*“The information that I really care about is ‘which medicine is effective for cancer’ and ‘how to ‘cure’ this disease’. This is what I really want to learn.”* (P12, Male, 45-year-old, Lung cancer, Stage IV)

*“I want to learn something about the continuing treatment after the completion of the active treatment, such as targeted therapy, to maintain the treatment effects and survive longer. Surviving for one more year will be better.”* (P13, Male, 54-year-old, Oesophageal cancer, Stage IV)

*“I want to cure his disease. What kinds of medications are good, what kinds of medications can he take and cannot take, are there any advanced medications with fewer side effects? For all of these aspects, I know nothing. I think the doctors know it, so I want to learn all this information.”* (C3, Wife, 49-year-old, Patient with lung cancer)

*“Currently, his condition is okay, seems stable. However, I want to know if there are any alternative treatments when his condition become worse and the chemotherapy doesn't work. The only thing that I want to know is whether there are any other therapeutic regimens.”* (C5, Son, 36-year-old, Patient with lung cancer)

Given that Traditional Chinese Medicine (TCM) plays an important role in Chinese culture, information about TCM was another commonly reported type of treatment-related information that patients preferred to receive, particularly patients at the follow-up stage who were not satisfied with Western medicine-type treatment and patients who suffered from too many side effects from Western treatment:

*“In addition, I want to learn [information about] medication. During the time at hospital, the hospital provided medicines to us. But after discharge, are there any recommended medicines that we can continue to take at home? For example, Chinese herbs. In China, Chinese herbs have played an important role since ancient times. Actually, we don't have to take Western medicine if we are sick, and the Traditional Chinese Medicine can also help control the disease. In the past, there was no surgery in China, and we used Traditional Chinese Medicine and it did make sense. Traditional Chinese Medicine has existed for thousands of years. When we were young, we used Traditional Chinese Medicine only when we were ill. Traditional Chinese Medicine is one of the*

*most important treatment therapies in China.” (P6, Male, 48-year-old, Hepatic cancer, Stage IV)*

*“We have visited the hospital many times, and we strictly followed the instructions of the doctors. I have received chemotherapy six times, oh, should be seven times. I cannot stand it anymore. I don’t want to continue the chemotherapy. He (the doctor) told me that I needed to take six times of chemotherapy, but he said this was a kind of...targeted medicine, so I need to actually take twelve times as two times together were counted as one time. There were actually no positive changes in the tumour size in the lung, no significant changes after the chemotherapy. Besides, the chemotherapy brought a lot of undesirable sufferings to me. So, I don’t want to receive the chemotherapy anymore. I plan to use traditional Chinese herbs to promote the recovery of my body. I want to learn some information about traditional Chinese herbs” (P7, Male, 60-year-old, Colorectal cancer [metastasized to the lung], Stage IV)*

*“I do not want to take the chemotherapy anymore if it recurred, as I suffered too much from the chemotherapy. I want to find a doctor of Traditional Chinese Medicine with rich experience and take some Chinese herbs.” (P10, Male, 63-year-old, Colorectal cancer, Stage IV)*

However, only a few informal caregivers mentioned that they wanted to learn more about TCM as a complementary therapy.

*“I would like to learn something about Traditional Chinese Medicine and have a try. My daughter called me just now and discussed it with me. She also would like to learn and try Traditional Chinese Medicine for her mother.” (C2, Husband, 53-year-old, Patient with lung cancer)*

*“I want to learn whether there are any Chinese medicines that can be used as a complementary therapy for cancer treatment in the hospital. I want to find an experienced doctor of traditional medicine for him.” (C3, Wife, 49-year-old, Patient with lung cancer)*

### **8.3.1.2 Daily life, particularly food therapy**

Approximately half of the patients (7/17) and informal caregivers (8/15) sought information about daily life. Although daily life care includes a wide range of components, such as eating (diet), exercise, dressing/bathing, toileting, hygiene, etc., given the belief in and popularity of food therapy within the Chinese culture, diet was mentioned most frequently by both patients and informal caregivers. They expressed a strong desire for information on diet/food therapy to promote the physical recovery of patients and to slow the deterioration of the disease:

*“Food therapy, you know, there are a lot of food remedies. When I was healthy, I usually made Chinese soup, putting some herbs, for example “Huang qi”, “angelica” in the soup to improve our health. However, now I am not sure if I can eat those herbs with this disease. For diet, now, what should I do, what food can I eat and what can I not eat; what kind of food is bad for my disease, and what kind of food is good for recovery from the disease? Those are what I want to know.”* (P5, Female, 36-year-old, Cervical cancer, Stage III)

*“The thing that I want to know is about diet, the types of healthy food which will not deteriorate my disease”* (P6, Male, 48-year-old, Hepatic cancer, Stage IV)

*“I think that the hospital should provide some information to our family members, like, what we should do at home after discharge and information about diet at home for the patients; they need not only biomedical therapies but also food therapies. Yes, those kinds of information you can provide [to us].”* (C8, Daughter, 33-year-old, Patient with hepatic carcinoma)

*“I want to know information in terms of diet, daily life, and nutritional support to control and delay the progression of the disease.”* (C14, Son, 32-year-old, Patient with gastric cancer)

A desire for information about daily life in terms of how to do exercise after chemotherapy was also reported by the patients:

*“[The information that I want to learn is]...for example, physical exercises after the chemotherapy. Another thing is daily life, particularly diet and exercises.”* (P12, Male, 45-year-old, Lung cancer, Stage IV)

### **8.3.1.3 Physical and psychological symptom management**

It is common that patients with advanced cancer experience unpleasant physical symptoms. In this study, although all the patients were advanced stage cancer patients, they were still receiving active anticancer treatment, particularly chemotherapy, which bring patients some chemotherapy-induced side effects. Several patients and informal caregivers indicated that they wanted to learn more about the management of physical symptoms, such as pain and chemotherapy-induced nausea and vomiting, as the following statements show:

*“I want to know whether there are any other approaches that I could use to relieve my pain. I don't want to depend on the painkiller only.”* (P17, Female, 55-year-old, Lung cancer, Stage IV)

*“Every time after he received the chemotherapy, he suffered from serious vomiting. So, I want to know how to relieve this symptom, to decrease his distress and make him comfortable.”* (C3, Wife, 49-year-old, Patient with lung cancer)

In addition to the management of physical symptoms, both the patients and the informal caregivers wanted to obtain more information on self-emotion management. Suffering from cancer was a stressor for patients, and they needed more information about psychological adjustment to maintain their own mental health:

*“I am not sure whether these methods [for emotions adjustment] were right or not, but at least I think my emotional status is okay. So, I think the methods that I used are okay. Of course, it would be better if you (healthcare professionals) could teach us some methods to adjust our emotions.”* (P1, Male, 56-year-old, Nasopharyngeal cancer, Stage III)

The informal caregivers also wanted to learn more about self-emotion management; however, their purpose was to conceal their own negative emotions and show more positive ones in front of the patient. As the son of a patient said:

*“As his family, I should keep happy in front of the patient to decrease his psychological burden. Because once we are not happy, the patient will subsequently feel more stressed. So, even if I am sad, I need pretend to be happy in front of the patient to let him have a good mood, but how can I do that? I want to know.”* (C14, Son, 32-year-old, Patient with gastric cancer)

#### **8.3.1.4 Financial support**

Adequate health insurance can relieve a family’s financial burden. In this study, the majority of patients had basic national insurance, which only partly alleviated the financial burden on them. However, several patients and informal caregivers reported that they learnt very little about national insurance coverage and wanted to learn more, particularly about the coverage offered and the reimbursement of expenses:

*“Every time after I received the chemotherapy, I needed to inject some medicines to increase the number of white blood cells and red blood cells. The price was more than one thousand for each injection. It seems that it was not covered by the insurance and we cannot claim any reimbursement. I want to know if it was really not covered. I indeed learnt little in terms of the insurance reimbursement.”* (P2, Male, 51-year-old, Lung cancer, Stage IV)

*“Now I want to know the types of medication that are covered by medical insurance and how to claim them for reimbursement. I learnt very little of these kinds of information.”* (P4, Female, 32-year-old, Cervical cancer, Stage IV)

*“Another thing that I want to learn is about medical reimbursement. We are not locals, so we are not clear about it. It seems that the reimbursement proportion is 65% if we claim it in Nanchong city. But I am not sure if we can claim more reimbursement when we come back to our city.”* (C3, Wife, 49-year-old, Patient with lung cancer).

Generally, both the patients and the informal caregivers desired to obtain more information about disease conditions, progression and treatment, daily life issues (particularly food therapy), physical symptom management, self-emotion management, and information on insurance coverage and reimbursement. In addition, the informal caregivers wanted to learn information on cancer prevention, and the patients wanted to obtain more information on prognosis.

### **8.3.2 Category 2: Reasons for information needs being unmet**

This category refers to the reasons for information needs of both the patients and the informal caregivers being unmet. The reasons were extracted from the interview data and sorted into three sub-categories: factors relating to healthcare professionals, factors relating to patients and informal caregivers (individual factors), and factors relating to family/social support.

#### **8.3.2.1 Healthcare professional factors**

##### Healthcare professionals have no time due to their heavy workload

The majority of the patients (13/17) and nearly half of the informal caregivers (7/15) said that healthcare professionals were too busy to provide them with detailed information. This was one of the most important reasons that their information needs were not being met. China is a populous country and the huge number of patients has placed a great workload on doctors and nurses. As a result, doctors and nurses are usually extremely busy and have little time to communicate with the patients and their family members:

*“Doctors are too busy to talk with us. You know, there are so many patients that the doctors cannot detail everything to us. The doctors can only tell us the most important things, like the condition of the disease.” (P1, Male, 56-year-old, Nasopharyngeal cancer, Stage III)*

*“Nurses are too busy to talk with us. We cannot say that the nurses didn’t tell us information as they are really too busy. Nursing actually is a kind of job and they work to earn money to support their families. Although I want to know more information, we need to understand the nurses as they really*

*have no time, working hard with a heavy workload.” (P6, Male, 48-year-old, Hepatic cancer, Stage IV)*

Some informal caregivers also shared their experiences of being rushed when seeking information from doctors:

*“They (doctors) are busy and they don’t have enough time to talk with us unless it is an urgent issue. Every time when I saw they were busy I did not ask them for information. Sometimes when I got the chance to ask, I felt sorry for occupying too much time as many other patients and families are waiting for the doctor. So, I cannot get too much information from the doctor, just a few sentences.” (C3, Wife, 49-year-old, Patient with lung cancer)*

*“Yes, to be honest, the doctors are very busy, and they usually tell us information using only a few sentences. But from the perspectives of patients and families, we indeed want to get detailed information and learn it clearly.” (C10, Wife, 52-year-old, Patient with oesophageal cancer)*

In addition to the heavy workload of healthcare professionals, getting uncertain answers from doctors was identified as another reason for patients’ unmet information needs:

*“Even if you ask the doctor, he or she won’t give you a definite answer. [He or she] won’t tell you to what extent the drug might help with your condition. Not 100 per cent...even 80 to 90 per cent... He won’t tell! How and what could you expect me to get such information [from the doctor]? He has no idea, me neither!” (P15, Female, 49-year-old, Lung cancer, Stage IV)*

*“No, it seems I didn’t get any information about treatment. Nobody can give us certain answers, including the doctors. They didn’t tell me definite information in terms of how to treat or prevent the cancer as individuals’ conditions are different. Even though we really want to learn some information about treatment, the doctors cannot provide us with certain answers.” (P5, Female, 36-year-old, Cervical cancer, Stage III)*



### 8.3.2.2 Individual factors

#### Knowledge and beliefs

Both the patients and the informal caregivers indicated that their poor literacy to some extent limited their ability to seek information and understand it when it was given:

*“For many things, I know it is important. However, I don’t know how to learn it more or in detail because of my poor education level. For example, many people know how to search for information online, but I don’t know how to do that. I usually cannot find the information that I want to know due to my poor literacy.”* (P8, Female, 45-year-old, Cervical cancer, Stage III)

*“I am illiterate. I have never received any formal education. So, sometimes I can’t understand the words that the doctor tells me unless he or she explains it to me several times.”* (C11, Wife, 70-year-old, Patient with oesophageal cancer)

Although information about daily life issues such as diet were reported as a type of information that the patients and informal caregivers wanted to obtain, they were not actively seeking this kind of information from their doctors. They usually viewed daily life information as less important compared with information about their disease and treatment. The doctors’ priority was ‘curing’ the disease rather than talking about daily life issues:

*“Generally, I ask for help from doctors when I feel unwell. For daily life issues, it is not urgent, just tiny issues.”* (P9, Female, 43-year-old, Nasopharyngeal carcinoma, Stage IV)

*“Just like diet, it is a tiny issue. If the doctors were really busy and had no time, I would not disturb and occupy the time of doctors due to this kind of tiny issue.”* (P5, Female, 36-year-old, Cervical cancer, Stage III)

*“When my husband feels unwell, I visit and report it to the doctor. I would feel relaxed if the doctor told me that the patient’s condition was okay. While for daily diet, I think it is not that urgent, I*

*seldom ask for this kind of information from doctors.” (C6, Wife, 53-year-old, Patient with oesophageal cancer)*

*“I am not sure, in my opinion, maybe the doctors think that daily life care and diet are not essential issues. Doctors’ duty is curing the disease rather than the daily life issues of patients. Daily life issues are the patients and family members’ own business.” (C7, Husband, 50-year-old, Patient with cervical cancer)*

### Poor health status of patients

Another commonly reported factor for patients’ unmet information needs was their own poor physical condition. Patients usually experienced unpleasant side effects such as nausea and vomiting after receiving chemotherapy. They were therefore not physically well enough to seek information until they had recovered from the side effects:

*“I am old now and I feel really unwell due to the nausea and vomiting after the chemotherapy. The poor fitness makes me not seek information.” (P3, Female, 55-year-old, Cervical cancer, Stage IV)*

The patients’ poor memory was also reported as a reason for a lack of information seeking:

*“Uh...I feel that the doctor actually told me something every time I visited them, but I usually forget it soon due to my bad memory.” (P11, Female, 43-year-old, Ovarian cancer, Stage III)*

Some informal caregivers faced the same situation, particularly elderly caregivers who suffered from a chronic disease. As an old informal caregiver with emphysema said:

*“I am now an emphysema patient, moderate emphysema, having insufficient oxygen supply to the heart and lungs. For my condition, the doctor told me it is a chronic disease and I have to avoid suffering from the cold as cold can deteriorate the emphysema. Now I have to look after her, and at night, I need to get up and help her get on clothes as long as she wants to go to the*

*toilet, no matter how many times. I am not physically [strong] enough to seek information due to my disease.” (C13, Husband, 73-year-old, Patient with breast cancer)*

#### Low motivation: Fear

Several patients expressed psychological conflicts in terms of information seeking. On the one hand, they wanted to obtain information, but on the other hand, they avoided asking for information as they were afraid of hearing bad news. Fear therefore had reduced their motivation to ask for information:

*“Sometimes...I feel that it would be worse if I learned more. Instead, learning little might be better. For instance, if my doctor told me that the review results were good, of course, I would be happy. However, if the results were not good, I would have totally different emotions. So, sometimes I feel conflicted in terms of learning information. I want to learn something but fear that it is bad information. So just let it go, not seek information actively, learning little might be better.” (P16, Male, 56-year-old, Lung cancer, Stage IV)*

Similarly, several informal caregivers also reported that sometimes they were reluctant to gain information because they feared to get bad news about their loved ones:

*“On the one hand, I really want to learn something about him, but on the other hand, I am afraid of knowing the truth. If you ask me whether I want to learn more information, of course, my answer is yes. But I am not willing to learn information by myself. I ask his young brother and our son-in-law to learn the information, and then I can learn something from them if I want to.” (C15, Wife, 57-year-old, Patient with colorectal cancer)*

#### **8.3.2.3 Family/social support factors**

Several informal caregivers reported that they were the only person who was available to take care of the patient. All the informal caregivers were female. Given the traditional gender role within Chinese culture, females usually have to attend to housework. The informal caregivers stated that

they not only had to look after the patient but also take care of all the domestic affairs. Insufficient support from other family members increased their caregiving burden and left them with no time and energy to search for information:

*“I am the only person who is taking care of him and I have to stay with him due to the transfusion, which makes me have no time to seek information.” (C6, Wife, 53-year-old, Patient with oesophageal cancer)*

*“I am the only person who is taking care of him since his diagnosis. Besides, there is still a lot of housework for me, so I don't have time and energy to seek information. I am very busy since his diagnosis. Every time after discharge, he was even too weak to wash his face by himself, and he depended on me to do everything for him. This time he looks a little bit better. I prepare meals for him and then he can eat by himself. I bring the water to him and he can wash his face by himself this time. Generally, I need to prepare or do everything for him. We live in the countryside, and I need to socialize with others for all the domestic issues since my husband got sick. For example, I need to do all the reception when relatives come to see him; when he is unwell, I need to visit the doctor; and I need cook at the same time, so I am too busy and have no time to seek information. We have only one child, he is young and needs to come out to make money to support his father's treatment expense. So, nobody can help me, and I need to take over all of the things.” (C3, Wife, 49-year-old, Patient with lung cancer)*

Many patients usually relied on their family caregivers to obtain information. The heavy caregiving burden imposed on the informal caregivers due to insufficient family support was therefore also mentioned as a reason for the patients' unmet information needs:

*“For most of the time, I have to depend on my family (wife) to learn the information, but actually she is very busy as she needs to undertake all the domestic affairs and take care of me. So, she is too busy to learn information, which is a big problem. Indeed, I want to learn information, but I*

*cannot get the information as I know my wife is exhausted every day.” (P2, Male, 51-year-old, Lung cancer, Stage IV)*

*“Sometimes, my wife learns some information for me; however, to be honest, she has no time to seek more information. We have only one child and she has her job, so it is my wife who does everything for me as well as the housework, I know she is burned out.” (P6, Male, 48-year-old, Hepatic cancer, Stage IV)*

One patient mentioned his experiences of social isolation since his diagnosis of cancer. Such isolation reduced his chances of obtaining information from others:

*“I am not an outgoing person. Since the diagnosis of cancer, I feel that I am further isolated from others, so I am not willing to communicate with others anymore. For example, when I come back home from hospital, I usually walk around alone and seldom have a chat with others. Actually, if I could have a chat with others, maybe I could obtain some information via chatting.” (P14, Male, 63-year-old, Oesophageal cancer, Stage IV)*

Overall, the heavy workload of healthcare professionals, poor literacy and beliefs of individuals, fear of bad information, and insufficient family support were common reasons for the information needs of patients and informal caregivers being unmet. Poor health status and social isolation due to the disease were two other unique reasons for the unmet needs of patients.

### **8.3.3 Category 3: Preferences for provision of information**

This category concerns the patients’ and informal caregivers’ preferences in terms of information provider, format, and timing of information, namely, from *whom*, in *what* format, and *when* during the disease trajectory the patients and informal caregivers wanted to receive information.

#### **8.3.3.1 Information provider**

Healthcare professionals, particularly doctors, were regarded as the ideal information providers by both the patients and the informal caregivers. In the minds of most patients and informal

caregivers, the information provided by healthcare professionals was much more reliable and believable than information from other sources:

*“The best thing is that the doctors can provide us with some information. If the doctors can tell us what kinds of food we can eat and what we should do to prevent a recurrence of the disease, it would be much better. We believe our doctors and they are the authority.”* (P5, Female, 36-year-old, Cervical cancer, Stage III)

*“Of course, I hope to learn some better information. There is too much information [outside] about diet, I cannot try each kind of food. If the doctors can tell me something about diet, it will be much better as I believe the doctors. Maybe the information provided by doctors is not 100% effective, but I think it is at least safe.”* (P17, Female, 55-year-old, Lung cancer, Stage IV)

*“[I want to learn information from doctors] because doctors are authorities and professionals. Their words are much more reliable and believable.”* (C1, Son, 34-year-old, Patient with lung cancer)

*“It would be better if the doctors and nurses could provide us with some professional and reliable information, particularly information on treatment.”* (C2, Husband, 53-year-old, Patient with lung cancer)

*“The disease conditions are different among patients, so getting information from the internet or folk information is less reliable than that of getting information from doctors, as doctors know their patients’ conditions better. So, I hope the doctors can communicate with us and patients more.”* (C8, Daughter, 33-year-old, Patient with hepatic carcinoma)

### **8.3.3.2 Information format**

Several forms of information provision were mentioned by both the patients and the informal caregivers, which usually included face-to-face conversations with healthcare professionals and written information. The patients most commonly mentioned written information, such as mobile

messages and printed materials, as written information could help patients overcome the problem of poor memory, allowing them to read the information in their own time and whenever it suited them:

*“I hope [healthcare professionals] can give us some printed materials, printing it on paper. On this occasion, we can take the booklets back home and read.”* (P1, Male, 56-year-old, Nasopharyngeal cancer, Stage III)

*“The best format is sending me information through mobile phone messages, sending the messages on my mobile phone. Because recently there are too many harassing calls, and I feel annoyed once I receive the harassing calls. I don’t like to answer these kinds of calls, but I want to get some suggestions. Sending me messages I think is the best form, which is better than calling me directly. I really don’t like to receive unknown calls because unknown calls are usually marketing calls like house sales. I am sick now, so I am irritable, and I am even more annoyed when I receive these calls. For mobile phone messages, I can read it based on my time. Sometimes, I may feel too tired or too busy to read it. In this case, I can read it later.”* (P6, Male, 48-year-old, Hepatic cancer, Stage IV)

*“For example, the healthcare professionals can give me a paper list and then I can take it back home. Although I am illiterate, my family members can read it. I mean, give us some printed materials at the time of discharge such as daily life care at home. We can read it at home as I will forget it soon if you tell me through an oral conversation.”* (P9, Female, 43-year-old, Nasopharyngeal carcinoma, Stage IV)

A few patients preferred face-to-face conversations, believing that this format provided them with much better tailored information:

*“I think ‘chatting’ is a good form because patients’ conditions are different. Talking can help doctors and nurses learn more about the patient and then they can give us more tailored information.”* (P1, Male, 56-year-old, Nasopharyngeal cancer, Stage III)

The informal caregivers, on the other hand, most commonly mentioned face-to-face conversations with healthcare professionals as their preferred format, with some expressing their concern about bad news being revealed to the patient. They preferred to hold back bad information from the patient during a conversation in order to minimize the patient's psychological burden:

*“For example, we can sit down and discuss together with the doctors [about the treatment regimens]. However, for information about disease conditions, particularly bad information, the doctors had better tell and discuss with our families only in the doctor's office [and exclude the patient from the discussion, particularly for bad information].”* (C4, Son, 35-year-old, Patient with lung cancer)

*“He is the core person of my family, and his disease might further deteriorate if he knows his condition too much. He will be happier if he knows little about himself, living with less psychological burden. So, for a patient's conditions, you ([the doctors] had better tell our family only, rather than the patient. It is not necessary to tell this kind of information to the patient as it might increase their psychological burden.”* (C14, Son, 32-year-old, Patient with gastric cancer)

### **8.3.3.3 Timing of information**

The information needs of both the patients and the informal caregivers were not static but changed and fluctuated throughout the disease trajectory. The fluctuating need for information by patients and informal caregivers was similar to the progression of the disease. At the time of diagnosis, the patients and informal caregivers had a substantial need for information about the condition and/or treatment of the disease.

*“[When it was diagnosed,] I didn't feel any pain or uncomfortable, so I thought it was not a very serious disease. At that time, the cancer actually had metastasized to my brain, but it didn't metastasize to the bones, so I had no pain. Except for the symptom of hand twitching, I didn't think I was a patient. So, I didn't believe that I suffered from cancer, and I visited many hospitals including hospitals in Chengdu, and the diagnosis of cancer was confirmed finally. After that, I*



*began to seek treatment information actively, I really wanted to find some information on treatment therapies, for example, if there were any effective medicines that I could use to “cure” my disease.”*

(P12, Male, 45-year-old, Lung cancer, Stage IV)

*“I had never learnt about cancer before, so I did not know what I should do when one of my family members suddenly suffered from cancer. I totally knew nothing. So, at the time when he was diagnosed with cancer, I really wanted to learn information about his disease like his disease conditions, whether it was curable, and how to cure his disease. I wanted to try my best to cure his disease.”* (C1, Son, 34-year-old, Patient with lung cancer)

When the patients completed active treatment, such as chemotherapy, their information needs and those of their informal caregivers shifted to daily life care and/or continuing treatment at home to maintain the treatment effects:

*“Now, I have completed the treatment in hospital. What I care about now is how to maintain the treatment effects and how to delay the progress of the disease through diet and daily care at home”*

(P6, Male, 48-year-old, Hepatic cancer, Stage IV)

*“I completed all six chemotherapies. The doctor told me that I would take a CT (Computed Tomography) examination later and, if the result was okay, I would be discharged. One month later, I would come back to the hospital to have a review. So, I want to learn something to maintain the treatment effects during the time at home. Apart from Chinese herbs, I want to learn something else. I mean information about any other medications. Using Chinese herbs is only one of the approaches to maintain the effects.”* (P8, Female, 45-year-old, Cervical cancer, Stage III)

*“When we complete this chemotherapy, I hope my doctor can discuss with us about continuing treatment initiatives, the continuing treatment. It is about what we can do to maintain the treatment effects and prevent a recurrence at home.”* (C5, Son, 36-year-old, Patient with lung cancer)

*“This is the last chemotherapy, then it will be the follow-up. I will stay at home for most of the time, so I am thinking about how to take care of her better. To maintain the treatment effects, what should I do during the time at home?”* (C7, Husband, 50-year-old, Patient with cervical cancer)

With the progression of the disease, the need for treatment information increased again for both the patients and the informal caregivers, especially when the patients’ condition became worse or the disease recurred:

*“The thing that I want to learn mostly is disease treatment, especially this time. To be honest, after this review, if I could get some good news, of course, I would be very happy about that. However, I learnt something not good. So, I want to learn the reasons for the ineffectiveness. In the past few times, the treatments produced effects more or less; however, there were almost no effects of the current treatment according to the review results. I have undertaken chemotherapy many times, so I took the review to examine the treatment effects; however, it was not a good result. So, I am not sure if there is a possibility to cure the disease? What kinds of medicine can be used to cure the disease? All of those are what I want to learn. However, how can I learn it, where can I learn it, I cannot find anybody [from which] to learn this information.”* (P15, Female, 49-year-old, Lung cancer, Stage IV)

*“Because the disease recurred, and chemotherapy didn’t make sense anymore, the tumour size is bigger than before.”* (P15, Female, 49-year-old, Lung cancer, Stage IV)

*“This time it has metastasized to the lung, so I had a stronger desire to learn [treatment information].”* (P17, Female, 55-year-old, Lung cancer, Stage IV)

*“Now it has metastasized to the whole body and the chemotherapy has not made too many positive effects. On this occasion, I want to know more treatment information.”* (C2, Husband, 53-year-old, Patient with lung cancer)

Overall, both the patients and informal caregivers preferred to obtain information from healthcare professionals, particularly doctors. For most patients, they preferred written information, while for informal caregivers, face-to-face conversations with healthcare professionals was the most commonly mentioned format. The fluctuation of information needs for the patients and informal caregivers throughout the disease trajectory were similar—information on disease condition and treatment at the stage of diagnosis, daily care information, continuing treatment information after the completion of chemotherapy, and treatment information at the time of recurrence or if disease conditions became worse.

#### **8.3.4 Category 4: The meaning and role of information**

Both the patients and the informal caregivers had a strong desire to obtain information during the disease trajectory and the caregiving process, with both groups indicating that information played an important role in their efforts to cope with cancer. For example, for the majority of the patients and informal caregivers, adequate information, such as treatment information, provided them with references when making medical decisions, increased their hope for and perhaps also chance of survival, and affected them psychologically, both positively and negatively. In addition to the above three sub-categories, gaining more information could assist patients in their self-management and prepare informal caregivers for their role.

##### **8.3.4.1 Decision-making**

‘Getting more information would benefit decision-making’ was mentioned by both the patients and the informal caregivers. Several patients and informal caregivers indicated that adequate information could help them make a medical decision wisely and comprehensively by understanding the potential treatment effects and side effects of the treatment regimens, as well as considering their own economic situation:

*“If I know more, it would be better for me. It means I will have more choices and I can make decisions while considering my own budget. For example, if it was too expensive and cannot be*

*claimed for any reimbursement, I will choose some alternatives.” (P13, Male, 54-year-old, Oesophageal cancer, Stage IV)*

*“Learning more information will benefit my disease as I will know what kind of drug is good, what is bad for my body, and what has fewer side effects. The chemotherapy drugs that I currently use brought serious side effects to me, especially vomiting. If I could learn the chemotherapy drugs clearly, maybe I will choose the drugs with fewer side effects.” (P2, Male, 51-year-old, Lung cancer, Stage IV)*

*“If the doctor can provide us with more treatment regimens, like the advantages, side effects, potential effects, and expense of each regimen, it would help us have a better understanding of the regimen and then make a better decision.” (C5, Son, 36-year-old, Patient with lung cancer)*

In addition, gaining more information might increase their sense of participation when making a medical decision in conjunction with healthcare professionals. As one informal caregiver stated:

*“Although I am not a professional, I would like to share my suggestions and opinions during the discussion with doctors if I have sufficient information. For example, I could speak of my own opinions, and if the doctors approve it, it would be great; if the doctors say no, of course, we will respect the doctor’s recommendations as they are professionals. Nevertheless, we could say something, and share our opinions, and it could strength my feelings of participation when making the decisions.” (C4, Son, 35-year-old, Patient with lung cancer)*

The informal caregivers stated that, apart from informing their and their patients’ medical decision-making, gaining adequate information about their loved ones could help them plan for the future as well:

*“Some pieces of information regarding the [cancer] condition and prognosis would...[at least] enable us to have some preparations and plans for the things ahead...[at least] with some clues for some future planning...yeah...just such sorts of feelings.” (C14, Son, 32-year-old, Patient with gastric cancer)*

#### 8.3.4.2 Hope for and chance of survival

Both the patients and the informal caregivers indicated that having adequate information meant a greater chance and more hope for survival. Cancer posed a financial burden on the majority of the families with cancer patients. Families experiencing economic hardship sometimes had to forego treatments for financial reasons. In such a situation, having more information about financial support, such as medical insurance coverage and reimbursements, could enable them to afford more and longer treatments, thus increasing their hope for survival.

*“If I had learnt the information about reimbursement of the medical insurance, maybe I would use some medications with better effects and claim more for reimbursement. The reimbursement could support me to get more treatments, and having more treatments means more chances to survive.”*

(P3, Female, 55-year-old, Cervical cancer, Stage IV)

*“Of course, I wish to know more about healthcare insurance. The healthcare insurance can, more or less, reimburse some coins...as you know the cancer and related treatments really cost us a big sum of money. Some reimbursement [from the healthcare insurance] would at least enable us to afford a longer treatment with greater hope.”* (C3, Wife, 49-year-old, Patient with lung cancer)

Many other patients and informal caregivers reported that learning more about treatment regimens meant that they would have more options and the chance to try different treatments, increasing their chance and hope for survival:

*“If we were informed of information on treatment regimens, we can select one to treat the disease continually. Only when we try more, the patient may have the chance to survive. So, learning more information on treatment regimens may enable us have a chance to choose the treatment and more chances for the patient to survive.”* (C2, Husband, 53-year-old, Patient with lung cancer)

*“Now I learn very little about cancer treatment regimens; if I could learn more, it would bring benefits. I would be much more confident as I could have more choices and more chances for us to have a try.”* (P7, Male, 60-year-old, Colorectal cancer, Stage IV)

### 8.3.4.3 Psychological impact

Adequate information had both a positive and a negative psychological effect on the patients and informal caregivers. They stated that gaining more information would help them to understand their/the patients' disease conditions better and more clearly, which could reduce the psychological pressure on them and increase their certainty and ease:

*“Information may influence our moods and psychological status. Knowing more information can help me learn my disease conditions better and know what I should do in daily life, which can enable me to feel certain. If I knew all this information clearly, I would not feel confused about my condition every day, such as “what is this?” and “what should I do?” I would feel much easier and relaxed.”* (P2, Male, 51-year-old, Lung cancer, Stage IV)

*“If I could learn more information, I would have a clear understanding about the patient's disease condition. For treatment regimens, if I learnt that the current treatment regimen is appropriate for him, of course, for us...no matter the patient or our family members, we will feel less stressed.”* (C4, Son, 35-year-old, Patient with lung cancer)

The patients and informal caregivers also indicated that being informed on how to access information, particularly disease-related information, would reduce their doubts and uncertainties:

*“Having information versus having no information, I think learning more information would make me feel certain. If I know nothing, there would be a doubt in my mind.”* (C12, Wife, 70-year-old, Patient with lung cancer)

*“Generally, learning more information would make me feel at ease in many aspects, including the psychological aspect, because there would be no doubt in my mind. If I learn little, I will doubt my disease conditions all the time, for example, if the disease has become better or not. Knowing sufficient information would let me have the feeling of certainty.”* (P12, Male, 45-year-old, Lung cancer, Stage IV)

Although the majority of the participants indicated a positive influence of having adequate information on their psychological state, negative impacts were also mentioned by several patients and informal caregivers. They stated that learning too much information might increase their psychological burden:

*“Learning too much, feeling much more upset. I, therefore, decide to follow the doctors and listen to them.”* (P5, Female, 36-year-old, Cervical cancer, Stage III)

*“I feel...if I learnt more and clearly, I would be much more upset and sad. So now I don’t want to know too much. Sometimes, I don’t even know how to continue my life if he passed away.”* (C15, Wife, 57-year-old, Patient with colorectal cancer)

In addition to the above three common sub-categories, having adequate information was reported to be a way of assisting patients in their self-management and a way of preparing informal caregivers for their caring role, as detailed in the following.

#### **8.3.4.4 Self-management (patients)**

Self-management is a “lifetime task”. Although all the patients in this study were cancer patients at an advanced stage, more than one-third expressed the view that knowing information, particularly information on daily life issues such as diet, could be a way of assisting them in the self-management of their own health. Several patients mentioned that gaining information about daily life could promote their adjustment to a different lifestyle and improve their capacity for self-management:

*“I think information makes sense, for example, now I avoid eating food that is bad for my disease, like pickled food, and I prefer to eat fresh food since my relative told me which food I can eat, and which I cannot eat. Gradually, I changed my previous bad habits in daily life.”* (P1, Male, 56-year-old, Nasopharyngeal cancer, Stage III)

*“Learning more information can help me have a better understanding of my disease, then I will know how to do it in daily life and how to take care of myself.” (P2, Male, 51-year-old, Lung cancer, Stage IV)*

*“In addition, since I had learnt some information [on daily life], there were some adjustments and changes in terms of my lifestyle. For example, if I learnt some information that may good for my disease, then I will try to follow that. Just like the “Huangqi”, a kind of Chinese herb. Since the head nurse told me that Huangqi can accelerate qi-blood circulation and may good for my disease, I put a piece of Huangqi in boiling water and drink the water every day.” (P6, Male, 48-year-old, Hepatic cancer, Stage IV)*

Other patients indicated that enhanced self-management in daily life, in combination with professional treatment, may contribute to better treatment results:

*“For example, if you could tell me how to prevent the recurrence of the disease, I would try to follow and adjust my lifestyle. A healthy lifestyle in combination with medical treatment, I think, will contribute to better results.” (P5, Female, 36-year-old, Cervical cancer, Stage III)*

*“When a person suffers from a disease, the patient should not only take medicines but also maintain a healthy lifestyle. Active treatment in combination with a healthy lifestyle could contribute to better results. That is why there is the saying “三分藥七分養 (for a disease, 30 per cent depends on medicine and 70 per cent depends on care)”. Sometimes, daily care might be much more important. Treatment is of course important, but apart from treatment, our body’s immunity might be much more important, so we need to take care of ourselves in daily life. When we are in hospital, we can depend on doctors, while when we are discharged and stay at home, we need to depend on ourselves. For us, the thing that we can do is enhance self-care in daily life, so learning more information on daily life care is needed.” (P6, Male, 48-year-old, Hepatic cancer, Stage IV)*



#### **8.3.4.5 Being more prepared for the caregiving role (informal caregivers)**

Being prepared for what lies ahead is an important aspect of feeling in control and relieving uncertainty. Some informal caregivers in this study reported that gaining adequate information would enable them to feel more prepared for their caregiving role:

*“Of course, information on diet is very helpful for us. For patients, actually they need not only the medical treatment but also the diet, the food therapy. As patients’ family members, knowing more information on diet will enable us to take care of the patient better at home. We will know what to do and how to take care of him.”* (C8, Daughter, 33-year-old, Patient with hepatic carcinoma)

*“For the aspect of diet, if our family members had sufficient information and knowledge, we would know how to make healthy food for her and would know which types of food would be good for her. In this way, I would feel at ease when I am taking care of her and the provided caregiving would be much more tailored, and I would feel more prepared in terms of making food for the patient.”* (C2, Husband, 53-year-old, Patient with lung cancer)

Two informal caregivers indicated that adequate information would enable them to be psychologically prepared for the death of the patient:

*“She has undertaken several times of chemotherapy and radiotherapy and will complete all of the [active] treatment. So, I want to know the overall condition of the patient, like the treatment effects. If her condition has become good, of course, we will be happy for that; if not, I...I mean knowing that could help me have a psychological preparation for her leaving. Nobody can survive forever, and everybody will leave at the end.”* (C7, Husband, 50-year-old, Patient with cervical cancer)

*“Learning more information, I think it would be helpful for us as we would feel calmed down when we meet some situations in the future. Learning more, I feel it would help us have preparation, such as the disease condition. Actually, I have learnt that this kind of disease cannot be cured, and he will die someday. Learning this can help us have a psychological preparation for the patient’s*

*leaving. We could adjust ourselves in advance to accept the result, which may enable us to feel not too saddened when the patient passes away.” (C14, Son, 32-year-old, Patient with gastric cancer)*

Overall, both the patients and the informal caregivers stated that adequate information could provide them with references for decision-making, could increase their hope and chance of survival, and could have both positively and negatively psychological effects. They also mentioned that adequate information may play an important role in their efforts to cope with cancer, as adequate information could improve patients’ capacity for self-management and help informal caregivers to prepare for their caregiving role.

#### **8.4 Summary of the qualitative findings**

This chapter described the results of the qualitative interviews. Seventeen patients with advanced cancer and 15 informal caregivers with unmet information needs as identified in the cross-sectional survey participated in the semi-structured interviews to elaborate on their unmet information needs and to describe their perceptions and experiences of their unmet information needs during the cancer trajectory and caregiving process. Four categories were extracted from the interview data of both the patients and the informal caregivers: ‘types of unmet information needs’; ‘reasons for information needs being unmet’; ‘preferences for provision of information’; and ‘the meaning and role of information’.

Both the patients and the informal caregivers reported several types of unmet information needs, including disease-related information (e.g., disease condition, progress, and prognosis), treatment-related information (e.g., treatment regimens and TCM), daily life care information (particularly concerning food therapy), physical and psychological symptom management, and information on financial support such as insurance coverage and reimbursements. Of these unmet information needs, information on treatment and daily life care were the two most commonly reported unmet information needs by both the patients and the informal caregivers.

The factors implicated in information needs not being met were mainly healthcare professional factors, individual factors, and family/social support factors. Healthcare professionals were usually too busy to provide patients and informal caregivers with adequate information. The patients' and informal caregivers' personal knowledge and beliefs, physical status, and motivation were mainly the individual factors implicated in their unmet needs. Due to insufficient support from other family members, the informal caregivers faced a heavy caregiving burden, which meant that they did not have the time to seek information for either the patients or themselves.

Both the patients and the informal caregivers indicated their preferences in terms of information provision, including information provider, format, and timing. Both groups preferred the healthcare professionals, particularly doctors, to provide information to them as it was much more reliable and believable. The patients preferred the information to be in written form, while the informal caregivers favoured face-to-face conversations with healthcare professionals. The patients and informal caregivers had different information priorities at different stages of the disease trajectory, with information on disease conditions and treatment at the time of diagnosis, daily care information and continuing treatment information after chemotherapy had been completed, and treatment information when disease conditions were worse.

Both the patients and the informal caregivers indicated that adequate information played an important role in their efforts to cope with cancer. Adequate information such as treatment information could provide them with references for decision-making, increase their chance of and hope for survival, and affect them psychologically, both positively and negatively. In addition, gaining more information was a way of enhancing the patients' capacity of self-management and a way of fully preparing the informal caregivers for their caring role.

The next chapter will discuss the findings and limitations of the whole study, as well as implications for future research and practice.

## **Chapter Nine: Discussion and Conclusion**

## **9.1 Introduction**

This chapter is the final chapter of the thesis, which will discuss the study findings of the doctoral research project and come to some conclusions. The study findings of the entire doctoral research project will be summarized in Section 9.2. The methodological issues and sample characteristics of the doctoral research project will be discussed in Section 9.3, while Section 9.4 and Section 9.5 will discuss the study findings from the cross-sectional survey and the semi-structured interviews, respectively. The strengths and limitations of this research project will be reported in Section 9.6, and implications for future research and practice will be discussed in Section 9.7. The final section, Section 9.8, will summarize and conclude the entire doctoral research project.

## **9.2 Summary of the study findings of the entire research project**

This doctoral research study primarily aimed to identify the palliative care needs of Chinese patients with advanced cancer and the needs of their informal caregivers within the context of China. Understanding patients' and informal caregivers' care needs and their predictors within the Chinese context was the first step in identifying evidence for researchers and policymakers in terms of developing tailored palliative care interventions and services to meet their needs better. To reach the study's aim and objectives, a multimethod research design (a quantitatively driven project followed by a qualitative project) was used, which included a cross-sectional survey and follow-up semi-structured interviews.

The cross-sectional survey was designed based on a palliative care needs conceptual framework. The findings from the quantitative survey revealed that both the patients and their informal caregivers had a wide range of unmet care needs, and their care needs were influenced not only by factors related to themselves but also by factors related to their partners. According to the conceptual framework, the potential factors were sorted into five categories, including sociodemographic factors, clinical factors, physiological factors (symptom distress), psychological factors (anxiety and depression, coping, quality of life), and the factor of social

support. Physiological and psychological factors were found to be more significant than demographic and clinical factors in predicting the palliative care needs of patients and the needs of their informal caregivers. Anxiety and depression, the use of coping strategies, and caregivers' quality of life were three common and significant predictors of the needs of both the patients and the informal caregivers. The patients' symptom distress was another negative factor in their own palliative care needs.

Information needs were identified as a common and prominent unmet need for both the patients and the informal caregivers. However, little information could be drawn from the quantitative results. Following the completion of the cross-sectional survey, semi-structured interviews were conducted with 17 patients and 15 informal caregivers to further elaborate on their information needs and to explore their perceptions and experiences of their unmet information needs. Four categories emerged from the qualitative interviews, which were types of unmet information needs, reasons for information needs being unmet, preferences for provision of information, and the meaning and role of information.

The quantitative and qualitative findings together contributed to a comprehensive and in-depth understanding of the palliative care needs of patients with advanced cancer and the needs of their informal caregivers within the Chinese context. In the following sections, details of the main study findings, strengths and limitations of this study, and implications for future research and practice will be subsequently interpreted and discussed.

### **9.3 Discussion of the methodological issues in and sample characteristics of this study**

Different from many other studies published in the current literature, a multimethod research design was employed in this current doctoral research project, which enhanced the sophistication and rigor of the research (Williamson, 2005). A multimethod research design can help to achieve complementarity when using at least two approaches to investigate different aspects of one phenomenon (Schutz et al., 2004). The goal of complementarity is 'to elaborate and enhance the

results of one method with the results of another method' (Schutz et al., 2004, p. 278). For example, a quantitative study can use a follow-up qualitative study to further explore unusual or unexpected results that were identified in the quantitative study (Schutz et al., 2004). In this doctoral research project, given that several specifically-designed instruments for palliative care needs assessment of advanced cancer patients and informal caregivers have been developed and used outside China (Wang et al., 2018b), a quantitatively driven study followed by a qualitative study [QUAN→qual] design was employed to examine the palliative care needs of advanced cancer patients and the needs of their informal caregivers within the context of China.

The quantitatively driven study was a cross-sectional survey, which was well designed following a conceptual framework that enhanced the understanding of the concepts in relation to palliative care needs and helped guide the needs assessment and the selection of potential covariates (influencing factors) of palliative care needs in a more evidence-based and structured approach. Moreover, all the measurements used in the cross-sectional survey were scales with well-established psychometric properties, which significantly maintained the reliability, validity, and accuracy of the findings from the survey study. For the instrument without a Chinese version, the PNPC-sv, a validation study was conducted first to examine its psychometric properties among Chinese advanced cancer patients (Wang et al., 2019). The validation results showed that the Mandarin Chinese version of the PNPC-sv was a valid, reliable, and user-friendly instrument for measuring the problems and palliative care needs of patients with advanced cancer in China (detailed information about the validation study is presented in Chapter Six). The cross-sectional survey quantified the palliative care needs of the patients and the needs of their informal caregivers, of which information needs was a common and prominent care need for both the patients and the informal caregivers, as well as an unexpected finding.

Although the quantitative method has the strengths of quantification, precision, and reliability, any other detailed information about the identified unmet information needs could not be drawn from

the quantitative study (Courtney, 2012). Therefore, a follow-up qualitative study was conducted to further elaborate the information needs of patients and informal caregivers, as well as the perceptions and experiences of the patients and informal caregivers regarding information needs via semi-structured interviews. Involving both quantitative and qualitative studies in this current research project ensured both the breadth and depth of this project (deMarrais & Lapan, 2003). More specifically, the findings from the cross-sectional survey and the semi-structured interviews offered a better and more comprehensive understanding of the palliative care needs of patients with advanced cancer and the needs of their informal caregivers within the Chinese context.

A total of 477 eligible patient-caregiver dyads were invited to participate in the survey, of which 428 patient and informal caregiver dyads responded to the survey. The response rate of 89.7% in the current study was slightly lower than that in some studies investigating either the palliative care needs of patients (94.9% in Hwang et al., 2004; 97.7% in Uchida et al., 2011) or the care needs of informal caregivers (93.3% in Mangan et al., 2003). One possible reason might be that the patients and their informal caregivers in the current study were invited and recruited in dyads, and the participants were included only when both the patients and their informal caregivers consented to participate. It was acceptable that the response rate for the cross-sectional survey among the recruited patient-caregiver dyads was lower than that in studies that recruited patients or informal caregivers only. One study (Park et al., 2013) investigating the prevalence and predictors of anxiety and depression among cancer patient-family caregiver dyads and another study (Shin et al., 2013) examining the preferences of cancer treatment decision-making in patients-caregiver dyads also support the results of the current study.

The percentage of 89.7% in the current study to some extent can be regarded as a good subject response rate as it was similar to other studies including either patients or informal caregivers, with response rates of 89.8% (Lee et al., 2014), 89.0% (Chen et al., 2008), and 90.0% (Au et al., 2013), respectively. Further comparisons of the response rate with other well-designed studies



investigating the palliative care needs of patients and the needs of informal caregivers are difficult because existing high-quality surveys regard patients with advanced cancer and their informal caregivers as a ‘whole unit’, and recruiting patients and their informal caregivers in dyads to assess palliative care needs is rare (Wang et al., 2018b). According to one published systematic review (Wang et al., 2018b), only one study with a robust methodological quality (Hwang et al., 2003) was identified, and its response rate was only 67.1%, which was significantly lower than that in the current study. One possible reason for the relatively good response rate in the current study might be that all the participants in this study were invited by the healthcare professionals who were caring for them.

Indeed, the response rate of surveys can be maintained using effective recruitment strategies, and a good relationship between healthcare professionals and patients is regarded as an important factor in promoting study recruitment and participation. Many studies have indicated that the patients were more inclined to participate in the study when they were invited and provided with research information by their healthcare professionals (Baquet, Commiskey, Mullins, & Mishra, 2006; Castel, Négrier, & Boissel, 2006; Mills et al., 2006). In this study, a majority of the patients had visited the oncology department in the study hospitals many times; therefore, rapport and trust relationships had already been established between the participants and the healthcare professionals. Moreover, healthcare professionals are generally considered authoritative in the Chinese context and are respected by patients and their families (Chang et al., 2007), which might be another possible contributor to the relatively good response rate in the current study.

The sample’s demographic and clinical characteristics in the current study were partly different from previous studies conducted in Shanghai (Liu, 2008; Miu et al., 2016) and in some international studies conducted in developed countries/regions, including Australia (Waller et al., 2012b), South Korea (Park et al., 2010), and Hong Kong (Lam et al., 2014). The current sample was predominantly middle-aged married patients, with only primary school education or below

and a low household income, while the studies conducted in Shanghai and other developed countries/regions mainly involved married patients with at least a high school education, and a fairly high household income. These differences may have been caused by economic differences among the study sites. The participants in this study were recruited from two hospitals located in southwest China, and a majority of them came from the countryside. Shanghai, as a metropolitan area, has taken a relatively leading position in China (Gu et al., 2016b; Ma & Qiang, 2015); its economic level and education resources are therefore better than those in southwest China. Likewise, southwest China is a developing area of China compared with Australia, South Korea, and Hong Kong. Thus, economic differences should be the possible reason why the sample in this study had lower education and household income levels.

The proportion of married patients in the current study was significantly higher than that in international studies conducted in developed countries/regions (Lam et al., 2014; Park et al., 2010; Waller et al., 2012b), and more than 85% of the patients in the current study had no religious beliefs. Generally, religion is more important to people in developing countries (World Economic Forum, 2016). However, according to the data from the World Economic Forum (2016), China is not a religious country, which might be a reason why a majority of the Chinese patients in this study had no religious beliefs. The informal caregivers of patients were mainly their husbands, wives, or children in both the current study and in previous domestic and international studies. However, the caregivers in the current study were younger family members with only a primary school education or below, which may have also been the result of the economic issues mentioned above.

Regarding clinical characteristics, the majority of the patients were stage IV cancer patients, had received cancer-related surgery, and were still undergoing active cancer treatments (81.6%) at the time of the survey, including chemotherapy and/or radiotherapy. These clinical characteristics were similar to two other Chinese studies (Liu, 2008; Miu et al., 2016), but were somewhat

different from other international studies conducted in developed countries/regions (Hall, D'Este, Tzelepis, Lynagh, & Sanson-Fisher, 2014; Lam et al., 2014; Yun et al., 2013), especially the percentage of patients receiving active cancer treatment. The percentage of 81.6% in the current study was obviously higher than that in the international studies, which were less than 35%. In the current study, chemotherapy was the most commonly used active anticancer treatment. Excessive anticancer treatments in patients with advanced cancer is a common medical phenomenon in China (Li et al., 2011). Many Chinese patients with advanced cancer receive excessive medical treatments against their will (Huang, Zeng, Mao, & Liu, 2018). Overaggressive treatment may be caused by the attitudes and beliefs of the oncologist and families (Li et al., 2011). Due to the lack of knowledge and understanding of the philosophy of caring for cancer patients and the concept of 'death with dignity', Chinese professionals and the families of patients usually have the attitude of curing patients at all costs, and they are inclined to overtreat patients rather than provide palliative care to maintain the patients' dignity (Li et al., 2011; Liu et al., 2015). Another explanation may be Chinese filial piety and 'face culture (面子文化)' (Li et al., 2011). Family members are inclined to select active cancer treatments for their dying loved ones as others may complain that they have 'given up' on the patient if they do not ask for active cancer treatments (Li et al., 2011).

#### **9.4 Discussion of the main findings from the cross-sectional survey**

##### **9.4.1 Palliative care needs of patients with advanced cancer and the needs of their informal caregivers**

A wide range of context-bound care needs were identified in both Chinese advanced cancer patients and their informal caregivers, and information needs was identified as a common and prominent unmet need for both the patients and the informal caregivers. These results reflect the answers to research objectives (1), (3), and (6) of the current research project. Details will be discussed in the following.

According to the findings of a previous systematic review (Wang et al., 2018b) of international studies, the three commonly reported needs domains for patients with advanced cancer were psychological, physical, and healthcare services and information. In the current study, apart from the three domains mentioned above, financial needs was identified as another prominent domain of palliative care needs for Chinese patients with advanced cancer. Although several international studies also revealed the financial needs of advanced cancer patients, the percentages were significantly lower than that in the current study, ranging from 6.6% to 23.0% (Houts et al., 1988; Hwang et al., 2004; Morasso et al., 1999; Osse et al., 2005; Rachakonda et al., 2015; Rainbird et al., 2009). This divergence may be related to differences in healthcare systems and economic levels as all the relevant studies were conducted in developed countries. When compared with one study conducted in Indonesia (Effendy et al., 2015a), the proportions of financial needs in the two studies were similar.

The commonly reported needs domains in the current study was consistent with the findings of a previous systematic review (Wang et al., 2018b) from a broader perspective, but it was difficult to further compare the divergence and convergence of the detailed needs within each domain due to the diverse assessment scales among the studies. However, differences in cultural contexts, healthcare systems, and economic levels can indeed result in some specific needs within each domain. For instance, high-income countries/regions generally have well-established healthcare service systems that can facilitate the timely identification and resolution of healthcare problems, as some physical symptoms require high-quality professional support (Morasso et al., 1999). In China, the reimbursement of national insurance in small and community hospitals is obviously higher than that in large hospitals. In this case, patients with a financial dilemma are inclined to visit small hospitals; however, high-quality professional support is usually sub-optimal in small and community hospitals. Due to the influences of Confucianism, silence is regarded as a virtue in many Asian countries, including China (Tsuchiya & Horn, 2009), which may reduce the willingness of patients to express their feelings and concerns with others, resulting in

psychological need that differ from those of patients in the West. The need for certain types of information, to the extent of which the patients need the information and the reasons for needing the information, may be specific within a certain culture, as people's perceptions are influenced by their culture and the society to which they belong (Charon, 1992).

Given that further comparisons of the detailed needs within each domain in international studies using variable instruments is questionable, several studies using the same instrument as in this study were identified, and their divergence and convergence will be further discussed. The current study findings demonstrated that the palliative care needs of patients with advanced cancer mainly focused on the domains of financial, information, physical (particularly the symptom of pain), and psychological (fear of physical suffering) needs, which were different from the findings in other international studies using the same measurement (i.e., the PNPC/PNPC-sv) (Khan et al., 2012; Osse et al., 2005; Uitdehaag et al., 2015). Of which, ADL (Khan et al., 2012), psychological (Osse et al., 2005), and physical needs, particularly fatigue (Khan et al., 2012; Uitdehaag et al., 2015), were identified as priorities. Details of the domains will be discussed in the following.

### **Financial needs**

The financial needs was also identified in two other studies (Effendy et al., 2015a; Osse et al., 2005), but the corresponding proportions were significantly lower than those in the current study (23.0% in Osse et al., 2005, and 72.0% in Effendy et al., 2015a, vs. 78.8% to 80.4% in this study). Indeed, cancer patients and their families, even insured patients in developed countries, face a financial burden due to increased care costs (Chino et al., 2014), and many third-party payers have shifted part of the cost burden to patients (Chino et al., 2014). However, healthcare systems in developed countries are well developed, and the differences in the healthcare systems and economic levels between China and the Netherlands (Osse et al., 2005) may partly contribute to the higher percentage of financial needs in the sample of the current study. There is no Medicare in China. Although a majority of citizens purchase national insurance, the insurance coverage is

very limited and the proportion of reimbursement is low, especially in large hospitals. Moreover, all the participants in this study were recruited from southwest China, and a majority of them came from rural areas, so economic levels and healthcare resources were therefore relatively poorer and sub-optimal, which might explain the higher financial needs in the current sample.

### **Physical needs—Pain management**

Pain is regarded as a major problem and concern for patients with advanced cancer (Liu & Guo, 2017). In the current study, nearly 70% of the patients suffered from pain, and half of them had a strong need to relieve pain. This result was quite consistent with the study conducted in Indonesia (Effendy et al., 2015a), with a percentage of 66.4%. Compared with another study conducted in Canada (Khan et al., 2012), the proportion of 70% in the current study was significantly higher (nearly triple) than that of the Canada study, which was only 25.0%, although ‘pain relief’ was rated as the top physical need. More than half of the patients were stage IV cancer patients with distance metastasis in the current study, which may have partly contributed to the results. Another most important reason for such a high unmet need of pain management in this study may have been the limited use of opioid analgesics. Although the use of opioid analgesics has increased in recent years in China (Berterame et al., 2016), the consumption of opioid analgesics is still lower than that in most other countries (Liu & Guo, 2017). With the traditional concepts of analgesics, many Chinese physicians and patients are reluctant to use opioids as they worry about addiction and respiratory depression (Li et al., 2011).

### **Psychological needs— ‘Fear of physical suffering’**

“Fear of physical suffering”, as an important item in the PNPC-sv scale for measuring psychological needs, was rated as the most common item in both the current study and two other studies in the Netherlands (Osse et al., 2005; Uitdehaag et al., 2015). One possible reason may be that cancer patients, particularly those at advanced stages, usually experience various unpleasant physical symptoms introduced by cancer and related treatments, including fatigue, pain, sleep

problems, nausea and vomiting, alopecia, stomatitis, and cardiac dysfunction, among others (Berger et al., 2015; Irwin, 2013; Monsuez, Charniot, Vignat, & Artigou, 2010; Partridge, Burstein, & Winer, 2001). Cancer patients in China usually receive excessive anticancer treatments against their will (Huang et al, 2018), and excessive cancer-related treatments may to some extent further increase their unpleasant physical symptoms, subsequently contributing to a higher percentage of “fear of physical suffering”.

### **Information needs**

In this study, the information needs was examined as another prominent palliative care need for advanced cancer patients, with a percentage of 75.2%. Among the studies using the same assessment scale, only one study demonstrated information needs as a top priority, with a percentage of 28.0% (Uitdehaag et al., 2015). Moreover, the prevalence in the current study was also higher than that in many other studies (using other measurements), ranging from 4.0% to 66.7% (Huang et al., 2008; Lam et al., 2014; Liao et al., 2011; Liu, 2008; Rachakonda et al., 2015; Templeton & Coates, 2003; Uchida et al., 2011; Voogt et al., 2005). Different from Western countries where the concept of ‘open communication’ is more valued (Tsuchiya & Horn, 2009, p. 150), in China, healthcare professionals and families are usually reluctant to provide patients with detailed information considering the disadvantages of such detailed information provision, for example, increasing psychological burden on patients (Tsuchiya & Horn, 2009). This point was verified in the qualitative interviews of the current study, where the informal caregivers tended to hold back unpleasant information from the patients. A study conducted in Taiwan (Liao et al., 2011) also reported a percentage of information needs similar to that in the current study. This might be related to the Chinese culture, in which people prefer to share ‘happiness’ rather than ‘worries’ (报喜不报忧) (Lyu, 2016) and have a ‘less open and more indirect’ (Tsuchiya & Horn, 2009, p. 149) communication style. Given that only one item in the PNPC-sv was used to measure

the information needs of patients, details of the patients' information needs, such as the types of information, could not be drawn from the quantitative survey.

As for the patients, the information needs was also quantified as one of the top priorities for the informal caregivers. According to a previous systematic review (Wang et al., 2018b), the most commonly reported information needs of informal caregivers of advanced cancer patients were care-related information and illness and treatment information. In the current study, apart from information on treatment, information on financial support was also highly reported in this sample. Patients with cancer and their informal caregivers usually cannot maintain their employment following the diagnosis (Ahn et al., 2009; Park et al., 2008), which can significantly decrease their family income. In this study, a majority of the informal caregivers (66.1%) were unemployed. High expenditures and less income together attributed to a heavy financial burden on the whole family (Yun et al., 2005), which should be one of the reasons for the informal caregivers' high need for information on financial support in the current sample. The quantitative findings were further enriched and supplemented by the findings from the following semi-structured interviews. According to the qualitative findings, the information needs of the informal caregivers were broadly similar to those of the patients, which mainly included information on disease and treatment, daily life care (particularly related to diet therapy), psychological and physical symptom management, and the information on financial support. More details regarding the information needs of patients and informal caregivers will be discussed later in Section 9.5.

#### **Needs for healthcare staff: Availability of and interactions with healthcare professionals**

In addition to information needs, the need for the availability of and interactions with healthcare professionals was another important care need identified for the informal caregivers of advanced cancer patients in the current study. This study finding was consistent with several previous studies on informal caregivers of cancer patients (Lund, Ross, Petersen, & Groenvold, 2015; Mazanec, Reichlin, Gittleman, & Daly, 2018; Shin et al., 2011). Informal caregivers are often extensively



involved in patients' diseases, especially for patients with life-threatening diseases like cancer (Lund et al., 2015). Informal caregivers usually have to undertake many unfamiliar and uncompensated caregiving tasks, including physical care (Haley, 2003; Kotkamp-Mothes, Slawinsky, Hindermann, & Strauss, 2005; Le et al., 2003; Resendes & McCorkle, 2006), emotional support (Ellis, 2012; Given, Given, & Kozachik, 2001; Molassiotis, Wilson, Blair, Howe, & Cavet, 2011b), and medical treatment monitoring (Given et al., 2001b; Haley, 2003; Le et al., 2003; Van Ryn et al., 2011). Cancer patients at an advanced stage often experience more symptom burden due to the progression of the disease, which can increase the caregiving tasks of informal caregivers (Hwang et al., 2003). Increasing caregiving tasks may subsequently increase informal caregivers' need for substantial interaction with significant others to improve their caregiving competencies and to deal with uncertainties and problems in relation to their patients during the caregiving process (Brown & Stetz, 1999; Lund et al., 2015).

Healthcare professionals are often the preferred information source for family members of cancer patients (Rees & Bath, 2000). Taken together, this can explain why the availability of and interactions with healthcare staff was rated as the greatest needs domain in this sample. "Nurses to promptly attend to patient discomfort and pain" was the item with the highest percentage (95.0%), which was inconsistent with another study (Shin et al., 2013) using the same instrument (CNAT-C) to measure the needs of informal caregivers of cancer patients ("seeing a doctor quickly and easily when in need" [85.9%] was the greatest rated item in Shin et al., 2013). One possible explanation for this inconsistency may be that the current study focused on patients at an advanced stage while Shin et al. (2003) included patients at any cancer stage, and pain is more of a major problem and concern for patients with advanced cancer (Liu & Guo, 2017).

### **Health and psychological support**

Different from patients who wanted to receive more professional attention to their physical and psychological needs, health and psychosocial support was reported as a relatively less important

need for informal caregivers during the caregiving process. These study findings were supported by several previous studies (Lin & Tsao, 2004; Park et al., 2010; Shin et al., 2011). Many studies have demonstrated that informal caregivers are usually patient-centred and are more concerned about the patient's conditions rather than their own needs (Friðriksdóttir et al., 2011; Sklenarova et al., 2015). In this study, the focus was on informal caregivers who were taking care of cancer patients at an advanced stage. Patients' disease conditions are usually unstable at an advanced stage, which may worsen the situation because the unstable condition of patients increases the need for caregivers to watch for acute symptoms and causes them to further ignore their own personal needs (Lin & Tsao, 2004).

### **Spiritual needs**

In addition to the need for health and psychosocial support, spiritual support was another relatively less important need for the informal caregivers, and similar findings were identified for the patients. This result was inconsistent with some international studies, which showed that spiritual needs were one of the most prominent palliative care needs (Effendy et al., 2015b; Osse et al., 2005). Spirituality is usually influenced by culture (Hsiao, Gau, Ingleton, Ryan & Shih, 2011), and religion is one form of spiritual expression (Emblen, 1992; Sinclair, Pereira, & Raffin, 2006). It has been found that cancer patients who have a religious attitude reported more and higher spiritual needs (Höcker, Krüll, Koch, & Mehnert, 2014), as religious beliefs and religious activities have “substantial” correlations with life satisfaction and happiness (Sinclair et al., 2006). In the current study, 85.2% and 93.9% of the patients and informal caregivers, respectively, had no religious beliefs, which might partly explain why the patients and informal caregivers reported spiritual needs as a relatively less important need. Moreover, according to Maslow's hierarchy of needs theory (McLeod, 2007), individuals report spiritual needs only when their physical needs are satisfied. The patients' and caregivers' high levels of other unmet needs might be another possible reason for their low spiritual needs.

## **Sexual needs**

The problem of sexual dysfunction was reported as an important physical problem in Effendy et al. (2015a) and Osse et al. (2005), of which 75.0% and 31.0% of the patients, respectively, needed more professional attention to their sexual dysfunction. These findings were different from the current study finding as only 5.1% of the patients wanted to receive more professional attention for this issue. This suggests that only a few patients in the present sample perceived sexual concerns and this result was in line with one previous study conducted in Hong Kong (Lam et al., 2014). Issues about sexuality are somewhat sensitive to Chinese as they are related to “personal privacy”. Considering the conservative culture in China, particularly for people living in rural areas (more than half of the patients in the current study were from rural areas), it was not surprising that ‘sexual dysfunction’ was not reported as a priority need for Chinese patients. Moreover, a previous study (Lam et al., 2014) suggested that the sexual needs of cancer patients were related to the cancer trajectory. In the present study, all the patients were at an advanced stage and a majority of them were still receiving active anticancer treatments at that time. Another possible explanation therefore might be that they were preoccupied with needs in relation to their cancer treatment, and sexual needs were a lower priority.

Although spiritual needs, sexual needs, and health and psychosocial support were identified as relatively less important needs in either patients or informal caregivers, the items with relatively low endorsement rates should not be interpreted as insignificant ones because an individual caregiver’s well-being might be significantly influenced by an uncommon problem (Osse et al., 2004).

### **9.4.2 Influencing factors in the palliative care needs of patients and the needs of their informal caregivers**

Patients with advanced cancer and their informal caregivers are a “whole unit” in fighting the illness (Lambert et al., 2012). It was hypothesized that the patients’ palliative care needs and the

informal caregivers' needs would be influenced not only by factors related to themselves but also by factors related to their partners. According to the conceptual framework of the current study, the potential factors were sorted into five categories, which were sociodemographic factors, clinical factors, physiological factors, psychological factors, and the factor of social support of patients and their informal caregivers. The above hypotheses were generally supported by the study findings, which showed the relevance of the conceptual framework in helping to understand the patients' and informal caregivers' needs.

Sociodemographic (e.g., marital status, length of caregiving time), clinical (e.g., cancer treatments), physiological (symptom distress), psychological (anxiety and depression, coping, and quality of life), and social factors (e.g., social support) in combination all played a role in either the patients' or the informal caregivers' needs, although different factors were associated with different domains of needs. For patients, the patients' symptom distress was identified as a negative significant predictor in almost all the domains of palliative care needs, excluding information needs; almost all dimensions of palliative care needs were influenced by the coping strategies of either the patients or their caregivers; and the emotional status (anxiety and/or depression) of the patients and their caregivers was a significant predictive variable in many need domains, including autonomy, social, psychological, spiritual, and information needs. The caregivers' quality of life was another significant influencing factor in the majority of the patients' palliative care needs. For the informal caregivers, their own quality of life was significantly associated with all the domains of care needs, and the caregivers' own emotional status (anxiety and/or depression) was another significant predictive variable in many need domains, including health and psychological problems, family/social support, information needs, and the total needs scores. Moreover, the majority of care needs domains were significantly influenced by the coping strategies of both the informal caregivers themselves and their patients. Taken together, emotional status (anxiety and/or depression) and coping strategies of either the patients or the informal caregivers, as well as the informal caregivers' quality of life, were the three most common and

influential independent variables in the prediction of the needs of both patients and their informal caregivers. The patients' symptom distress was another unique negative factor in their palliative care needs. Moreover, some clinical and sociodemographic characteristics of either the informal caregivers or the patients were also identified as influencing factors in some specific needs domains. These results reflect the answers to research objectives (2), (4), and (5) of this doctoral research project. The influential independent variables mentioned above will be discussed in the following sections one by one.

### **Anxiety and depression**

The current study findings confirmed the hypothesis that the patients' and informal caregivers' needs were influenced by the emotional status (anxiety and/or depression) of either the patients or their informal caregivers.

Anxiety and depression in both patients and their informal caregivers were measured by the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). High anxiety and depression levels were identified in this sample, with 50.8% and 47.8% of the patients having clinical or borderline cases. Emotional distress was higher than one previous study (Liao et al., 2011), in which only patients with lung cancer were included. In the current study, a mixed sample was recruited, and the heterogeneity of cancer types might be the reason for the divergent findings in the two studies.

The patients' anxiety was a significant predictive factor in various domains of their own palliative care needs, including psychological, information, social, autonomy, spiritual needs, and the overall needs score. These findings are similar to some previous studies (Hasegawa et al., 2016; Liao et al., 2011; Sarkar et al., 2015; Schmid-Büchi, Halfens, Müller, Dassen, & van den Borne, 2013), which showed that anxiety was a significant contributor to cancer patients' unmet needs, particularly psychological needs and information needs. Sarkar et al. (2015, p. 571) suggested that higher emotional distress like anxiety might lead to "stronger needs for security, stability, and

protection to regain a more predictable life". All these aspects are related to a higher need for psychological support (Sarkar et al., 2015). Voogt et al. (2005) have suggested that patients with anxiety are more likely to express the need for additional information; in turn, a lack of information can lead to emotional distress for patients (Jefford & Tattersall, 2002). Feelings of having insufficient information may be a result of anxiety, as patients with anxiety are more likely to forget information (Kessels, 2003). These study findings suggest that the information needs of patients cannot be addressed optimally only by increasing the amount of information. The underlying reasons for unmet information needs such as patients' emotional status should be considered when giving information (Voogt et al., 2005).

Other studies (Hasegawa et al., 2016; Liao et al., 2011; Sarkar et al., 2015) have shown that patients' anxiety significantly predicted their care needs in physical and daily living, arguing that patients who received more active cancer treatments and had higher impairments in relation to physical problems and activities of daily living were usually patients at high risk of cancer progression (Sarkar et al., 2015). The progression of an illness can increase patients' worries about their disease and lead to a stronger need to address their physical problems and higher needs in coping with everyday life (Sarkar et al., 2015). Nevertheless, these study findings were not confirmed in the present study because all the participants in this study were patients at an advanced stage, and more than 80% of them were receiving active cancer treatments at that time.

The patients' needs regarding daily living (5.7% to 11.5%) were extremely low across all the needs domains in this sample, and it was also significantly lower than in many other studies (Johnsen et al., 2013; Khan et al., 2012; Waller et al., 2012b). In China, it is common that informal caregivers accompany their patients day and night to provide daily living support even during the period at the hospital, which can significantly minimize patients' concerns about daily life issues. This might be the reason why the patients' anxiety did not predict their care needs in daily living in this sample. Although the patients' anxiety was not proved as a predictor of physical needs and ADL

needs in the stepwise regression analysis, significant associations were identified in the bivariate analysis. However, it should be noted that statistically significant correlations between dependent and independent variables may not indicate a certain clinical relevance (Chu, 2009). Therefore, more studies are needed in future to further explore the prediction of anxiety in the physical needs and daily living of patients.

Informal caregivers are usually considered as fellow sufferers alongside patients (Proot et al., 2004), and they are at high risk of suffering from concurrent emotional distress due to the extensive demands associated with delivering care to the patient with advanced cancer (Rumpold et al., 2016). Anxiety and depression are commonly reported emotional distress, and the incidence for caregivers is sometimes even higher than that of the patients (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Grunfeld et al., 2004; Janda et al., 2008). In this study's sample, 46.4% and 42.2% of the informal caregivers were identified as having clinical or borderline cases of anxiety (HADS-A  $\geq$  8) and depression (HADS-D  $\geq$  8), respectively, which was similar to another study on caregivers of advanced cancer patients using the same HADS cut-off level (Rumpold et al., 2016).

In the current study, the incidence of anxiety and depression in the informal caregivers was not higher but similar to that of the patients. Caregivers' problems are closely linked with patients' well-being and health outcomes (Hodgkinson et al., 2007; Milbury et al., 2013). However, whether patients' care needs are associated with caregivers' health outcomes like emotional status is still unclear as limited evidence has been drawn from current studies (Wang et al., 2018b). To the best of the doctoral researcher's knowledge, only one prior study has reported that informal caregivers' unsolved emotional distress increased their patients' unmet care needs (Liu, 2008), and the findings were in accordance with those in this study. Specifically, the informal caregivers with anxiety and/or depression in this study increased the patients' needs in the ADL, autonomy, and spiritual aspects. One possible interpretation may be that emotional distress, particularly

depression in informal caregivers, reduced their interest in providing care and support to their patients.

In addition to the patients' palliative care needs, it was found that the informal caregivers' emotional distress also increased their own care needs. More specifically, the informal caregivers with anxiety and/or depression were more likely to report higher needs in dealing with their own health and psychological problems, family/social support, information, practical support, and the total needs score. The current study findings were consistent with some previous studies, which suggested that informal caregivers' emotional distress was significantly associated with increased caregiver unmet needs, including the domains of emotional and psychological needs, healthcare professionals/healthcare services, information, and family support (Chen et al., 2016; Friðriksdóttir et al., 2011; Sklenarova et al., 2015). According to symptom management theories (Dodd et al., 2001; Henly, Kallas, Klatt, & Swenson, 2003), individuals may have higher care needs when they have anxiety because emotional status is positively associated with the need for help seeking.

It has been suggested that anxiety can increase an individual's need for information seeking (Voogt et al., 2005), which might be the reason why the informal caregivers with anxiety in this study reported stronger information needs. In the current study, nearly two-thirds of the caregivers were spousal caregivers, and nearly 70% of them reported that they were the only person who was taking care of the patient. The heavy caregiving burden eventually may have not only deteriorated their emotional well-being but also negatively affected their ability to provide ongoing care to their patients (Tan, Molassiotis, Lloyd-Williams, & Yorke, 2018), which might be one interpretation of the prediction of emotional distress resulting in higher needs for family/social support and practical support. With the progression of the disease, the caregivers had increasing fears of the loss of their loved one, which may partly interpret the prediction of caregivers'



emotional distress leading to higher needs for the availability of and interactions with healthcare professionals.

Taken together, these study findings implied that the emotional distress of the informal caregivers was just as important as that of the patients, and it may require individual support for informal caregivers in some cases.

### **Use of coping strategies**

The Brief-COPE (Carver, 1997) was employed to measure the use of coping strategies of both the patients and their informal caregivers in the current study. Problem-focused coping strategies, such as active coping and planning, were the most frequently reported coping strategies for both the patients and their informal caregivers, followed by adaptive coping such as acceptance. These results were partly in line with some previous studies on cancer patient-family caregiver dyads (Dodd, Dibble, & Thomas, 1992; Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004), which showed that the coping strategies of cancer patients and their family caregivers were similar, and active and adaptive coping, particularly the strategy of acceptance, were the most commonly used strategies. Other studies (Nipp et al., 2016; Thomsen, Rydahl-Hansen, & Wagner, 2010) concluded that patients with advanced cancer used more emotion-focused coping than problem-focused coping as patients with advanced cancer experienced physical deterioration so that they do not have physical resources to cope with the situation in a problem-focused way (Thomsen et al., 2010). In the current study, although all the patients were diagnosed at an advanced stage, their clinical condition still allowed the majority of them to cope with some daily life situations.

A major finding of the present study was that, as hypothesized, the patients' palliative care needs were influenced by certain coping strategies of both the patients and their informal caregivers. A greater use of problem-focused coping by patients predicted lower ADL and social needs. Problem-focused coping refers to active-based coping strategies (i.e., active coping, planning, and use of instrumental support) (Zabalegui, Cabrera, Navarro, & Cebria, 2013), in which the patient

deals with the problem causing the distress actively by seeking advice and help from others or making a plan of action. The active responses of patients to a stressful situation can enable them to control and engage with the stressor/problem (Chu, 2009). Moreover, the present study identified that the use of adaptive coping by patients was an effective way to decrease some specific care needs. For example, the patients who used more adaptive coping such as acceptance had lower spiritual needs. As suggested by Kershaw et al. (2004, p. 152), “acceptance does not imply passivity but rather an active attempt to learn to live with the illness and the reality of one’s situation”. Therefore, patients who use more acceptance strategies may be more likely to accept their illness and the reality of their situation. In this study, whether the patients accepted their disease was measured by one item in the PNPC-sv (“difficulties to accept the disease”) to reflect patients’ spiritual needs, with less than half of the patients needing more professional attention for this aspect.

Coping with advanced cancer is also a major challenge for informal caregivers (Northouse, Dorris, & Charron-Moore, 1995). In the present study, problem-focused coping was identified as the most commonly used coping strategy in the informal caregivers, and it was a predictive factor in almost all domains of the patients’ palliative care needs. Compared to cancer patients at an early stage, patients with advanced cancer usually suffer more severe symptoms so they have a higher need for active caregiving (Kershaw et al., 2004). Informal caregivers, especially partners, are regarded as patients’ primary source of support across the illness trajectory (Ell, Nishimoto, Mantell, & Hamovitch, 1988). The amount of care needs for patients to a great extent depends on caregivers’ caregiving, and patients can usually benefit more from caregivers who use more active coping strategies (Kershaw et al., 2004), as those caregivers are more likely to seek external help and information to address troubling problems (Mukwato, Mweemba, Makukula, & Makoleka, 2010). Although studies exploring the relationship between care needs and coping strategies in advanced cancer patient-caregiver dyads are limited, several studies have shown that the use of active coping by either patients or their informal caregivers contributes to better health outcomes and higher

quality of life for patients (Kershaw et al., 2004; Nipp et al., 2016). Patients with a higher quality of life usually reported fewer unmet needs (Liu, 2008). The study findings therefore confirmed the hypothesis that the patients' unmet palliative care needs would be closely associated with the use of active coping strategies by their informal caregivers.

Another major finding from this study was that the informal caregivers' care needs were significantly influenced by certain coping strategies of both themselves and the patients. A greater use of problem-focused coping strategies by the informal caregivers was a predictive factor in lower needs in dealing with health and psychological problems. Problem-focused coping strategies mainly refer to active-based coping, such as planning and the use of instrumental support, which is regarded as an effective coping strategy (Houts, Nezu, Nezu, & Bucher, 1996). Several studies (McMillan, et al., 2006; Papastavrou, Charalambous, & Tsangari, 2012) have claimed that informal caregivers report less caregiving burden and a higher quality of life when they use more problem-solving coping strategies. Relatively less caregiving burden can help informal caregivers live with greater physical and psychological well-being (Blum & Sherman, 2010), which might be the reason why the informal caregivers who used more problem-focused coping strategies in this study reported less need for help in addressing their health and psychological problems.

For some other need domains, including healthcare staff, information, and hospital facilities and services, the greater use of problem-focused coping strategies predicted a higher need for the availability of and interactions with healthcare staff and a higher need for information and hospital facilities and services. According to the stress and coping theory (Lazarus & Folkman 1984), the goal of problem-focused coping strategies is to find solutions to resolve the problems causing stress. Some strategies, including learning new skills and seeking external help, are usually used to solve troubling problems (Mukwato et al., 2010). In this study, the informal caregivers were mainly family members of cancer patients at an advanced stage, and they were stressed (Mukwato et al., 2010) and extensively involved in the patients' disease management (Lund et al., 2015). To

improve their caregiving competencies and to deal with uncertainties and problems during the caregiving process (Brown & Stetz, 1999; Lund et al., 2015), caregivers usually seek external help and information from healthcare professionals, such as practical care skills, information on the cause and management of patient symptoms, and available services in times of need (Mukwato et al., 2010). Therefore, it is reasonable that a greater use of problem-focused coping strategies can increase the need for the availability of and interactions with healthcare staff, information, and hospital facilities and services.

In addition to the informal caregivers' own coping strategies, the patients' coping strategies were also a predictive factor in caregivers' care needs. In this study, the informal caregivers reported less needs in several domains, namely, health and psychological problems, family/social support, spiritual support, and practical support, when their patients used more problem-focused coping strategies. It has been suggested that patients who use problem-focused coping strategies are more active in terms of help seeking to deal with the problems they encounter (Lazarus & Folkman, 1984). Information seeking has been documented as a key active coping strategy of cancer patients in managing their illness-related stressors, such as the shock of the cancer diagnosis, side effects management, and uncertainties about treatment and prognosis (Lambert, Loiselle, & Macdonald, 2009). Such an active-based coping strategy may enable patients to solve their own problems timely, and then live with fewer unmet needs, which may be the reason why informal caregivers have less care needs when their patients use more problem-focused coping strategies. Sklenarova et al. (2015) have suggested that patients' unmet needs was a negative predictor of caregivers' needs, including healthcare services and information needs, psychological needs, and social needs. This view (Sklenarova et al., 2015) was also supported by the findings of the current study, which showed that there were positive correlations between the needs of the patients and those of their informal caregivers.

Based on these study findings, researchers and clinicians should note that the coping strategies of both patients and their informal caregivers are very influential in patients' and caregivers' care needs. Family-based programmes that include both patients and their informal caregivers are needed to improve their coping and problem-solving skills (McMillan et al., 2006), which may be a more effective way to decrease patients' as well as caregivers' unmet care needs.

### **Caregivers' quality of life**

Cancer, as a chronic disease, affects not only the quality of life of patients but also that of significant others, particularly family caregivers, across all stages of the disease trajectory (Kim, Kashy, Spillers, & Evans, 2010). In this study, the informal caregivers' quality of life was measured by the Caregiver Quality of Life Index-Cancer (CQOLC) (Duan, 2012; Weitzner et al., 1999). The sub-scale of "financial concerns" was the most significant component of their poor quality of life, and the sub-scale of "disruptiveness" was rated the lowest score (higher scores indicate poorer quality of life) in the present study's sample. This result indicated that cancer placed a heavy economic burden on informal caregivers (more than 95% of the informal caregivers in this study were family members of the patients), which significantly decreased their quality of life. This result also supported another finding of this study—the domain of financial needs was one of the most commonly reported unmet needs domain for patients in this study.

The value of family union and family ties are usually stronger in Eastern cultures. Once a family member is diagnosed with cancer, other family members feel that they have an obligation to provide limitless care (Coolbrandt et al., 2015; Senden et al., 2015). Most family members feel that they are lacking humanity or are disobeying Chinese filial piety (Li et al., 2011) if they complain that caregiving is disrupting their own lives. These cultural issues might be one possible reason why the informal caregivers in this study reported less 'disruptiveness'. Unlike some previous studies (Effendy et al., 2015b; Yun et al., 2005), the sub-scale of 'positive adaption' was not the highest rated domain in the current study. One possible interpretation may be that the

majority of the patients in this study were inclined to use active-based coping strategies. Active coping can contribute to a positive adaptation to stressors (Feenstra, Banyard, Rines, & Hopkins, 2001) because active coping strategies can affect a person's causal attributions and behaviours of help seeking during the process of adapting to stressful situations (Pizzolato, 2004).

As hypothesized, the current study showed that the informal caregivers' poor quality of life had a negative impact on the care needs of both themselves and their patients. Cancer is a concern of the entire family, not solely the problem of the person with the diagnosis of cancer (Kim & Given, 2008). Informal caregivers, particularly family members, usually take responsibility and commit to providing limitless care (Coolbrandt et al., 2015; Senden et al., 2015). However, they usually have no training experience and very limited resources. Despite these limitations, informal caregivers are still required to provide a wide range of care and assistance, for example, management of physical symptoms, disease and treatment monitoring, emotional support, practical support in daily life, and economic support, in addition to managing their own well-being (Given, 2001b; Yun et al., 2005).

Patients with a serious disease have most of their care needs met by their informal caregivers (Emanuel et al., 1999). The caregiving role, particularly for family members, usually lasts for months and even years. Such a long-term caregiving role and heavy caregiving burden affect informal caregivers' well-being physically, emotionally, socially, and financially (Blum & Sherman, 2010). According to some previous studies, the informal caregivers of cancer patients suffer from not only physical distress (Cho, Dodd, Lee, Padilla, & Slaughter, 2006) but also an increased prevalence of anxiety and depression (Tan et al., 2018). In the current study, 23.2% and 18.1% of the informal caregivers reported clinical anxiety and depression, respectively, which was higher than that of the general population (Löwe et al., 2010). Moreover, informal caregivers usually face the risk of losing their job. In the current study, 66.1% of the informal caregivers were unemployed. High medical costs and low income due to the loss or reduction of work increase

financial burden (Yun et al., 2005). The physical, emotional, and financial burden may have motivated the informal caregivers to seek external help, support, and/or information to address their problems, which may be one possible reason why informal caregivers living with a poorer quality of life were more likely to report more needs.

In addition, if informal caregivers are facing a high level of burden and are struggling to cope with it, they may not be able to provide their patients the required support, and the patients in turn may suffer more and report more unmet care needs (Hodgkinson et al., 2007). In this study, more than half of the caregivers were partner caregivers, and nearly 70% of them reported that they were the only person who was taking care of the patient. The heavy caregiving burden eventually not only negatively affects caregivers' ability to function effectively in their role of providing ongoing support to their patients but also deteriorates their own quality of life (Kim & Given, 2008). Taken together, this can explain why the informal caregivers with a poorer quality of life attributed to the patients having more unmet needs in the current study.

This study finding suggests that the importance of informal caregivers' well-being should be recognized. Healthcare professionals should provide informal caregivers with adequate practical guidance such as skills training to improve caregivers' capacity for caregiving and their confidence in providing effective care (Bee, Barnes, & Luker, 2009).

### **Patients' symptom distress**

In this study, the Edmonton Symptom Assessment Scale (ESAS) (Bruera et al., 1991; Dong et al., 2015) was used to measure the patients' symptom distress in relation to the disease and side effects from anticancer treatments. The current study indicated that the patients' overall symptom distress had a significant negative impact across almost all domains of their palliative care needs, including ADL, physical, autonomy, social, psychological, spiritual, and financial needs. It was not surprising that the patients with more symptom distress experienced higher palliative care needs, and this finding was consistent with that of many previous studies (Au et al., 2013; Hwang et al.,

2004; Lam et al., 2014; Liao et al., 2011). Many studies (Cooley, Short, & Moriarty, 2003; Liao et al., 2011; Tishelman, Petersson, Degner, & Sprangers, 2007) have suggested that fatigue is the symptom that causes the greatest distress in patients, especially lung cancer patients. In the present study, more than one-third of the participants (35.3%) were lung cancer patients at an advanced stage, and fatigue (68.5%) was identified as one of the most prevalent physical symptoms alongside pain (69.9%) and sleep problems (66.2%). Some studies have suggested that fatigue, pain, and sleep problems can significantly reduce patients' performance status in either work or daily life (Byar, Berger, Bakken, & Cetak, 2006; Chu, 2009; Janz et al., 2007).

Patients living with poor physical functioning usually report a higher level of unmet needs in daily life activities (Hwang et al., 2004). Patients at an advanced stage usually experience more and different undesirable physical symptoms than those at an early stage, and the presence of physical distress can increase their uncertainty in terms of disease prognosis (Lam et al., 2014; Waller et al., 2012b), which may be an explanation for their psychological burden and stronger demands to receive support and professional attention to address worries and physical distress (Lam & Fielding, 2003). Moreover, more professional attention and support might subsequently increase their medical expenditures, and, perhaps, it may be one possible reason for the close association between symptom distress and financial needs.

Although several previous studies (Au et al., 2013; Lam et al., 2014; Liao et al., 2011) have demonstrated that patients' symptom distress was a significant predictor of information needs, the current study findings suggest that the patients' symptom distress did not significantly predict their information needs. In this study, considering some symptoms, including pain, fatigue, sleep problems, and shortness of breath, were conceptualized as a component of palliative care needs and measured by the PNPC-sv scale (Osse et al., 2007), these individual items were not used as potential predictors in the multiple regression analysis. Only overall symptom distress was used as a potential predictor in each palliative care need domain of the PNPC-sv, which might be partly



an explanation of why symptom distress was not identified as a predictor of information needs in this study. Although the patients' symptom distress was not identified as a predictive factor in information needs in the multiple stepwise regression analysis, significant associations between individual symptoms and information needs were identified in the correlation analysis. According to the findings from the semi-structured interviews, the patients' information needs were associated with their symptom distress, as some participants said that suffering too much distress from cancer and/or cancer treatments, like the side effects of chemotherapy, lowered their motivation to seek information.

Based on the present findings, symptom distress was indeed an important predictor of the patients' palliative care needs, which highlighted the importance of symptom distress assessment in clinics when delivering palliative care services. Relieving patients' symptom distress and helping them live in relative comfort should be a priority of healthcare services. For information needs, it can only be preliminarily inferred that there was a close association between symptom distress and the information needs of patients with advanced cancer, so more studies are needed in future to verify this inference.

## **Demographic and clinical characteristics**

### Patients' palliative care needs

The current study found that low income was a significant factor in predicting higher palliative care needs of patients. It was not surprising that the patients with a lower income reported higher needs, particularly financial needs, as these results were consistent with those in previous studies (Houts et al., 1988; Liu, 2008). Several previous studies have examined the prediction of marital status regarding patients' needs, but the results were inconsistent across studies (Wang et al., 2018b). The current study showed that married patients had higher unmet ADL needs. One explanation may be that married patients usually undertake more housework, and they therefore tend to have more needs in daily life than singles (Hasegawa et al., 2016). Some previous studies

have indicated that patients' physical needs decrease with age (Houts et al., 1988; Liu, 2008; Teunissen et al., 2006). However, the present study showed an opposite finding. One plausible reason might be that younger patients were more likely to express their demands and to seek help positively to address their problems compared with their older counterparts (Steginga et al., 2008).

For clinical characteristics, the patients' treatments were identified as the most significant predictor of their higher needs. This study finding was inconsistent with previous studies, in which the patients' treatments were not related to their care needs (Liao et al., 2011; Voogt et al., 2005). This study showed that the patients receiving chemotherapy and radiotherapy had higher ADL, autonomy, and social needs compared with those without treatment. Chemotherapy and radiotherapy are regarded as two effective antineoplastic treatment approaches for cancer patients (Hawkins & Grunberg, 2009). However, these treatments have many undesirable side effects (Hawkins & Grunberg, 2009), which can negatively affect patients' physical and mental functions and reduce patients' performance status in daily life (Byar et al., 2006; Chu, 2009; Janz et al., 2007). It has also been found that patients living with physical and psychological distress are more likely to report higher care needs (Wang et al., 2018b).

Cancer stage has been identified as a predictor of some specific domains of palliative care needs in previous studies (Houts et al., 1988; Hwang et al., 2004; Liu, 2008). However, those findings were not confirmed in the current study. One explanation may be the relative homogeneity of the sample. Nearly 70% of the patients were at stage IV, and the variation of this variable was therefore limited. In this study, none of the demographic characteristics of the informal caregivers were identified as a significant predictor of patients' palliative care needs. This result partly demonstrated that the influence of the informal caregivers' demographic characteristics on the patients' palliative care needs was limited, although it should be interpreted prudently, and more relevant studies should be conducted to gain more evidence.

#### Informal caregivers' needs

For the factor of caregivers' caregiving time, mixed findings were identified in studies (Cui et al., 2014; Liu, 2008). In the current study, the caregivers who had taken care of their patients for one to six months reported less needs than those who had taken care of their patients for more than six months for the domains of healthcare staff, information, and hospital facilities and services. There might be two possible reasons for this. First, informal caregivers usually need a period of time for personal adjustment due to the shock of the cancer diagnosis before facing the role of caring (Ezer et al., 2006). Moreover, informal caregivers' burden and strain may increase with the length of time (Gbiri, Olawale, & Isaac, 2015), and the increasing burden and strain may increase caregivers' need for interactions with healthcare professionals, information, and healthcare services. Caregivers' marital status was also identified as an influencing factor, with married caregivers reporting higher needs for their own health and psychological problems compared with singles. One possible explanation may be that married caregivers usually have more social roles and responsibilities, which places a significant burden on their physical and mental health (Blum & Sherman, 2010; Ellis, 2012).

Several studies (Fukui, 2004; Liu, 2008; Osse et al., 2006) have examined the prediction of the caregivers' age for their needs, which found that older caregivers had less financial, social, and information needs. However, age was not identified as a predictive factor in the present study. The different results may partly relate to the method used for categorizing the variable of age. In this study, the caregivers' age was viewed as a continuous variable; however, in previous studies (Fukui, 2004; Liu, 2008), it was viewed as a dichotomous variable using the cut-off point of 60 years old. Some studies have suggested that female caregivers experience more care needs than males do (Sklenarova et al., 2015). However, the current study showed that the caregivers' gender was not a significant predictor. This result partly demonstrated that the influence of gender on their care needs was limited, but more studies should be conducted to gain more evidence.

For clinical characteristics, the patients' treatments, complications, cancer stage, and cancer type were identified as significant predictors in some specific domains of caregivers' needs. For example, the caregivers reported more need for family/social support when the patients were receiving chemotherapy and radiotherapy. Treatment-related side effects can impair patients' physical and psychological health, reduce patients' performance status (Byar et al., 2006; Chu, 2009; Janz et al., 2007), and increase patients' need for active caregiving (Kershaw et al., 2004). Caregivers therefore face an increased caregiving burden, which may be the reason for their increasing need of family/social support in this study. The patients' complications were identified as a predictive factor in the domain of health and psychological problems. One possible reason may be similar to the factor of treatment, as patients' complications can also increase caregivers' caregiving burden. For cancer type, the caregivers of patients with reproductive system cancer were more likely to report less needs. However, this result regarding the relationship between the caregivers' needs and the patients' cancer type should be interpreted as preliminary, because the cancer types were categorized based on which system it belonged to (e.g., gastric cancer and oesophageal cancer were categorized as digestive system cancer). Studies focusing on some specific types of cancer could be designed in future to further explore this relationship.

Overall, the influences of the demographic and clinical characteristics were relatively limited in predicting patients' and caregivers' care needs.

## **9.5 Discussion of the findings from the semi-structured interviews**

Information needs as a common and prominent palliative care need of patients and need of their informal caregivers identified in the quantitative survey have been briefly discussed in Section 9.4.1. More details about information needs that were drawn from the semi-structured interviews will be discussed in the following. These results reflect the answers to research objectives (7) and (8) of the current doctoral research project.

### **9.5.1 Types of unmet information needs**

Several types of unmet information needs were identified through the qualitative interviews for both the patients and the informal caregivers, which mainly included information on the disease and treatment, daily life care (particularly diet therapy), psychological and physical symptom management, and information on financial support. The information needs of patients were broadly similar to those of the informal caregivers. Two previous systematic reviews regarding the information needs of cancer patients (Rutten, Arora, Bakos, Aziz, & Rowland, 2005) and their family members (Adams, Boulton, & Watson, 2009) also concluded that the information needs of cancer patients and their family members were similar. This suggests that both patients and their informal caregivers should be involved in conversations with healthcare professionals, such as joint meetings with patients and their family members (Doyle, Hanks, Cherny, & Calman, 2004). According to the two previous systematic reviews (Adams et al., 2009; Rutten et al., 2005), cancer-specific information and treatment-related information were the two most frequently mentioned information needs of both patients and family members. Consistent with previous study findings, disease and treatment information was also identified as one of the most commonly unmet information need in the current qualitative study for both the patients and their informal caregivers. Given that the majority of the participants in this qualitative study were still receiving active cancer treatment at the time of the interviews, the finding that the patients and informal caregivers frequently sought disease and treatment information was not surprising. As Rutten et al. (2005) suggested, patients at the treatment stage are more interested in exploring their treatment options and learning about the potential treatment effects and side effects associated with their treatment options.

In addition to information on active anticancer treatments, TCM was also emphasized as a type of important treatment-related information by both the patients and the informal caregivers in the current qualitative study. Within the Chinese context, a majority of Chinese cancer patients hold a positive view and belief towards Chinese complementary medicine and other traditional

treatment approaches (Tan, 2017). Given the belief and popularity of TCM in Chinese culture, using TCM to fight illnesses and maintain health and well-being is regarded as a natural part of the cultural practices of Chinese people (Kwok & White, 2014). More than 90% of Chinese have the experience of seeking for TCM in their lifetimes (Jin et al., 2014; Xu & Chen, 2008). Individuals' attitudes and beliefs towards TCM have been shown to directly influence their interest in and decision to learn and use TCM (Balneaves, Truant, Kelly, Verhoef, & Davison, 2007). Currently, TCM is included in the Chinese healthcare system and is accessible in both hospitals and the community (Xu & Chen, 2008), which has enabled TCM to continuously play an important role in the Chinese healthcare system. Taken together, this may explain why the patients and informal caregivers in this study were so eager to learn information on TCM.

Different from some previous studies (Adams et al., 2009; Rutten et al., 2005), information on daily life care, particularly diet therapy, was another important and common unmet information need emphasized by both the patients and the informal caregivers in the current qualitative study. "No other culture is as food-conscious as that of the Chinese" (Lyu, 2016, p. 166). In the Chinese culture, food is believed to be "a human's first necessity (民以食为天)" as it provides necessary nutrition for life and health (Zou, 2016). According to TCM theories, food is not only a diet for nutritional support but also medication for illness. Health is a matter of balance and harmony between Yin and Yang; illness, therefore, is caused by an imbalanced Yin and Yang (Leung & Chan, 2015).

Traditional Chinese believe that different types of food have different effects on "Zang Fu" organs. A proper diet can nourish Zang Fu organs and balance Yin and Yang to maintain an individual's health, prevent and treat disease, and promote the rehabilitation of disease (Zou, 2016). Consistent with the "Yin Yang" theory, all food has its own nature, including "温" (warm), "热" (hot), "寒" (cold), "cool" (凉) (Zou, 2016), of which, warm and hot belong to Yang and cold and cool are parallel to Yin. To treat a disease, the nature of food should therefore be selected appropriately

based on the disease condition (differential diagnosis from the TCM paradigm). For example, a cancer patient who is diagnosed with a “cold body” condition based on the TCM paradigm should select food with a “hot” or “warm” nature to promote the balance between Yin and Yang. Eating the wrong food will worsen the patient’s disease conditions as the patient’s health is already out of balance (Zou, 2016).

Taken together, the belief and popularity of food therapy in the Chinese culture may explain why the patients and informal caregivers in this study were so eager to learn information on diet in terms of how to select and eat the appropriate food to promote the patients’ health. Although all cancer patients, regardless of their ethnic and racial background, need information on their disease (Chelf et al., 2002), this study finding highlighted that patients’ and informal caregivers’ information needs were context-bound, and some culturally sensitive information should be assessed and provided within a certain context, for example, the treatment options of TCM and Chinese food therapy within the Chinese culture.

For information on physical and psychological symptom management, the current study findings demonstrated that both the patients and the informal caregivers desired to optimize patient’s comfort and deal with their own negative emotions by learning more relevant information. The findings to some extent were consistent with some previous studies (Adams et al., 2009; Rutten et al., 2005), which showed that cancer patients and family members demanded symptom management information and emotional support information to relieve patients’ physical distress and maintain their own mental health. However, it should be noted that in the current study, the motivation for the informal caregivers to learn information on psychological adjustment was to cover their own negative emotions in front of their patients rather than to maintain their own mental health. This indicated that Chinese informal caregivers were usually patient-centred, and they were concerned more about their patients’ conditions than their own health (Friðriksdottir et al., 2011; Sklenarova et al., 2015).

Information on financial support, including insurance coverage and reimbursement, was another important type of information that the patients and informal caregivers desired to learn. This study finding was in line with some previous studies (Adams et al., 2009; Rutten et al., 2005). In this study, national insurance was the only insurance for the majority of the families; this insurance, therefore, was essential and provided certain assistance to those families. Many informal caregivers were unemployed and had financial difficulties due to non-reimbursed expenses, which made them feel extremely stressed. The patients and informal caregivers therefore intended to partly decrease their financial burden by learning more information on insurance coverage and reimbursement as it may have enabled them to claim more for reimbursement. They believed it would be helpful for families with cancer patients if the Chinese Government would extend the scope of insurance coverage and increase the portion of reimbursement. Although financial issues emerged as a significant concern for both the patients and the informal caregivers, very few families expressed that they would choose to withdraw treatment and care for their patients due to financial strains. Generally, the informal caregivers had the attitude to treat the disease of their patients at all costs (Li et al., 2001). There is a need for the Chinese Government to evaluate the existing supportive financial programmes for families with cancer patients, and some strategies could be taken to encourage different levels of community support, such as charity agencies and the media, to solicit financial support for families with cancer patients (Lyu, 2016).

### **9.5.2 Reasons for information needs being unmet**

The patients and informal caregivers listed several reasons for their information needs not being met, including healthcare professionals factors, individual factors, and family/social support factors. 'Healthcare professionals were too busy to communicate with them' was cited as the most prominent reason in relation to the healthcare professionals factors. In this study, healthcare professionals were cited as the ideal information source, particularly doctors, by both the patients and the informal caregivers. This study finding was consistent with that in many previous studies



(Rees & Bath, 2000; Rutten et al., 2005; Todd & Hoffman-Goetz, 2011). Although healthcare professionals were the preferred information providers, the patients and informal caregivers discussed the difficulties in having detailed and meaningful communication with them due to time constraints. Having a heavy clinical workload did not allow the health professionals to communicate with the patients and their family members. This finding was supported by previous research (Ahmad et al., 2004; Liu, So, & Quan, 2007), which showed that cancer patients had lower satisfaction with doctors and were less comfortable asking their physician questions due to their time constraints. In this study, some patients and informal caregivers were even reluctant to approach healthcare professionals for information, not wanting to disturb or occupy too much of their time as they were extremely busy. Future studies are needed to understand the underlying reasons why the patients and/or informal caregivers were reluctant to approach healthcare professionals. Regardless, the current finding that healthcare professionals had limited conversation time with patients and informal caregivers emphasizes the importance of taking measures to ensure that conversations are more effective and efficient.

Several individual factors in information needs not being met were reported by the participants, such as knowledge and beliefs and low motivation due to fear. One previous study indicated that patients with a higher education were more likely to seek information from various sources to meet their needs (Eakin & Strycker, 2001). In this study, the majority of the patients and informal caregivers had only primary school education or below, which to some extent restricted their information-seeking capacity. They had to mainly, and at times solely, depend on healthcare professionals to learn information. However, healthcare professionals were usually not available due to time constraints. Thus, this may explain why the participants thought that their unmet information needs were related to their poor literacy. Some patients and informal caregivers held the belief that daily life and diet issues were unimportant issues, and they did not want to bother healthcare professionals with these issues even though they desired to learn information, particularly on food therapy. Understanding the reasons why they felt that these issues did not

deserve healthcare professionals' limited time is important for a future study. This study did not provide insights into the reason for this perception, but low self-worth and the high instrumental value placed on authority within the Chinese culture may be considered (Todd & Hoffman-Goetz, 2011).

'Being afraid of facing bad news' was identified as another major reason for the patients' and caregivers' information needs not being met. In this study, the patients and informal caregivers, on the one hand, desired to learn information and welcomed positive or good information, but on the other hand, they were afraid of negative or bad news. This study finding was consistent with that in previous research, which showed that fear was a prominent barrier that prevented cancer patients from seeking information (Davis, Diaz-Mendez, & Garcia, 2009). According to the information-seeking paradigm proposed by Miller (1980) and Lazarus and Folkman (1984), not all individuals deal with health threats by actively seeking information; others prefer distraction and avoid receiving too much information. The self-evaluation theory suggests that some individuals might be inclined to engage in self-protection, which they use to protect themselves by avoiding aversive information (Loiselle, 1996), preferring self-enhancement in information seeking to obtain positive rather than negative information (Sedikides, 1993). This study finding indicated that the cancer patients, even those at an advanced stage, and their informal caregivers were active information seekers when they encountered health threats. Meanwhile, it should be recognized that there are differences in individuals' desire for cancer information, as not everyone can benefit from the same amount of information (Lambert et al., 2009). For some patients, too much information may increase their psychological distress (Schwartz, Lerman, Miller, Daly, & Masny, 1995), so blunting information-seeking behaviour might be an effective strategy to decrease their worry (Miller, 1995).

Insufficient family/social support was reported as another reason for the patients' and informal caregivers' unmet information needs. In this study, all the patients were advanced cancer patients.

Unpleasant physical distress and chemotherapy-induced side effects rendered them physically unable to seek information; therefore, they mainly depended on their family members to obtain information. This study finding was in line with that in some previous studies (Kwok & White, 2014; Konecny, 2010), which showed that family is regarded as a central source of social support for Chinese cancer patients. However, family support was sometimes limited and difficult to obtain because available family members tended to be a small group due to the one-child policy. In this case, the spouse of the patient was required to take care of the patient as well as carry out all the domestic tasks, particularly female caregivers. The imbalance between families' capabilities and demands imposed heavier burdens on them (Lyu, 2016), which prevented them from having the time and energy to seek information for either the patients or for themselves. This study finding indicates that healthcare professionals should be concerned about the insufficient family support experienced by some patients and caregivers and proactively assess and provide them with appropriate types and amounts of information based on their preferences.

### **9.5.3 Preferences for provision of information**

In this study, healthcare professionals, particularly doctors, were reported as the ideal information source by both the patients and the informal caregivers. Doctors as an important and reliable source for health information has been observed in many studies on Chinese cancer patients (Lim, Butow, Mills, Miller, & Goldstein, 2017; Todd & Hoffman-Goetz, 2011). This study finding emphasizes the crucial role of healthcare professionals, particularly doctors, in meeting the information needs of Chinese patients and informal caregivers (Rutten et al., 2005). Such a strong reliance on healthcare professionals may be a reflection of strong interpersonally oriented cultural values (Todd & Hoffman-Goetz, 2011). Many studies have shown that Chinese patients and many other Asians prefer interpersonal information sources (Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003; Pang, Jordan-Marsh, Silverstein, & Cody, 2003). They prefer to receive information from healthcare professionals in person rather than from any other information

sources such as the internet (Lim et al., 2017). Despite the rapid growth of online health information, healthcare professionals remain the most trusted information source (Hesse et al., 2005). In this study, the participants reported that they preferred to obtain information through verbal conversations with professionals, as well as written information. It may thus be advisable to consider intervention programmes with involvement of healthcare professionals via the format of face-to-face verbal conversation in combination with written information in clinical practice.

Due to the proliferation of the use of digital technology, the internet has become a popular information source for cancer patients, particularly in countries outside China (Ankem, 2007; Balmer, 2005; Hesse et al., 2005;). Web-based information is usually the most up-to-date information (Lambert et al., 2009), and obtaining it is much more convenient for patients who live in rural areas without easy access to healthcare resources (Lim et al., 2017). Although the patients and informal caregivers in the current study mainly relied on interpersonal information sources, some also mentioned the internet and had experience in seeking for information online. However, they felt overwhelmed due to the significant amount of information online and were unsure in terms of how to discern which information was reliable and accurate. This view towards online information was also reported in another study on Chinese cancer patients (Lim et al., 2017). As suggested by Deng, Liu, and Hinz (2015c), whether the patients followed the received information depended on the trust the patients had in the information sources. Therefore, how to provide reliable, high-quality online information and how to improve cancer patients and informal caregivers' trust in accessing online health information should be considered when designing online information to encourage users to use health information received online in future.

Another issue that healthcare professionals should recognize is the value of having separate conversations with patients and their informal caregivers, as some informal caregivers in this study mentioned that they preferred to hold back unpleasant information from their patients with the purpose of protectiveness. The issue of caregiver protectiveness of patients in terms of information

provision was also documented in some overseas studies (Clayton, Butow, & Tattersall, 2005; Friedrichsen, Strang, & Carlsson, 2001). According to some studies, it was not uncommon that patients wanted to be told the truth, with the percentage up to 83% (Noone, Crowe, Pillay, & O’Keeffe, 2000); some advanced cancer patients emphasized that they hoped to be respected, and any separate discussions between healthcare professionals and their family members should be conducted based on the patients’ permission first (Clayton et al., 2005). Holding back information from patients and discussing their disease without permission and present of patients was therefore considered unethical because the patients’ autonomy was not respected (Clayton et al., 2005). Indeed, this has been identified as an ethical dilemma for healthcare professionals in terms of how to respond to the family members’ request to hold back information from the patients (Anderlik, Pentz, & Hess, 2000; Taboada & Bruera, 2001). As has been suggested (Clayton et al., 2005), healthcare professionals should recognize that they have an obligation to answer patients’ questions honestly, but sometimes they should be flexible regarding how much they try to facilitate an open discussion with the patients. Given that the views of patients and family members regarding truth telling and patient autonomy are culturally sensitive (Clayton et al., 2005; Rutten et al., 2005), more studies are needed in future to explore the perceptions of patients, caregivers, and healthcare professionals regarding the issue of truth telling within the Chinese context.

In addition, the patients’ and informal caregivers’ preferences for the types of information were not static but changed across the cancer trajectory in the current study. Around the time of diagnosis, the patients and informal caregivers had a strong desire to learn information on disease conditions and treatment-related information. After completing active treatments, they demonstrated a continued need for information about the continuing treatment options and daily life care at home to delay the progression of the disease. With the progression of the disease, the patients’ need for active treatment regimens increased again when the disease worsened. This finding was consistent with that in some previous studies (Lim et al., 2017; Rees & Bath, 2000), which indicates that because the information needs of patients and informal caregivers fluctuates

across the cancer journey, different types of information should be provided at the appropriate time.

Taken together, the preferences of patients and informal caregivers may help healthcare professionals have a better understanding in terms of *from whom* and *in what format* they prefer to receive the information, and *when* during the cancer course. Knowing this information will promote effective conversations among healthcare professionals, patients, and informal caregivers, which are vital in ensuring the delivery of high-quality cancer care (Rutten et al., 2005).

#### **9.5.4 The meaning and role of information**

Information seeking has been demonstrated to play a critical role in individuals' efforts to cope with cancer (Arora et al., 2002). Knowing the diagnosis of cancer is traumatic for both the patients and their family members (Lim et al., 2017). Patients and their family members often feel stressed about making medical decisions due to the severity and life-limiting nature of cancer (Garcia, Hahn, & Jacobs, 2010). They therefore often have a strong desire to learn information across the cancer continuum, from the diagnosis stage to the palliative care phase (Lim et al., 2017). Several studies have demonstrated that appropriate information provision can increase patients' involvement in decision-making and result in greater satisfaction with treatment options (Cawley, Kostic, & Cappello, 1990; Luker et al., 1995; Matthews, Sellergren, Manfredi, & Williams, 2002). Conversely, inadequate information can potentially lead to ill-considered decisions for treatment regimens (Lerman et al., 1993). In accordance with previous studies, the patients and informal caregivers in the current study also indicated that having adequate and appropriate information on treatment regimens could facilitate informed decision-making regarding better treatment selection.

In addition to its benefits in decision-making, the patients and informal caregivers in the current study perceived that appropriate and adequate information could increase their hope for survival and reduce their psychological burden. This study finding was consistent with that in some previous studies, which showed that providing appropriate information that was congruent with

the patients' and family members' needs could reduce their mood disturbance, such as anxiety and depression (Husson, Mols, & Van de Poll-Franse, 2011; Meredith et al., 1996). According to Husson et al. (2011, p. 769), appropriate information provision refers to three aspects, including "satisfaction with the received information", "fulfilled information needs", and "high quality and clear information". Inadequate information and low-quality information can both result in mental distress as well as poorer health-related quality of life (Husson et al., 2011).

Patients and informal caregivers differ in the type and amount of information they require, and the satisfaction with received information is more related to the extent of the information needs met than to having received all available information (Husson et al., 2013). Some types of information or an inappropriate amount of information can indeed increase individuals' mental distress and their feeling of hopelessness (Leydon et al., 2000), as too much information may render patients unable to cope with their health threats due to high levels of fear and anxiety (Llewellyn, McGurk, & Weinman, 2005). In the current study, the view of 'too much information may increase psychological burden' was also cited by some patients and informal caregivers. Thus, how to develop and provide tailored and appropriate information provision regarding information type and amount to patients and informal caregivers should be considered.

Additionally, the patients and informal caregivers in the current study perceived that receiving adequate and appropriate information could be a way of improving the patients' capacity for self-management and a way of increasing a sense of control and certainty for family members taking care of them. The current study findings were in line with several previous studies, which suggested that patients who did not obtain adequate information that they desired had less confidence regarding their ability to manage health-related issue (Arora et al., 2002). Patients who are adequately informed about their disease are also better able to maintain a sense of control over the cancer (Arora et al., 2002; Lerman et al., 1993), as well as to deal with the uncertainty of the disease (Molleman et al., 1984). Information provision with appropriate types and amounts of

information can contribute to improved health competence and better symptom management (Arora et al., 2002; Griggs et al., 2007).

Taken together, the appropriate provision of information may be one of the most important contributors to better health outcomes, which can facilitate informed decision-making and result in greater satisfaction with treatment options, reductions in psychological disturbances, enhanced confidence and ability of self-management to cope with the illness, and the ability to anticipate and prepare for caregiving.

## **9.6 Strengths and limitations of the study**

### **9.6.1 Study strengths**

This doctoral research project has several strengths. First, different from many other studies published in the current literature, the design of this research project followed a conceptual framework to investigate the palliative care needs of advanced cancer patients and the needs of their informal caregivers, as well as influencing factors. The conceptual framework was developed based on the Supportive Care Needs Framework for Cancer Care (SCNF), the findings from systematic review II, and the social-ecological theory. The framework enabled a better understanding of the concepts in relation to palliative care needs and offered guidance in choosing the palliative care needs assessments and the selection of outcome variables for the cross-sectional study in a more evidence-based and structured approach.

Another strength of this doctoral research project is its multimethod research design, with the combination of quantitative and qualitative research. Given the research questions and objectives of this doctoral research project, a cross-sectional survey as the driven method was designed and conducted first to quantify the palliative care needs of the patients and the needs of their informal caregivers, as well as the influencing factors. A follow-up qualitative study (semi-structured interviews) was then conducted to further elaborate and explore the perceptions and experiences of the information needs of the patients and their informal caregivers that were identified in the



quantitative survey. Involving both quantitative and qualitative studies in a research project can ensure both the breadth and depth of the project (deMarrais & Lapan, 2003). In the current research project, the findings from the qualitative interviews supplemented and enhanced the quantitative results, which improved the overall ability of the research design to achieve the study's goals—learning the palliative care needs of patients with advanced cancer and the needs of their informal caregivers comprehensively.

For a cross-sectional study, many scales are usually used to measure the outcomes, and the reliability of the study findings is closely associated with the validity and reliability of the scales. Unlike many other studies published in the current literature, to ensure the reliability, validity, and accuracy of the study findings, all the measurements used in this research project were scales with well-established psychometric properties, and the majority of the scales were designed specifically for cancer patients at an advanced stage. For example, given the absence of a Chinese version of the PNPC-sv, it was translated into Chinese and its psychometric properties were examined among Chinese patients before the commencement of the survey. Meanwhile, the internal consistency of all the scales used in this study were examined in this sample, and the Cronbach's alpha coefficient was above 0.80.

Unmet needs assessment on the basis of viewing advanced cancer patients and their informal caregivers as a 'whole unit' is sub-optimal in the current literature. The current research project filled in this research gap and included patients and their informal caregivers in dyads to explore the palliative care needs of patients and the needs of their informal caregivers, as well as the interrelationships between the patients and their informal caregivers. Moreover, compared with many other studies published in the current literature, this doctoral research project involved a large sample size. The sample size was determined using an evidence-based approach via a formula for prevalence studies, which enabled the estimation of the prevalence of the palliative care needs of patients and the needs of their informal caregivers with good precision.

### **9.6.2 Study limitations**

Although this doctoral research project contributed to a better and more comprehensive understanding of the palliative care needs of patients with advanced cancer and the needs of their informal caregivers, it has several limitations. First, a cross-sectional survey was used to quantify the palliative care needs of the patients and the needs of their informal caregivers, as well as the influencing factors. The design of the cross-sectional survey could not determine the temporal order of associations between the dependent (palliative care needs of patients and needs of informal caregivers) and independent variables (potential predictors). Therefore, causality could not be drawn from the current study findings. According to the stepwise regression analysis, only the direction (e.g., positive or negative), strength of a significant relationship between the independent variables and dependent variables, and the variance in the prediction of the dependent variables could be identified. The interrelationships among the various independent variables and the path of the relationships in predicting the dependent variables are still unknown. Path analysis therefore can be considered in future studies to further explore the relationships among the independent and dependent variables. Moreover, although the cross-sectional study design is regarded as the best way to examine prevalence and a very useful method for identifying the associations between risk factors and the outcome of interest (Levin, 2006; Mann, 2003), how advanced cancer patients and/or their informal caregivers' unmet needs changed across the illness trajectory could not be drawn from the current study, so a longitudinal study is therefore required in future.

Although a high subject response rate (89.7%) was achieved in the cross-sectional survey, there were still limitations in relation to the sampling in this current project. First, convenience sampling was used for participant recruitment; therefore, the study sample may not represent the general population of Chinese patients with advanced cancer and their informal caregivers. Moreover, the sample in this study was mainly recruited from two hospitals in southwest China; the generalization of these study findings to patients and informal caregivers in other geographic

regions of China, particularly developed regions, is limited due to differences in economic and education levels. Furthermore, the current study focused on patients with advanced cancer (stage III or IV) only, and a majority of the patients were still receiving active anticancer treatments such as chemotherapy and/or radiotherapy at the time of the survey. The study findings therefore were limited to cancer patients at an advanced stage and to those who were undergoing active medical treatments. In addition, palliative care needs based on type of cancer and type of treatment would have been interesting to explore. However, comparisons of the palliative care needs among patients with different types of cancer were not conducted in this study, as approximately 30% of the included patients were lung cancer patients and the number of participants with many specific cancer types was limited. Although sub-group analyses in relation to the type of treatment were preliminarily performed in the current study, the classifications of treatments were relatively rough (i.e., all types of chemotherapy regardless of the regimens were categorized as ‘chemotherapy treatment’), so more studies should be performed in future to further explore the differences in the needs of patients receiving different chemotherapy regimens.

The quantitative data of this doctoral research project were collected from face-to-face survey interviews. Personal interviews are regarded as one of the best approaches for survey data collection as they can improve the quality of the data (Polit & Beck, 2004). Three people, including the doctoral researcher and two research assistants, were involved in the face-to-face data collection process, and many participants in the current study completed the assessment scales with the assistance of the researcher and/or the research assistants (i.e., by reading the items in the scales one by one to the participants). Hence, bias may have been introduced by the way that the items in the scales were read and the questions that were asked. Therefore, interviewer bias during the data collection process cannot be definitely excluded, although standard training had been provided to the research assistants before the commencement of the data collection, and all participants indicated their own responses on each item of the scales.

Although a multimethod study design was used in this research project, only the information needs of patients and informal caregivers as an unusual quantitative finding was further elaborated and explored using semi-structured interviews. Many other palliative care needs identified in the survey could be further explored in future studies, which may enhance our understanding of the palliative care needs of Chinese patients with advanced cancer and the needs of their informal caregivers. Moreover, semi-structured interviews were used in the follow-up qualitative study, which to some extent may have prevented the interviewees from expanding on their perceptions and experiences regarding their information needs. Furthermore, given that all the recruitment was conducted in hospital settings, the perceptions and experiences of patients in other settings who have unmet information needs were not captured.

In conclusion, although there are several limitations, the primary aim of this doctoral research project was to provide preliminary evidence to researchers and policymakers in terms of developing tailored palliative care interventions and services to better meet the palliative care needs of patients with advanced cancer and the needs of their informal caregivers. By using the multimethod study design, this research project answered all the research questions and provided a better and more comprehensive understanding of the palliative care needs of advanced cancer patients and the needs of their informal caregivers. The study findings also add important information in terms of developing tailored care services and interventions to meet their needs—these needs cannot be addressed optimally by only increasing the amount of external help and resources; how to maintain patients' and caregivers' emotional status and improve coping and problem-solving skills should be included as an important component in the development of care services and interventions.

### **9.7 Implications for future research, practice and policy**

Despite the limitations of this study that were mentioned above, the study results and findings raised several issues that may be beneficial for future research, clinical practice and policy.

### **9.7.1 Implications for future research**

This doctoral research project has several implications for future research. First, although this project adopted a relatively large sample size survey, additional survey studies can be conducted in future with a larger sample size, such as a national survey, by including various types of cancer patients, patients in various sites of settings (e.g., home-based, hospital-based, etc.), and patients in different regions of China. A larger sample cross-sectional survey will allow sub-group analysis and comparative studies among patients with different cancer types, settings, and regions in relation to their palliative care needs.

Second, the palliative care needs of advanced cancer patients and the needs of their informal caregivers were context-bound. The healthcare system, economic level, and environmental factors all could have affected the patients' and informal caregivers' care needs. Given the context-bound feature, their unmet needs should be assessed and interpreted within a given context. The current research project focused on advanced cancer patients and their informal caregivers in southwest China, and the study findings from this project therefore cannot be directly used on other Chinese patients with advanced cancer who are living in other regions of China and Chinese immigrants living overseas. Thus, replicating the survey of this study in other geographical regions can be considered in future. The findings of future studies would inform healthcare professionals whether the findings from the current research project can be generalized to other regions. More studies involving patients in different regions may provide healthcare professionals and healthcare policymakers with more information in terms of developing context-based healthcare services and interventions to meet patients' and informal caregivers' needs. Moreover, the current research project focused on cancer patients at an advanced stage, and a majority of the patients were receiving active anticancer treatments at the time of the survey; thus, the study findings cannot be generalized to cancer patients at an early stage and cancer survivors, as type of treatment and

cancer stage are both influencing factors in palliative care needs. Hence, studies focusing on patients at an early stage of cancer and cancer survivors should be explored in future.

Third, although the direction (e.g., positive or negative), strength of significant relationships between potential predicting variables and dependent variables (palliative care needs), and the variance in the prediction of the dependent variables have been identified in the current research project using stepwise regression analysis, the interrelationships among various independent variables and the path of the relationships in predicting the dependent variables are still unknown. To better examine and understand the interrelationships among the predictors of palliative care needs, path analysis modelling can be considered in future studies. This may add to and enhance the current findings, as the indirect effects of the predictors on other predictor variables in terms of palliative care needs can be examined. Moreover, for some need domains, such as spiritual needs and information needs, the identified factors could only explain a small portion of the palliative care needs. Therefore, qualitative study designs can be used to further explore the potential predictors of or reasons for their needs not being met.

Fourth, the potential influencing factors of palliative care needs for patients and the needs of their informal caregivers were identified in the current research project using a cross-sectional survey, describing the relationships between dependent and independent variables at one time point. Causality therefore could not be drawn from the current study findings. To further explore how advanced cancer patients' and/or their informal caregivers' unmet needs change, and how the predictors influence their care needs across the illness trajectory, a longitudinal study design can be used in future studies. By understanding the changes of patients' and informal caregivers' care needs and its predictors, healthcare professionals can better develop tailored healthcare services and interventions, and then assist patients and informal caregivers gain the maximum benefits from these healthcare services and interventions.

Fifth, according to the principles of healthcare needs assessment, healthcare needs should be assessed from the perspectives of all relevant stakeholders, including patients, informal caregivers, and healthcare professionals (Field & Clark, 2001). In the current research project, only the patients and their informal caregivers were involved. Having a better understanding of healthcare professionals' needs in terms of meeting the identified needs of patients, as well as the gaps between the patients' needs and the currently provided healthcare services from the perspectives of healthcare professionals, could benefit the development of palliative care education and training programmes. In this case, more studies should be conducted in future to explore the healthcare needs or wanted support of healthcare professionals in terms of meeting patients' and caregivers' identified needs during the caregiving process.

Finally, although a multimethod study design was used in this project, the follow-up qualitative semi-structured interviews focused on information needs only. It should be noted that the other domains of palliative care needs of either the patients or the needs of the informal caregivers should not be interpreted as insignificant ones. To further enhance our understanding of the palliative care needs of Chinese patients with advanced cancer and the needs of their informal caregivers, a mixed methods study design can be considered in future studies to explore patients' and informal caregivers' care needs using both quantitative and qualitative approaches, and then establishing a whole picture in relation to patients' and informal caregivers' care needs by mixing the quantitative and qualitative findings. Moreover, the qualitative interviews in the current project only explored the types of unmet information needs, reasons for information need being unmet, preferences for the provision of information, and the meaning and role of information needs, leaving room for future studies to explore other unmet needs in more depth, for example, exploring the information-seeking behaviours or patterns of patients with advanced cancer and their informal caregivers within the Chinese context.

### **9.7.2 Implications for clinical practice and policy**

The current study findings provide a direction and reference for policymakers and healthcare professionals to develop and incorporate effective, tailored and family-centered healthcare services and intervention programmes into practice to address patients' and their informal caregivers' needs. In the current research project, the patients with advanced cancer and their informal caregivers were viewed and recruited as a 'whole unit', and the study findings supported this view. Both the patients and their informal caregivers had a wide range of care needs, and a majority of their need domains were correlated with each other. More importantly, the palliative care needs of the patients and the needs of their informal caregivers were influenced not only by factors related to themselves but also by factors related to their partners. These quantitative findings made clear practice and policy-making implications as follows:

(1) Developing and incorporating dynamic screening of palliative care needs into conventional clinical practice by viewing patients and caregivers as a "whole unit". According to the study findings of this current research project, both the patients with advanced cancer and their informal caregivers had a wide range of care needs and their needs were interrelated. Many palliative care needs were context specific. These results suggest that it is necessary to develop and perform palliative care needs screening programmes in conventional clinical practice by viewing patients and caregivers as a 'whole unit' to support the development of tailored palliative care intervention protocols and the establishment of palliative care services. More attention should be paid to the identified context-specific palliative care needs, such as the significant physical needs of pain management and prominent information needs. For example, pain management should be one of the key components of cancer care; moreover, policy makers can consider to widen the access to opioid analgesics for advanced cancer patients, and healthcare professionals can also take some measures to improve patients' and their families' understanding of the use of opioid analgesics, as many patients, particularly those in rural areas, are reluctant to use opioids due to concerns of addiction and respiratory depression (Li et al., 2011; Su et al., 2010). Meanwhile, the identified relatively less important needs, such as spiritual needs and sexual needs, should not be interpreted



as insignificant ones because an individual's well-being might be significantly influenced by an uncommon problem (Osse et al., 2004).

(2) Developing effective and tailored healthcare services and interventions by considering the influencing factors of patients' and caregivers' needs. For patients, the four most influential factors for various palliative care needs were symptom distress, anxiety and depression, use of specific coping strategies, and caregivers' quality of life. The study findings suggested that the patients' needs cannot be addressed optimally by only increasing the amount of external help, as influential factors should be considered as well when developing healthcare services and intervention programmes. In particular, screening of the presence, frequency, intensity, and distress of both the physical and psychological symptoms of patients can be incorporate into clinical practice as a conventional assessment. Once problematic symptoms are identified, strategies should be implemented to deal with the problems, for example, providing available psychological assessment and counselling and using targeted strategies to reduce physical symptoms such as pain, fatigue, and sleep problems. To maintain the effects of the interventions in relation to physical and psychological symptoms, healthcare professionals can teach patients some self-management skills (Browall et al., 2008; Janz et al., 2007). As the patients who used more specific coping strategies such as problem-focused coping (i.e., active coping, planning, and use of instrumental support) had a lower risk of reporting unmet palliative care needs, assessment of the use of certain coping strategies therefore can be incorporated into conventional clinical practice, which can help healthcare professionals to determine the target group for more specific interventions to address their needs and concerns. Moreover, to address their needs effectively, how to change and improve patients' coping and problem-solving skills should be considered (McMillan et al., 2006), such as coping skills-based psychological interventions (Ganz et al., 2003; Shapiro et al., 2001), to assist them in re-examining their coping strategies and adjusting to the problems they encounter. Given that those aforementioned needs and relevant influencing factors refer to different discipline, policy makers should recognize the importance of multidisciplinary

health care team in palliative care needs management, and some strategies such as multidisciplinary training programmes should be developed to enhance the capacity of the entire healthcare professional for better identifying and addressing patients' and caregivers' unmet needs. The implications and concerns mentioned above are also applicable to informal caregivers, as anxiety and depression, use of specific coping strategies, and caregivers' QoL were also identified as the three significant predictors of informal caregivers' care needs.

(3) Developing and incorporating family-centred healthcare services and interventions into clinical practice. Although the study findings indicated that the informal caregivers suffered from a wide range of unmet care needs, the needs assessment of caregivers is still seldom practiced clinically. Traditionally, informal caregivers are usually regarded as patients' primary source of support and care (Ell et al., 1988), and they are not considered clients by healthcare professionals (Shin et al., 2011). Moreover, the majority of healthcare professionals are reluctant to assess informal caregivers' needs because healthcare services in relation to informal caregivers are not reimbursed in the current healthcare system (Feinberg, 2008; Shin et al., 2011). However, according to the current study findings, the patients' and caregivers' needs were interrelated, and the patients' unmet palliative care needs were significantly influenced by their informal caregivers' outcomes, such as caregivers' quality of life and coping strategies. Therefore, policy makers and healthcare professionals should pay attention to the importance of caregivers. Significant changes in healthcare policy and clinical practice are required to shift the patient-centred healthcare services to family-centred services in palliative care or cancer care system.

Based on the qualitative findings in relation to the information needs of the patients and their informal caregivers, the following implications can be drawn:

(1) Although healthcare professionals were proposed as the ideal information providers, they have very limited time to communicate with patients and caregivers due to heavy clinical workload. Therefore, how to make the conversation effective is a vital issue to be considered, and the study

findings regarding the types, providers, format, and timing of the information can provide references (Rutten et al., 2005). It can help healthcare professionals decide on the most appropriate type of information to offer at a given time using an appropriate format, such as face-to-face conversations in combination with written information. Nevertheless, the amount of some specific information, particularly information on prognosis and treatment, should be flexible as it may have disadvantages and increase psychological burden for some patients and caregivers. Besides, given that some interviewees in this study also showed interest in web-based information, continued evaluation of the sources from which the patients and caregivers seek information is also necessary for tracking potential shifts in information sources and increasing information access (Rutten et al., 2005). Increased information sources and access can address not only the information needs of patients and caregivers but also reduce the workload burden of healthcare professionals.

(2) Given the limited time and the similarity of the information needs of patients and caregivers, viewing patients and caregivers as a 'whole unit' and providing them with information may be an appropriate approach to making the conversation effective among healthcare professionals, patients, and informal caregivers. However, the value of having separate conversations with patients and their informal caregivers should also recognize, as some informal caregivers in this study mentioned that they preferred to hold back unpleasant information, such as information on disease condition and prognosis, from the patients with the purpose of protectiveness. Meanwhile, the separate conversations should be performed with caution, as holding back information from patients and discussing the patients' disease without permission and without being in the presence of patients is considered an unethical issue (Clayton et al., 2005).

(3) The study findings suggested that the information needs of the patients could not be addressed optimally by only increasing the amount of information, as the underlying problems with or reasons for their information needs should be considered when giving information (Voogt et al.,

2005). Apart from the healthcare professionals factors (e.g., limited time), the patients' emotional status and knowledge and beliefs should also be considered when providing information.

### **9.8 Summary and conclusion of the doctoral research project**

Understanding patients' and informal caregivers' care needs and their predictors by viewing patients and their informal caregivers as a 'whole unit' within a given context can provide evidence to researchers and policymakers in terms of developing tailored palliative care interventions and services. The current doctoral research project was therefore designed and implemented using a multimethod research design. To the best of the doctoral researcher's knowledge, this doctoral research project is the first study at present in Mainland China to examine the palliative care needs of Chinese cancer patients with advanced cancer and the needs of their informal caregivers, as well as the influencing factors, by viewing the patients and informal caregivers as a 'whole unit' using a multimethod research design. The study findings, which emerged from the cross-sectional survey and follow-up interviews, have contributed to a comprehensive and in-depth understanding of the palliative care needs of patients with advanced cancer and the needs of their informal caregivers within the Chinese context, and a final conclusion of the findings of this doctoral research project was reached. Details are presented as follows:

(1) Both patients and caregivers had a wide range of context-specific care needs, such as higher levels of physical needs in relation to pain management, financial needs, and information needs, compared with other international studies in developed countries, and the needs of the patients and caregivers were interrelated.

(2) Information needs was identified as a common and prominent unmet need for both patients and their caregivers in the quantitative survey.

(3) The patients' and caregivers' needs were influenced not only by factors related to themselves but also by those related to their partners. Anxiety and depression of either the patients or the caregivers, coping strategies of either the patients or the caregivers (particularly less use of

problem-focused strategies), and caregivers' poorer quality of life were three common and important predictors of higher levels of needs for both patients and caregivers. The patients' greater severity of symptom distress was another negative factor in patients' needs.

(4) The findings drawn from the quantitative survey highlighted that it is necessary to incorporate the assessment of the presence of physical and psychological distress, as well as the use of coping strategies, into clinical practice to identify those in need for more clinical attention and specific interventions.

(5) The caregivers' unmet needs, well-being, use of coping strategies, and emotional status was found to be just as important as those of the patients. The needs of patients and caregivers should be fulfilled simultaneously through family-based healthcare services and interventions.

(6) Through the following semi-structured interviews, information was found to play a critical role in the patients' and caregivers' efforts to cope with the cancer, and they perceived that appropriate information provision may be one of the most important contributors to better health outcomes.

(7) Adequate and appropriate information was found that may facilitate informed decision-making and result in greater satisfaction with treatment options, reductions in psychological disturbances, enhanced confidence and ability of self-management to cope with the illness, and the ability to anticipate and prepare for caregiving.

(8) The findings drawn from the semi-structured interviews can promote healthcare professionals' understanding in terms of *what* and *how much* information, *from whom* and *in what format* the patients and caregivers prefer to receive the information, and *when* during the course of cancer.

## **Appendices**

## Appendix I: Written Informed Consent, English Version



護理學院  
School of Nursing

香港 九龍 紅磡  
Hung Hom Kowloon Hong Kong

### CONSENT TO PARTICIPATE IN RESEARCH

Palliative Care needs of the patients with advanced cancer and their informal caregivers in China

I \_\_\_\_\_ hereby consent to participate in the captioned research supervised by Prof. Alex Molassiotis and Dr. Betty Pui Man Chung and conducted by Ms. Tao Wang.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e., my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained. I understand the benefits and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Signature of participant \_\_\_\_\_

Signature of Parent or Guardian (if applicable) \_\_\_\_\_

Name of researcher \_\_\_\_\_

Signature of researcher \_\_\_\_\_

Date \_\_\_\_\_

**Written Informed Consent, Chinese Version**



護理學院  
School of Nursing

香港 九龍 紅磡  
Hung Hom Kowloon Hong Kong

**參與研究同意書**

**晚期癌症患者及其長期照顧者的姑息護理需求探討**

本人 \_\_\_\_\_ 同意參加由 \_\_\_\_\_ 莫禮士教授和鍾佩雯博士  
負責監督, \_\_\_\_\_ 王濤女士 \_\_\_\_\_ 執行的研究項目。

我理解此研究所獲得的資料可用於未來的研究和學術交流。然而我有權保護自己的隱私,我的個人資料將不能洩漏。

我對所附資料的有關步驟已經得到充分的解釋。我理解可能會出現的風險。我是自願參與這項研究。

我理解我有權在研究過程中提出問題,並在任何時候決定退出研究而不會受到任何不正常的待遇或被追究責任。

參加者簽名: \_\_\_\_\_

父母姓名或監護人姓名: (如需要) \_\_\_\_\_

父母或監護人簽名: (如需要) \_\_\_\_\_

研究人員姓名: \_\_\_\_\_

研究人員簽名: \_\_\_\_\_

日期: \_\_\_\_\_



## Appendix II: Baseline Data Assessment Form

### Baseline Data Assessment Form (Patients)

人口学资料			
姓名(首字母) _____	年龄 _____	性别 _____	住院/门诊 _____
民族 _____	电话 _____	居住住址 _____	
<b>教育程度</b>	<input type="checkbox"/> 未接受正式教育 <input type="checkbox"/> 小学 <input type="checkbox"/> 初中 <input type="checkbox"/> 高中或中专 <input type="checkbox"/> 大专 <input type="checkbox"/> 大学或以上	<b>婚姻状况</b>	<input type="checkbox"/> 未婚 <input type="checkbox"/> 已婚 <input type="checkbox"/> 离婚 <input type="checkbox"/> 丧偶
<b>职业状况</b>	<input type="checkbox"/> 专业技术人员 <input type="checkbox"/> 体力劳动者 <input type="checkbox"/> 家庭主妇 <input type="checkbox"/> 文书或管理工作 <input type="checkbox"/> 其他 <input type="checkbox"/> 失业 <input type="checkbox"/> 退休	<b>宗教信仰</b>	<input type="checkbox"/> 佛教 <input type="checkbox"/> 道教 <input type="checkbox"/> 基督教 <input type="checkbox"/> 天主教 <input type="checkbox"/> 伊斯兰教 <input type="checkbox"/> 无 其他 _____
<b>家庭收入(每月)</b>	<input type="checkbox"/> 3000 元及以下 <input type="checkbox"/> 3 000-6000 元 <input type="checkbox"/> >6000-10000 元 <input type="checkbox"/> 10000 元以上	<b>居住状态</b>	<input type="checkbox"/> 和家人一起 <input type="checkbox"/> 独居
		<b>长居地</b>	<input type="checkbox"/> 农村 <input type="checkbox"/> 城市
患者疾病相关资料			
<b>原发癌症类型</b>	<input type="checkbox"/> 肺癌 <input type="checkbox"/> 肝癌 <input type="checkbox"/> 大肠癌 <input type="checkbox"/> 乳腺癌 <input type="checkbox"/> 胃癌 <input type="checkbox"/> 肾癌 <input type="checkbox"/> 膀胱癌 <input type="checkbox"/> 食管癌 <input type="checkbox"/> 胰腺癌 <input type="checkbox"/> 宫颈癌 <input type="checkbox"/> 其他(请列出具体名称) _____	<b>癌症确诊时间</b>	诊断时间 _____年_____月
<b>目前癌症分期</b>	<input type="checkbox"/> IIIA <input type="checkbox"/> IIIB <input type="checkbox"/> IIIC <input type="checkbox"/> IV	<b>是否曾接受癌症手术治疗</b>	<input type="checkbox"/> 否 <input type="checkbox"/> 是 手术类型: _____ 手术时间 _____年_____月
<b>曾经接受并已完成癌症治疗</b>	<input type="checkbox"/> 手术治疗 <input type="checkbox"/> 放化疗结合 <input type="checkbox"/> 化疗 <input type="checkbox"/> 激素治疗 <input type="checkbox"/> 放疗 <input type="checkbox"/> 缓解症状为主 <input type="checkbox"/> 定期随访	<b>目前主要癌症治疗</b>	<input type="checkbox"/> 手术治疗 <input type="checkbox"/> 放化疗结合 <input type="checkbox"/> 化疗 <input type="checkbox"/> 激素治疗 <input type="checkbox"/> 放疗 <input type="checkbox"/> 缓解症状为主 <input type="checkbox"/> 定期随访

注: 该表信息由问卷发放者从医疗记录中获取。对于不能从医疗记录中获取的信息, 由问卷发放者询问患者后填写(比如标记\*的项目)。

### Baseline Data Assessment Form (Informal Caregivers)

照顾者人口学资料			
姓名（首字母） _____ 年龄 _____ 性别 _____		民族 _____ 电话 _____	
<b>教育程度</b>	<input type="checkbox"/> 未接受正式教育 <input type="checkbox"/> 小学 <input type="checkbox"/> 初中 <input type="checkbox"/> 高中或中专 <input type="checkbox"/> 大专 <input type="checkbox"/> 大学或以上	<b>宗教信仰</b>	<input type="checkbox"/> 佛教 <input type="checkbox"/> 道教 <input type="checkbox"/> 基督教 <input type="checkbox"/> 天主教 <input type="checkbox"/> 伊斯兰教 <input type="checkbox"/> 无其他_____
<b>目前婚姻状况</b>	<input type="checkbox"/> 未婚 <input type="checkbox"/> 已婚 <input type="checkbox"/> 离婚 <input type="checkbox"/> 丧偶	<b>照顾者当前工作状态</b>	<input type="checkbox"/> 没有工作/辞职状态 <input type="checkbox"/> 有兼职工作，具体为_____ <input type="checkbox"/> 有全职工作，具体为_____
<b>已照顾患者多长时间</b>	<input type="checkbox"/> <1 个月 <input type="checkbox"/> 1~2 个月 <input type="checkbox"/> 2~3 个月 <input type="checkbox"/> 3-6 个月 <input type="checkbox"/> 6~12 个月 <input type="checkbox"/> > 12 个月	<b>期间是否与其他人轮流替换照顾患者</b>	<input type="checkbox"/> 几乎没有人替换 <input type="checkbox"/> 偶尔有人替换 <input type="checkbox"/> 定期有人替换
<b>照顾者与患者关系 (即，您是患者的：)</b>	<input type="checkbox"/> 妻子 <input type="checkbox"/> 丈夫 <input type="checkbox"/> 母亲 <input type="checkbox"/> 父亲 <input type="checkbox"/> 儿子 <input type="checkbox"/> 儿媳 <input type="checkbox"/> 女儿 <input type="checkbox"/> 女婿 <input type="checkbox"/> 朋友 <input type="checkbox"/> 兄弟/姊妹 <input type="checkbox"/> 其他, 请说明_____	<b>主要看护地点</b>	<input type="checkbox"/> 家里 <input type="checkbox"/> 医院, 请列出具体科室 <input type="checkbox"/> 其他, 请列出具体名称 _____
<b>是否与患者一起居住</b>	<input type="checkbox"/> 是 <input type="checkbox"/> 否	<b>患者是否伴随其他疾病</b>	<input type="checkbox"/> 无 <input type="checkbox"/> 有, 请写明-----

**注：**该表信息由照顾者自行填写，或询问照顾者后由问卷发放者填写。

**Appendix III: Problems and Needs in Palliative Care- short version (PNPC-sv),  
English version**

**DIRECTIONS:** This questionnaire is designed to clarify what problems you experience, and for what issues you need (extra) attention or care.

At each item you will be asked 2 questions:

**Left:** Do you experience the item to be a **problem**?

**Right:** Do you need (extra) professional **attention** for the item?

**So please provide 2 answers at each item!**

Is this a problem?			Your problems and needs for care	Do you want professional attention for this?		
Yes	Some-what	No		Yes, more	As much as now	No
<b>Daily activities</b>						
			Body care, washing, dressing, or toilet			
			Personal transportation (cycling, driving a car, using public transportation etc.)			
			Doing light housework (tidying up, etc.)			
<b>Physical symptoms</b>						
			pain			
			Fatigue			
			Sleeping problems			
			Shortness of breath			
			Cough			
			Itch			
			Sexual dysfunction			
			Prickling or numb sensation			
			(Nightly) Sweating or hot flushes			
<b>Autonomy</b>						
			Difficulties in continuing the usual activities			
			Difficulty to give tasks out of hands			
			Being dependent of others			
			Experiencing loss of control over one's life			
<b>Social issues</b>						
			Problems in the relationship with life companion			
			Difficulties in talking about the disease with life companion			
			Finding it difficult to talk about the disease, because of not receptive to talking about the disease			
			Finding others not receptive to talking about the disease			

			Difficulties in finding someone to talk to (confidant)			
<b>Psychological issues</b>						
			Depressed mood			
			Fear of physical suffering			
			Fear of metastases			
			Difficulty coping with the unpredictability of the future			
			Difficulties to show emotions			
<b>Spiritual issues</b>						
			Difficulties to be engaged usefully			
			Difficulties to be avail for others			
			Difficulties concerning the meaning of death			
			Difficulties to accept the disease			
<b>Financial problem</b>						
			Extra expenditures because of the disease			
			Loss of income because of the disease			
<b>Need of information</b>						
			Insufficient information e.g. about the disease and its treatment, aids and agencies that can provide help, alternative healing methods, etc.			
<b>Are important issues missing from this list? Please add your personal issues below!</b>						
			1.			
			2.			
			3.			

**Appendix IV: Comprehensive Needs Assessment Tool for Cancer Caregivers (CNAT-C), English version**

**DIRECTIONS:** This questionnaire is designed to clarify what needs or help you want during the period (in the last month) of taking care of your loved one who suffering from advanced cancer. Please ticking the most suitable answer based on your condition. There is no right or wrong answer for each item.

Item	Rating			
	No need	Low need	Moderate need	High need
1. My own health problems	0	1	2	3
2. Concerns about the patient	0	1	2	3
3. Depression	0	1	2	3
4. Feelings of anger, irritability, or nervousness	0	1	2	3
5. Loneliness or feelings of isolation	0	1	2	3
6. Feelings of vague anxiety	0	1	2	3
7. Help with patient over-dependence	0	1	2	3
8. Help with patient lack of appreciation of the caregiving	0	1	2	3
9. Help with difficulties in family relationships after cancer diagnosis	0	1	2	3
10. Help with difficulties in interpersonal relationship after cancer diagnosis	0	1	2	3
11. Help with my own relaxation and my personal life	0	1	2	3
12. Being respected and treated as a person by my doctor	0	1	2	3
13. Doctor to be clear, specific, and honest in his/her explanation	0	1	2	3
14. Seeing doctor quickly and easily when in need	0	1	2	3
15. Being involved in the decision-making process in choosing any tests or treatments that the patient receive	0	1	2	3
16. Cooperation and communication among health-care staff	0	1	2	3
17. Sincere interest and empathy from my nurse	0	1	2	3
18. Nurses to explain treatment or care that is being given to the patient	0	1	2	3
19. Nurses to promptly attend to patient discomfort and pain	0	1	2	3
20. Information about the current status of a patient's illness and its future course	0	1	2	3
21. Information about tests and treatment	0	1	2	3
22. Information about caring for the patient (symptom management, diet, exercise, etc.)	0	1	2	3

23. Guidelines or information about complementary and alternative medicine	0	1	2	3
24. Information about hospitals or clinics and physicians who treat cancer	0	1	2	3
25. Information about financial support for medical expenses, either from government and/or private organizations	0	1	2	3
26. Help with communication with the patient and/or other family members	0	1	2	3
27. Information about caregiving-related stress management	0	1	2	3
28. Religious support	0	1	2	3
29. Help in finding the meaning of my situation and coming to terms with it	0	1	2	3
30. A designated hospital staff member who would be able to provide counselling for any concerns, and guidance with the course of the treatment, from the point of diagnosis to the period after discharge	0	1	2	3
31. Guidance about hospital facilities and services	0	1	2	3
32. Need for space reserved for caregivers	0	1	2	3
33. A visiting nurse service for home	0	1	2	3
34. Opportunity to share experiences or information with other caregivers	0	1	2	3
35. Welfare services (e.g. psychological counselling) for caregivers	0	1	2	3
36. Transportation service for getting to and from the hospital	0	1	2	3
37. Treatment near home	0	1	2	3
38. Lodging near hospital where the patient is treated	0	1	2	3
39. Help with the economic burden caused by cancer	0	1	2	3
40. Someone to help me with housekeeping and/or child care	0	1	2	3
41. Assisted care in hospital or at home	0	1	2	3

**Comprehensive Needs Assessment Tool in Cancer for Caregivers (CNAT-C), Chinese version**

**病人照顾者的综合需求评估工具**

请认真阅读，并根据您最近一个月的情况，根据您是否有如下的需求，需求的程度是高、中、低哪个层次，在符合您的状况选项后面划（✓）。

条目	不需要	需要		
		低	中	高
健康和心理问题：	0	1	2	3
1. 我需要帮助来应对我自己的健康问题。	0	1	2	3
2. 我需要帮助来应对我对病人的担心。	0	1	2	3
3. 我需要帮助来应对我的抑郁情绪。	0	1	2	3
4. 我需要帮助来应对我生气、易怒或者神经过敏的情绪。	0	1	2	3
5. 我需要帮助来应对我的孤独感或者孤立感。	0	1	2	3
6. 我需要帮助来应对我的不明焦虑的情绪。	0	1	2	3
家庭和社会支持：	0	1	2	3
7. 当病人过分依赖时，我需要帮助。	0	1	2	3
8. 当病人对照顾缺乏认同时，我需要帮助。	0	1	2	3
9. 我需要帮助应对癌症诊断后出现的家庭关系的困难。	0	1	2	3
10. 我需要帮助应对癌症诊断后出现的人际关系困难。	0	1	2	3
11. 我需要帮助应对自我放松和个人生活	0	1	2	3
医护人员：	0	1	2	3
12. 我希望我的医生能够尊重我的人格。	0	1	2	3
13. 我希望我的医生在解释时能够清楚、详细并诚实。	0	1	2	3
14. 我希望在需要的时候能够快捷简便地见到医生。	0	1	2	3
15. 我希望积极地参与检查和治疗的决策过程。	0	1	2	3
16. 我希望医护人员能够相互协作沟通良好。（包括医生与医生之间、医生和护士之间）	0	1	2	3
17. 我希望护士能够给予真诚的关心和深深的同感。	0	1	2	3
18. 我希望护士能够解释所做的治疗和护理。	0	1	2	3
19. 我希望护士能够及时的护理病人的不适和疼痛。	0	1	2	3
知识信息：	0	1	2	3
20. 我需要关于病人目前的疾病状态和未来疗程的信息。	0	1	2	3
21. 我需要关于检查和治疗的信息。	0	1	2	3

22. 我需要关于在家中护理病人的信息（症状管理、饮食、运动等等）。	0	1	2	3
23. 我需要关于补充替代疗法（针灸、按摩、沉思、祈祷、催眠、饮食补充剂疗法）的指导和信息。	0	1	2	3
24. 我需要关于治疗癌症的医院或诊所和医生的信息。	0	1	2	3
25. 我需要关于医疗费用的财政支持信息，无论是政府还是私营机构给予的支持。	0	1	2	3
26. 我需要帮助来与病人或/和家庭成员进行沟通。	0	1	2	3
27. 我需要管理与照顾相关的压力的信息。	0	1	2	3
宗教、精神支持：	0	1	2	3
28. 我需要宗教的支持。	0	1	2	3
29. 我需要帮助来寻找现在处境的意义并适应它。	0	1	2	3
医院的设施和服务：	0	1	2	3
30. 我需要从刚开始诊断到出院之后的期间里，都有一个指定的医院工作人员，能够针对我的任何担心，提供咨询，并能在治疗的整个疗程期间提供指导。	0	1	2	3
31. 我需要关于医院设施和服务的指导。	0	1	2	3
32. 我需要有给照顾者预留的空间。	0	1	2	3
33. 我需要家访的护理服务。	0	1	2	3
34. 我需要有机会能够和其他照顾者分享经验和信息。	0	1	2	3
35. 我需要有为照顾者提供的福利事业（比如：心理咨询）。	0	1	2	3
实际支持：	0	1	2	3
36. 我需要往返医院的交通运输服务。	0	1	2	3
37. 我需要离家近的治疗。	0	1	2	3
38. 我需要在病人治疗的医院附近的住宿服务。	0	1	2	3
39. 我需要帮助由于癌症而带来的经济负担（比如：治疗费用、收入的损失）。	0	1	2	3
40. 我需要有人能够说明我做家务和/或照顾孩子。	0	1	2	3
41. 我需要在医院或者家中的辅助照顾	0	1	2	3



**Appendix V: Edmonton Symptom Assessment Scale (ESAS), English version**

**DIRECTIONS:** These statements are related to the common symptoms experienced by yourselves. The severity at the time of assessment of each symptom is rated from 0 to 10 on a numerical scale; with **0 meaning that the symptom is absent** and **10 that it is the worst possible severity**. Please circle the most appropriate number to indicate where the symptom is between the two extremes.

<b>1. Pain</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>2. Fatigue</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>3. Nausea</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>4. Depression</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>5. Anxiety</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>6. Drowsiness</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>7. Shortness of breath</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>8. Appetite</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>9. Difficulty in sleeping</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>10. Feeling of well-being</b>										
0	1	2	3	4	5	6	7	8	9	10
<b>11. Other:</b>										
0	1	2	3	4	5	6	7	8	9	10

## Edmonton Symptom Assessment Scale (ESAS), Chinese version

### 埃德蒙顿症状评估量表

以下各项症状是您在疾病过程中可能会经常体验的症状，**每一条症状均按 0-10 评分。0 分代表完全没有该项症状体验，10 分代表该症状非常严重。**请按照您的实际情况圈出与您症状相匹配的数字。

1. 疼痛:										
0	1	2	3	4	5	6	7	8	9	10
2. 疲乏:										
0	1	2	3	4	5	6	7	8	9	10
3. 恶心:										
0	1	2	3	4	5	6	7	8	9	10
4. 抑郁:										
0	1	2	3	4	5	6	7	8	9	10
5. 焦虑:										
0	1	2	3	4	5	6	7	8	9	10
6. 困倦:										
0	1	2	3	4	5	6	7	8	9	10
7. 呼吸短促:										
0	1	2	3	4	5	6	7	8	9	10
8. 胃口、食欲:										
0	1	2	3	4	5	6	7	8	9	10
9. 睡眠问题:										
0	1	2	3	4	5	6	7	8	9	10
10. 整体健康状况:										
0	1	2	3	4	5	6	7	8	9	10
11. 其他:										
0	1	2	3	4	5	6	7	8	9	10

**Appendix VI: Hospital Anxiety and Depression Scale (HADS), English version**

**DIRECTIONS:** These statements are related to anxiety and depression you may feel. Please tick one response from the four given for each statement. There is no right or wrong answer. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

Item	Rating			
	Most of the time	A lot of the time	From time to time, occasionally	Not at all
1. I feel tense or 'wound up'				
2. I still enjoy the things I used to enjoy				
3. I get sort of a frightened feeling as if something awful is about to happen				
4. I can laugh and see the funny side of things				
5. Worrying thoughts go through my mind				
6. I feel cheerful				
7. I can sit at ease and feel relaxed				
8. I feel as though I am slowed down				
9. I get a sort of frightened feeling like 'butterflies' in the stomach				
10. I have lost interest in my appearance				
11. I feel restless as I have to be on the move				
12. I look forward with enjoyment to things				
13. I get sudden feelings of panic				
14. I can enjoy a good book or radio or TV program				

## Hospital Anxiety and Depression Scale (HADS), Chinese version

### 医院焦虑抑郁量表

情绪在大多数疾病中起着重要作用，如果医生了解您的情绪变化，他们就能给您更多的帮助，请您阅读以下各个项目，在其中最符合你过去一个月的情绪评分上画一个圈。对这些问题的回答不要做过多的考虑，立即做出的回答往往更符合实际情况。

条目	选项			
	0	1	2	3
1. 我感到紧张(或痛苦)	根本没有	有时候	大多数时候	几乎所有时候
2. 我对以往感兴趣的事情还是有兴趣	肯定一样	不像以前那样多	只有一点	基本上没有了
3. 我感到有点害怕好像预感到什么可怕的事情要发生	根本没有	有一点，但并不使我苦恼	是有，不太严重	非常肯定和十分严重
4. 我能够哈哈大笑，并看到事物好的一面	我经常这样	现在已经不太这样了	现在肯定是不太多了	根本没有
5. 我的心中充满烦恼	偶然如此	时时，但并不轻松	时常如此	大多数时间
6. 我感到愉快	大多数时间	有时	并不经常	根本没有
7. 我能够安闲而轻松地坐着	肯定	经常	并不经常	根本没有
8. 我对自己的仪容失去兴趣	仍然像以往一样关心	我可能不是非常关心	并不像我应该做的那样关心我	肯定
9. 我有点坐立不安，好像感到非要活动不可	根本没有	并不，很少	是不少	却是非常多
10. 我对一切都是乐观地向前看	差不多是这样做	并不完全是这样做的	很少这样做	几乎从不这样做
11. 我突然发现有恐慌感	根本没有	并非经常	非常肯定，十分严重	确实很经常
12. 我好像感到情绪在渐渐低落	根本没有	有时	很经常	几乎所有时间
13. 我感到有点害怕，好像某个内脏器官变化了	根本没有	有时	很经常	非常经常
14. 我能欣赏一本好书或意向好的广播或电视节目	常常如此	有时	并非经常	很少

**Appendix VII: Medical Outcomes Study-Social Support Survey (MOS-SSS), English version**

**DIRECTIONS:** How often is each of the following kinds of support available to you if you need it? Please choose the answer that most suitable for your condition.

Item	Rating				
	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional/informational support					
1. Someone you can count on to listen to you when you need to talk					
2. Someone to give you information to help you understand a situation					
3. Someone to give you good advice about a crisis					
4. Someone to confide in or talk to about yourself or your problems					
5. Someone whose advice you really want					
6. Someone to share your most private worries and fears with					
7. Someone to turn to for suggestions about how to deal with a personal problem					
8. Someone who understands your problems					
Tangible support					
9. Someone to help you if you were confined to bed					
10. Someone to take you to the doctor if you needed it					
11. Someone to prepare your meals if you were unable to do it yourself					
12. Someone to help with daily chores if you were sick					
Affectionate support					
13. Someone who shows you love and affection					
14. Someone to love and make you feel wanted					
15. Someone who hugs you					
Positive social interaction					
16. Someone to have a good time with					
17. Someone to get together with for relaxation					
18. Someone to do something enjoyable with					
Additional item					
19. Someone to do things with to help you get your mind off things					

## Medical Outcomes Study-Social Support Survey (MOS-SSS), Chinese version

### 医疗社会支持量表中文版 (MOS-SSS-C)

以下一些问题是关于您能获得的社会支持情况，请您根据自己的实际情况回答。

人们有时候会向别人寻求陪同、帮助或其他形式的支持，请问在你需要时，您有多少时候能得到以下支持呢？请在相应的表栏中打“√”。

条目	完全没有	少许时候	有些时候	大部分时候	所有时候
1. 如果你只限于卧床活动，有人能够给予你帮助。					
2. 在你需要倾诉的时候，能够指望某些人来倾听。					
3. 在艰苦危难的时候，有人给你很好建议或忠告。					
4. 如果你有需要，有人会带你去看病。					
5. 有人向你表达挚爱及对你的关心。					
6. 有人和你一起欢度时光。					
7. 有人给予你一些信息/数据，说明你明白当时的处境。					
8. 有人值得你信任，可向他倾诉你自己的事或问题。					
9. 有人会呵护你。					
10. 有人和你聚在一起轻松一番。					
11. 如果你不能自己做饭，有人会帮你做。					
12. 有些人的忠告是你真正渴求的。					
13. 有人与你一起做一些事，使你能放下心里的事。					
14. 当你身体不适时，有人会替你处理日常琐事。					
15. 有人分担你心底最深的恐惧及担心。					
16. 可向一些人询问有关如何处理个人问题的建议。					
17. 有人和你一起做一些快乐的事情。					
18. 有人明白你的问题。					
19. 你有一些爱的人，并且有被需要的感觉。					

**Appendix VIII: Brief Coping Orientations to Problems Experienced Scale (Brief-COPE), English version**

**DIRECTIONS:** There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Please don't answer the item on the basis of whether it seems to be working or not – just whether or not you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

Item	Rating			
	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things				
2. I've been concentrating my efforts on doing something about the situation I'm in				
3. I've been saying to myself "this isn't real"				
4. I've been using alcohol or other drugs to make myself feel better				
5. I've been getting emotional support from others				
6. I've been giving up trying to deal with it				
7. I've been taking action to try to make the situation better				
8. I've been refusing to believe that it has happened				
9. I've been saying things to let my unpleasant feelings escape				
10. I've been getting help and advice from other people				
11. I've been using alcohol or drugs to help me get through it				
12. I've been trying to see it in a different light, to make it seem more positive				
13. I've been criticizing myself				
14. I've been trying to come up with a strategy about what to do				
15. I've been getting comfort and understanding from someone				
16. I've been giving up the attempt to cope				
17. I've been looking for something good in what is happening				
18. I've been making jokes about it				
19. I've been doing something to think about it less, such as going to the movies, watching TV,				

reading, daydreaming, sleeping or shopping				
20. I've been accepting the reality of the fact that it has happened				
21. I've been expressing my negative feelings				
22. I've been trying to find comfort in my religion or spiritual beliefs				
23. I've been trying to get advice or help from other people about what to do				
24. I've been learning to live with it				
25. I've been thinking hard about what steps to take				
26. I've been blaming myself for things that happened				
27. I've been praying or meditating				
28. I've been making fun of the situation				



## Brief Coping Orientations to Problems Experienced Scale (Brief-COPE), Chinese version

### 问题应对方式调查问卷

这个问卷希望能了解你在面对困境或是压力事件时，会有什么样的反应。当然，每个人处理事情的方式都不一样，但我们关心的是你自己如何处理问题。每一个项目都描述着一个特殊的因应方式，我们想了解你会采用这些项目来处理问题的程度有多少或多常。不要根据你认为该项目适不适合用来处理问题来回答，只要根据你采不采用它来回答就好。使用下列的评分选项，试着在心中对每一个题目分别地评分，尽量越接近『你自己』真实的情况越好。请根据使用频率在合适的表栏中打“√”。

条目	不会这么做	很少这么做	有时这么做	常常这么做
1. 我会转向工作或其他活动以避免去想问题				
2. 我会尽全力解决我所遇到的问题				
3. 我会告诉自己『这不是真的』				
4. 我会使用酒或其他药物让自己感觉变好				
5. 我会从他人身上得到情感支持				
6. 我会放弃去尝试解决问题				
7. 我会采取行动来把情况变好				
8. 我会拒绝相信这件事已经发生				
9. 我会诉说以让不愉快的感觉消失				
10. 我会去获取别人的协助与建议				
11. 我会藉由酒或其他药物来度过				
12. 我会试着从不同的角度看待问题，让问题变得更正向				
13. 我会批评我自己				
14. 我会试着想出处理的策略				
15. 我会寻求他人的安慰与了解				
16. 我会放弃去处理问题				
17. 我会从发生的事情当中找出它的正向意义				
18. 我常用开玩笑的方式来处理问题				
19. 我会借着做一些事以减少去想问题的次数，例如看电影、看电视、阅读、做白日梦、睡觉或逛街				
20. 我会接受事情已经发生的事实				
21. 我会表达负向的感觉				
22. 我会试着在我的宗教或信仰中寻求安慰				
23. 我会寻求别人的帮助或建议				
24. 我会学习着与事情（问题）共处				
25. 我很认真地想下一步要怎么做				
26. 对于那件发生的事情，我会责怪自己				
27. 我会祷告、冥想或拜拜、念经				
28. 我会让情况变得更有乐趣				

**Appendix IX: EORTC Quality-of-life Questionnaire Core 15-PC (QOL-C15-PAL),  
English version**

**DIRECTIONS:** We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers.

Item	Rating					
	Not at All	A Little	Quite a Bit	Very Much		
1. Do you have any trouble taking a shortwalk outside of the house?						
2. Do you need to stay in bed or a chair during the day?						
3. Do you need help with eating, dressing, washing yourself or using the toilet?						
4. Were you short of breath?						
5. Have you had pain?						
6. Have you had trouble sleeping?						
7. Have you felt weak?						
8. Have you lacked appetite?						
9. Have you felt nauseated?						
10. Have you been constipated?						
11. Were you tired?						
12. Did pain interfere with your daily activities?						
13. Did you feel tense?						
14. Did you feel depressed?						
For the following question please circle the number between 1 and 7 that best applies to you.						
15. How would you rate your overall quality of life during the past week?						
1	2	3	4	5	6	7
Very poor						Excellent

**EORTC Quality-of-life Questionnaire Core 15-PC (QOL-C15-PAL), Chinese version**

**EORTC 生活质量问卷- 姑息护理**

我们有兴趣知道一些有关您和您的健康的事情。请亲自回答所有问题，并圈出最切合您的情况的一个数字。大拿没有对与错之分。您提供的所有数据将绝对保密。

条目	完全没有	有一点	很多	非常多		
1. 在屋外作近距离的步行您会感到困难吗?	1	2	3	4		
2. 您是否需要在白天时躺在床上或坐在椅子上?	1	2	3	4		
3. 您是否需要别人协助吃饭、穿衣、洗澡或如厕?	1	2	3	4		
在过去一个星期内						
4. 您是否感到气促?	1	2	3	4		
5. 您曾感到疼痛吗?	1	2	3	4		
6. 您曾感到难以入睡吗?	1	2	3	4		
7. 您有感到软弱无力吗?	1	2	3	4		
8. 您有感到没有胃口吗?	1	2	3	4		
9. 您有感到恶心吗?	1	2	3	4		
10. 您曾便秘吗?	1	2	3	4		
11. 您是否感到疲倦?	1	2	3	4		
12. 您的疼痛有干扰您的日常活动吗?	1	2	3	4		
13. 您感到紧张吗?	1	2	3	4		
14. 您感到沮丧吗?	1	2	3	4		
下一个问题，请从 1 至 7 之间的数字圈选出最切合您情形的答案。						
15. 您对过去一星期内您的整体生活质量如何评价?						
1	2	3	4	5	6	7
非常差						非常好

**Appendix X: Caregivers Quality of Life Index- Cancer (CQOL-Cancer), English version**

**DIRECTIONS:** Below is a list of statements that other people caring for loved ones, either relatives or friends, with cancer. Please indicate how true each statement has been for you during **the past 7 days** by circling one of the answer that most suitable for your condition.

Item	Rating				
	Not at all	A little bit	Somewhat	Quite a bit	Very much
1. It bothers me that my daily routine is altered.					
2. My sleep is less restful.					
3. My daily life is imposed upon.					
4. I am satisfied with my sex life.					
5. It is a challenge to maintain my outside interests.					
6. I am under a financial strain.					
7. I am concerned about our insurance coverage.					
8. My economic future is uncertain.					
9. I fear my loved one will die.					
10. I have more of a positive outlook on life since my loved one's illness.					
11. My level of stress and worries has increased.					
12. My sense of spirituality has increased.					
13. It bothers me, limiting my focus to day-to-day.					
14. I feel sad.					
15. I feel under increased mental strain.					
16. I get support from my friends and neighbours.					
17. I feel guilty.					
18. I feel frustrated.					
19. I feel nervous.					
20. I worry about the impact my loved one's illness has had on my children or other family members.					
21. I have difficulty dealing with my loved one's changing eating habits.					
22. I have developed a closer relationship with my loved one.					
23. I feel adequately informed about my loved one's illness.					
24. It bothers me that I need to be available to chauffeur my loved one to appointments.					
25. I fear the adverse effects of treatment on my loved one.					
26. The responsibility I have for my loved one's care at home is overwhelming.					
27. I am glad that my focus is on getting my loved one well.					

28. Family communication has increased.					
29. It bothers me that my priorities have changed.					
30. The need to protect my loved one bothers me.					
31. It upsets me to see my loved one deteriorate.					
32. The need to manage my loved one's pain is overwhelming.					
33. I am discouraged about the future.					
34. I am satisfied with the support I get from my family.					
35. It bothers me that other family members have not shown interest in taking care of my loved one.					

## Caregivers Quality of Life Index- Cancer (CQOL-Cancer), Chinese version

### 癌症照顾者生活质量量表

请依据您过去一周的状况，选择您认为适合您的一个答案，在□中打“√”。

1. 我在意照顾病人对我的日常生活产生的影响				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很小	<input type="checkbox"/> 有些	<input type="checkbox"/> 较大	<input type="checkbox"/> 很大
2. 照顾病人使我的睡眠受到干扰				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
3. 照顾病人使我的日常生活受到影响				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很小	<input type="checkbox"/> 有些	<input type="checkbox"/> 较大	<input type="checkbox"/> 很大
4. 我对自己的性生活感到满意				
<input type="checkbox"/> 非常满意	<input type="checkbox"/> 满意	<input type="checkbox"/> 不知道	<input type="checkbox"/> 不满意	<input type="checkbox"/> 非常不满意
5. 保持自己原来的兴趣爱好是一种挑战				
<input type="checkbox"/> 完全不是	<input type="checkbox"/> 有点	<input type="checkbox"/> 有些困难	<input type="checkbox"/> 很困难	<input type="checkbox"/> 非常困难
6. 我正处于经济有压力中				
<input type="checkbox"/> 一点也没有	<input type="checkbox"/> 有一点	<input type="checkbox"/> 有一些	<input type="checkbox"/> 较大压力	<input type="checkbox"/> 有很大压力
7. 我关心医疗保险				
<input type="checkbox"/> 从不关心	<input type="checkbox"/> 很少关心	<input type="checkbox"/> 有些关心	<input type="checkbox"/> 很关心	<input type="checkbox"/> 非常关心
8. 我担心未来的经济状况				
<input type="checkbox"/> 从不担心	<input type="checkbox"/> 很少担心	<input type="checkbox"/> 有些担心	<input type="checkbox"/> 很担心	<input type="checkbox"/> 非常担心
9. 我最近常担心 病人会去世				
<input type="checkbox"/> 从不	<input type="checkbox"/> 很少担心	<input type="checkbox"/> 有时担心	<input type="checkbox"/> 很担心	<input type="checkbox"/> 非常担心
10. 自从亲人患病后，我对生活有了更乐观的看法				
<input type="checkbox"/> 完全没有	<input type="checkbox"/> 很少有	<input type="checkbox"/> 有些	<input type="checkbox"/> 很多	<input type="checkbox"/> 非常多
11. 我的压力和担心的程度越来越高				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很小	<input type="checkbox"/> 有些	<input type="checkbox"/> 很多	<input type="checkbox"/> 非常
12. 我的灵性有了升华				
<input type="checkbox"/> 没有	<input type="checkbox"/> 有一点	<input type="checkbox"/> 有些	<input type="checkbox"/> 很多	<input type="checkbox"/> 非常多
13. 过一天算一天的日子让我困扰				
<input type="checkbox"/> 从不	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
14. 每天照顾病人让我感到沮丧				
<input type="checkbox"/> 从不	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
15. 我觉得的心理压力越来越大				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
16. 我的亲朋好友们支持我				
<input type="checkbox"/> 完全没有	<input type="checkbox"/> 有点支持	<input type="checkbox"/> 有些支持	<input type="checkbox"/> 很支持	<input type="checkbox"/> 非常支持
17. 亲人的病让我感到愧疚和亏欠				
<input type="checkbox"/> 从不	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
18. 每天对病人的护理让我很有挫败感				
<input type="checkbox"/> 从不	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
19. 我感到紧张不安				
<input type="checkbox"/> 从不	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
20. 我担心 病人的对 我的孩子和家里其他人有 影响				
<input type="checkbox"/> 完全没有	<input type="checkbox"/> 有点	<input type="checkbox"/> 有些	<input type="checkbox"/> 较大	<input type="checkbox"/> 很大
21. 我觉得病人的饮食习惯改变让我很难应对				
<input type="checkbox"/> 完全没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直

22. 照顾病人使我和病人的关系更亲近了				
<input type="checkbox"/> 完全没有	<input type="checkbox"/> 亲近了一点	<input type="checkbox"/> 亲近了许多	<input type="checkbox"/> 亲近了很多	<input type="checkbox"/> 非常亲近了
23. 医护人员向我充分的对我解释病人的病情				
<input type="checkbox"/> 完全没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
24. 必须接送病人到医院让我很困扰				
<input type="checkbox"/> 完全没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
25. 我担心治疗的副反应会对病人造成影响				
<input type="checkbox"/> 从不	<input type="checkbox"/> 很少担心	<input type="checkbox"/> 有时担心	<input type="checkbox"/> 经常担心	<input type="checkbox"/> 非常担心
26. 照顾病人的压力大让我喘不过气来				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很小	<input type="checkbox"/> 有些	<input type="checkbox"/> 较大	<input type="checkbox"/> 很大
27. 我很高兴自己目前最关注的是病人早日康复				
<input type="checkbox"/> 从不	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
28. 自从亲人患病后，家庭成员的沟通增加了				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有些	<input type="checkbox"/> 很多	<input type="checkbox"/> 非常多
29. 我对必须改变生活的优先次序让困扰				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很小	<input type="checkbox"/> 有些	<input type="checkbox"/> 较大	<input type="checkbox"/> 很大
30. 必须保护病人的心态让我很困扰				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
31. 看到病人的身体状况越来越差我很难过				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
32. 需要处理病人的疼痛问题让我喘不过气来				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
33. 我觉得未来无望				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直
34. 我满意家人给我的支持				
<input type="checkbox"/> 非常满意	<input type="checkbox"/> 满意	<input type="checkbox"/> 不知道	<input type="checkbox"/> 不满意	<input type="checkbox"/> 非常不满意
35. 家人并不关注病人的护理让我很困扰				
<input type="checkbox"/> 没有	<input type="checkbox"/> 很少	<input type="checkbox"/> 有时候	<input type="checkbox"/> 经常	<input type="checkbox"/> 一直

## Appendix XI: Semi-structured interview guide

### Interview guide for patients

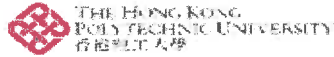
	English	Simplified Chinese
Introductory question	Can we start by finding out some information about you? -How many chemotherapy/radiotherapy/any other treatments have you had? - What treatments you are having now?	我们能从关于你的一些基本情况开始吗? -你目前已经接受了多少次化疗/放疗/或者其他的治疗方式呢? - 你现在正在接受的治疗是什么呢?
Transitional question	In the survey, you mentioned that you need more information, could you please tell me a little more about that?	在前期的调查问卷中, 您提到您需要更多的信息, 您能再多跟我多讲一点吗?
Key questions	<b>1. What kind of information do/did you need since the diagnosis?</b> - What information is most important to you? - Why did/do think the information is important to you?	<b>1. 自从您诊断患病之后, 哪些信息是您想了解的呢?</b> - 您觉得什么信息对您来说最重要呢? -为什么会觉得这些信息对您很重要呢?
	<b>2. When did you need the information most (phase of diagnosis, treatment, follow up)?</b> - Could you please tell me why did you need the information at that time?	<b>2. 您觉得在什么时候您最需要这些信息呢? (例如: 得知诊断的时候、治疗的过程中、治疗结束随访过程中)</b> - 您能告诉我为什么感觉在那个时候最需要这些信息呢?
	<b>3. What information you have already received?</b> -Where did you receive? - Who provided? - In what format it provided?	<b>3. 那您已经获得了哪些信息呢?</b> - 您是从哪里获得这些信呢? -是谁提供给您这些信息呢? -这些信息是以什么样的形式提供给您呢?
	<b>4. What is your feeling about the information you have received?</b> - Are these information useful to you? - In what way you used the information? - Could it be better – if so how?	<b>4.对于您觉得你已经获得的那些信息, 您觉得怎么样呢?</b> -这些信息对您来说有用吗? -你在哪些方面使用了这些信息呢? -如果这些信息能够以更好的方式提供给你, 你希望是什么样的呢?
	<b>5. In your opinion, what are the factors or reasons that make your information need unmet?</b> - How did you handle it? - What was the most challenging part when you handle it?	<b>5.在您看来, 是什么因素或者原因让你不能够的得到您想要的信息呢?</b> -您是怎么解决的呢? -在您解决过程中, 您觉得最大的挑战/困难是什么呢?
	<b>6. If you get sufficient information that you just mentioned, how it might have/will affected your experience?</b> - Can you give me an example?	<b>6.如果您能够得到足够的信息, 就是您刚刚提到的那些信息, 你觉得这些信息会给您带来什么样的影响呢?</b> -您可以给举个例子吗?
Concluding question	<b>Is there anything else you would like to say regarding your information need before we conclude this interview?</b>	关于您信息方面的需求, 还有什么补充的吗?



### Interview guide for informal caregivers

	<b>English</b>	<b>Simplified Chinese</b>
Introductory question	Can we start by finding out some information about you? -How long have you taking care of the patient? - Do you think information is important to caregiver?	我们能从关于你的一些基本情况开始吗? -您已经照顾他/她多久了呢? -您觉得信息对于照顾者来说重要吗?
Transitional question	In the survey, you rated a high information need as a caregiver, could you please tell me a little more about that?	前期的调查问卷发现，您有很高的信息需求，有关您的需求您能再多跟我多讲一点吗?
<b>Key questions</b>	<b>1. As a family caregiver, what kind of information do/did you need since you knew the diagnosis of patient?</b>  - What information is most important to you? - Why did/do think the information is important?	<b>1. 自从他/她被诊断患病之后，作为照顾者，哪些信息是您想了解的呢?</b>  - 您觉得什么信息对您来说最重要呢? - 为什么觉得这些信息很重要呢?
	<b>2. When did you need the information most (phase of diagnosis, treatment, follow up)?</b>  - Could you please tell me why did you need the information at that time?	<b>2. 您觉得在什么时候您最需要这些信息呢? (例如：得知诊断的时候、治疗的过程中、治疗结束随访过程中)</b>  - 您能告诉我为什么感觉是在那个时候最需要这些信息呢?
	<b>3. What information you have already received?</b>  -Where did you receive? - Who provided? - In what format it provided?	<b>3. 那您已经获得了哪些信息呢?</b>  - 您是从哪里获得这些信呢? - 是谁提供给您这些信息呢? - 这些信息是以什么样的形式提供给您呢?
	<b>4. What is your feeling about the information you have received?</b>  - Are these information useful to you? - In what way you used the information? - Could it be better – if so how?	<b>4. 对于您觉得你已经获得的那些信息，您觉得怎么样呢?</b>  - 这些信息对您来说有用吗? - 您在哪些方面用到了这些信息呢? - 如果这些信息能够以更好的方式提供给，您希望是什么样的呢?
	<b>5. In your opinion, what are the factors or reasons that make your information need unmet?</b>  - How did you handle it? - What was the most challenging part when you handle it?	<b>5. 在您看来，是什么因素或者原因让您不能够的得到您想要了解的信息呢?</b>  - 您是怎么解决的呢? - 在您解决过程中，您觉得最大的挑战/困难是什么呢?
	<b>6. If you get sufficient information that you just mentioned, how it might have/will affected you and the patient?</b>  - Can you give me an example?	<b>6. 如果您能够得到足够的信息，就是您刚刚提到的那些信息，你觉得这些信息会给您和病人带来什么样的影响呢?</b>  - 您可以给举个例子吗?
Concluding question	<b>Is there anything else you would like to say regarding your information need before we conclude this interview?</b>	关于您信息方面的需求，还有什么补充的吗?

## Appendix XII: Ethical approvals of the doctoral research project



To Molassiotis Alexandros (School of Nursing)  
From Vaelimaeki Maritta Anneli, Chair, Departmental Research Committee  
Email maritta.vaelimaeki@polyu.edu.hk Date 18-Sep-2017

### Application for Ethical Review for Teaching/Research Involving Human Subjects

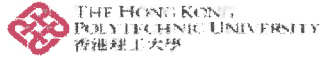
I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 16-Oct-2017 to 01-May-2019:

**Project Title:** Assessing palliative care needs from the perspectives of advanced cancer patients, their informal caregivers and healthcare professionals in Mainland China: A mixed methods study  
**Department:** School of Nursing  
**Principal Investigator:** Molassiotis Alexandros  
**Project Start Date:** 16-Oct-2017  
**Reference Number:** HSEARS20170911003

You will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In the case of the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Human Subjects Ethics Sub-committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

Vaelimaeki Maritta Anneli  
Chair  
Departmental Research Committee



THE HONG KONG  
POLYTECHNIC UNIVERSITY  
香港理工大學

To Molasiotis Alexandros (School of Nursing)  
From Vaelimaeki Maritta Anneli, Chair, Departmental Research Committee  
Email maritta.valimaki@ Date 29-Jul-2019

**Application for Ethical Review for Teaching/Research Involving Human Subjects**

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 16-Oct-2017 to 01-May-2019:

**Project Title:** Palliative Care needs of the patients with advanced cancer and their informal caregivers in Mainland China: A mixed methods study  
**Department:** School of Nursing  
**Principal Investigator:** Molasiotis Alexandros  
**Project Start Date:** 16-Oct-2017  
**Reference Number:** HSEARS20190710001

You will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In case the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Human Subjects Ethics Sub-committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

Vaelimaeki Maritta Anneli  
Chair  
Departmental Research Committee (on behalf of Human Subjects Ethics Sub-Committee)

## Appendix XIII: Information Sheet, English Version



護理學院  
School of Nursing

香港 九龍 紅磡  
Hung Hom Kowloon Hong Kong

### INFORMATION SHEET

#### **Palliative Care needs of the patients with advanced cancer and their informal caregivers in China**

You are invited to participate in a study supervised by Prof. Alex Molassiotis and Dr. Betty Pui Man Chung and conducted by Ms. Tao Wang, who is a PhD student of the School of Nursing in The Hong Kong Polytechnic University. The project has been approved by the Human Subjects Ethics Sub-committee (HSESC) of The Hong Kong Polytechnic University (Reference number: HSEAR20170911003).

The overall purpose of this study is to assess the palliative care needs of advanced cancer patients and their informal caregivers in China. This study consists of two phases, phase one is a cross-sectional study and phase two is qualitative interview. The objectives of phase one are to identify the palliative care needs and its associated variables of advanced cancer patients, to identify the needs and its associated variables of their informal caregivers, to determine the relationships between the palliative care needs of patients and the needs of their informal caregivers. For the phase two interviews, it aims to further elaborate the prominent unmet needs of you that identified in the cross-sectional survey, and to further explore your perceptions and experiences in relation to the identified unmet need. The findings of this study will provide evidence for the improvement of the healthcare services.

If you and your informal caregivers agree to participate in this study, in phase one, you and your informal caregiver will get a questionnaire booklet to fill out separately by yourselves. Patients and informal caregivers who have participated in the phase one survey and completed all the questionnaires will have the opportunities to be invited to take part in the phase two interviews. The phase two will be face-to-face interviews in a comfort setting with some questions about your experiences in relation to your unmet care needs that identified in the survey. The interview will be recorded and transcribed into text for research purpose. Potential risks of this study (including phase one and phase two) to the participants will be very minimal. There only might be a small

risk that you might feel sad when you are completing the questionnaires or talking about unhappy experiences. For these cases, psychological support will be provided for free if necessary. Of course, sharing your experience might to some extent release your pressure and make you feel relax.

All information related to you will remain confidential, and will be identifiable by codes known only to the researcher.

You have every right to withdraw from the study before or during the study without any penalty.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Miss Cherrie Mok, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in person or in writing (c/o Research Office of the University).

If you would like to learn more information about this study, please contact Ms. Tao Wang at telephone number (86)1368032 or email address: tao.jy.wang@

Thank you for your interest.

Principal Investigator: Prof. Alex Molassiotis

Co-investigator: Dr. Betty Pui Man Chung, Ms. Tao Wang

## Information Sheet, Chinese version



護理學院  
School of Nursing

香港 九龍 紅磡  
Hung Hom Kowloon Hong Kong

## 有關資料

### 晚期癌症患者及其長期照顧者的姑息護理需求探討

誠邀閣下參加莫禮士教授和鍾佩雯博士負責監督, 王濤女士負責執行的研究計劃。王濤女士是香港理工大學護理學院在讀博士生。

這項研究的目的是明確晚期癌症患者及其長期照顧者的姑息護理需求。本研究將採用橫斷面調查研究結合質性訪談的方法以實現以下研究目的：明確晚期癌症患者姑息護理需求及相關影響因素；明確患者長期照顧者的需求及相關影響因素；以及晚期癌症患者自身姑息護理需求與其長期照顧者自身需求的相關性。本項研究的結果將為醫療衛生服務的提升和改善提供依據。本項研究不會涉及任何干預和治療，不會給研究物件帶來任何顯著的風險與不利。

本項研究的適宜人群為晚期癌症患者及其長期照顧者。本研究包括兩部分，第一部分是一個針對晚期癌症患者及其長期照顧者的大樣本橫斷面調查研究。若閣下及閣下的長期照顧者願意參加本研究，那麼在第一階段，閣下及閣下的長期照顧者將會被邀請填寫一份由數份問卷組成的小冊子（患者的小冊子包括 6 份問卷，照顧者的小冊子包括 5 份問卷）。閣下及閣下的照顧者在完成問卷調查之後，將有可能會被邀請參加第二階段的訪談，在此階段，閣下及閣下的照顧者將會被研究者問及幾個關於疾病體驗，看護體驗，以及閣下未滿足的需求的相關經歷。每個問題均沒有正確答案，閣下僅需要根據問題自由的表達自己的經歷及看法等。整個訪談過程將全程錄音，以做后期研究所用。

问卷填写和/或访谈过程可能会给您带来心理上的不适，但是分享您的压力也可能使您感到轻松，如果访谈过程你感到不适或是不便，访谈可以随时终止，如若需要，我们将免费提供适当的心理支持，这不会对您及您的家人带来任何负面影响。閣下享有充分的權利在研究開始之前或之後決定退出這項研究，而不會受到任何對閣下不正常的待遇或被追究責任。凡有關閣下的資料將會保密，一切資料的編碼只有研究人員得悉。

如果閣下對這項研究有任何的不滿，可隨時與香港理工大學人類實驗對象操守小組委員會秘書莫小姐聯絡(地址：香港理工大學研究事務處轉交)。

如果閣下想獲得更多有關這項研究的資料，請與王濤女士聯絡，電話(86)1368032 或郵箱 tao.jy.wang@

謝謝閣下有興趣參與這項研究。

### **主要研究員 (PI)**

莫禮士教授 鍾佩雯博士 王濤女士

## Appendix XIV: Content validity assessment for the PNPC-sv, Chinese version

### 致专家信 (Cover Letter)

尊敬的专家：

您好！首先非常感谢您能够在百忙之中抽空参与这份中文版患者姑息护理问题与需求量表（PNPC-sv）的评价。该量表主要用于评价癌症患者的姑息护理问题与需求。感谢您对我们这一项研究的支持！

此次函询旨在评价中文版 PNPC-sv 各个条目文化适应性的内容效度。参与本内容效度测评的专家包括从事肿瘤相关科研及临床实践两类专家。肿瘤相关科研专家须为在高等院校进行肿瘤支持治疗研究的教授或副教授或具有博士学位的教学科研人员，并在肿瘤支持治疗国内或国际同行评议期刊上发表过高水平学术论文者。临床实践专家则为具备副高级及以上职称的取得资格的肿瘤科医生（主任医师或副主任医师）及肿瘤科护师（主任护师或副主任护师），且具备至少 10 年的肿瘤患者治疗/护理经验。

本评价表共分为两部分，第一部分即为此致专家信，第二部分为 PNPC-sv 文化适应性的内容效度评价表。请您逐条判断每一个条目是否适宜于中国患者进行理解，并进行评分，每一个条目都按照文化相关性程度分为了四等，即：非常合适（4 分），合适（3 分），一般合适（2 分）以及不合适（1 分）。请您根据您的判断在每个条目对应的 4 个分值内进行选择并在空格内作“√”标记。

此问卷以匿名形式函询，您的资料仅用于统计分析 & 研究方案修改，绝不它用，绝对保密。请您在收到问卷的 2 周内发回至研究者邮箱，或者联系研究者，研究者将在您方便的时候到您的单位取回该表。若您对此评价表有疑问或其他咨询，请拨打电话（86）1368032（联系人：王涛）；或者发送邮件 tao.jy.wang @ . 欢迎您随时提供宝贵意见。

再次感谢您对本研究的支持。

香港理工大学护理学院

博士研究生 王涛

电子邮箱：tao.jy.wang @

移动电话（中国大陆）：(86) 1368032





### 内容效度评价表(Content Validity Assessment Form)

说明：请您根据您的判断在每个条目对应的 4 个分值内进行选择，并在对应空格内打“√”。

条目	条目内容						条目的文化适应性评分				
							非常合适 (4)	合适 (3)	一般合适 (2)	不合适 (1)	
<p><b>指导语：</b>该问卷主要用于评价您在患病期间可能存在的一些问题以及对于这些存在的“问题”是否需要（额外）的专业帮助。问卷的每个条目均有两个部分需要您回答：</p> <p>（1）在条目的<u>左侧</u>，请您回答：“该条目所描述的情况于您而言是不是一个问题？”</p> <p>（2）在条目的<u>右侧</u>：请您回答：“针对该条目所描述的情况，您是否需要（额外）专业帮助？”</p> <p>请您根据您自己真实的感受，回答左右两侧的问题，在对应的空格内打“√”。</p>											
条目	于您而言，这是否是一个问题？			您的问题及护理需求	针对这个问题，您是否需要专业帮助？						
	是	部分是	不是		需要更多	就目前这些即可	不需要				
<b>日常生活方面</b>											
<b>1</b>				身体日常护理（如洗澡），洗衣，穿衣，或如厕							
<b>2</b>				个人日常出行（骑自行车，开车，乘坐公共交通等）							
<b>3</b>				做一些较轻的家务劳动（如收拾房间等）							
<b>躯体症状方面</b>											
<b>4</b>				疼痛							
<b>5</b>				疲劳							
<b>6</b>				睡眠问题							
<b>7</b>				气促							
<b>8</b>				咳嗽							

9				皮肤瘙痒							
10				性功能障碍							
11				刺痛或麻木感							
12				(夜间)盗汗或潮热							
13				持续日常活动有困难							
14				难以完成手头工作							
15				依赖他人							
16				感觉无法掌控自己的生活							
<b>社会交往方面</b>											
17				和生活伴侣间的关系出现问题							
18				在与生活伴侣谈论自己疾病时感到有困难							
19				发现很难与他人讨论自己的疾病 (因为自己不愿意谈论)							
20				发现他人不愿意倾听与疾病相关的内容							
21				很难找到可以倾诉的人 (密友)							
<b>心理方面</b>											
22				抑郁情绪							
23				害怕躯体症状带来的痛苦 (即身体痛苦)							
24				害怕转移							
25				很难应对不可预知的未来							
26				很难表达自己的情绪							

灵性（精神）方面											
27				很难有效地投入/专心做事							
28				很难做到对他人有帮助							
29				难以理解死亡的含义							
30				难以接受自己的疾病							
经济方面											
31				因病产生额外支出							
32				因病造成收入减少							
信息需求方面											
33				信息不足，比如：关于疾病及治疗方面，提供帮助的机构以及其他替代治疗方法等							
其他											
				如果您还存在其它没有被提及到的重要的问题和/或需求，请在以下的空白处补充！							
				1.							
				2.							
				3.							
<p>请同时回答以下三个问题：</p> <p>1. 该量表是否能真正评价癌症患者存在的姑息护理问题与需求？</p> <p>_____</p> <p>2. 该量表的条目是否适合评价中国文化背景下的晚期癌症患者？</p> <p>_____</p> <p>3. 该量表的条目在理解上是否有困难？若有，请指出并提出您的修改建议。</p> <p>_____</p>											

**Appendix XV: EORTC Quality-of-life Questionnaire Core 30 (EORTC QLQ-C30),  
English version**

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

<b>Item</b>	Not at All	A Little	Quite a Bit	Very Much
1 . Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2 . Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
<b><u>During the past week:</u></b>	Not at All	A Little	Quite a Bit	Very Much
6 . Were you limited in doing either your work or other daily activities?	1	2	3	4
7 . Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8 . Were you short of breath?	1	2	3	4
9 . Have you had pain?	1	2	3	4
10 . Did you need to rest?	1	2	3	4
11 . Have you had trouble sleeping?	1	2	3	4
12 . Have you felt weak?	1	2	3	4
13 . Have you lacked appetite?	1	2	3	4
14 . Have you felt nauseated?	1	2	3	4
15 . Have you vomited?	1	2	3	4
16 . Have you been constipated?	1	2	3	4
17 . Have you had diarrhea?	1	2	3	4
18 . Were you tired?	1	2	3	4

19 . Did pain interfere with your daily activities?	1	2	3	4		
20 . Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4		
21 . Did you feel tense?	1	2	3	4		
<b><u>During the past week:</u></b>	Not at All	A Little	Quite a Bit	Very Much		
22 . Did you worry?	1	2	3	4		
23 . Did you feel irritable?	1	2	3	4		
24 . Did you feel depressed?	1	2	3	4		
25 . Have you had difficulty remembering things?	1	2	3	4		
26 . Has your physical condition or medical treatment interfered with your family life?	1	2	3	4		
27 . Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4		
28 . Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4		
For the following questions please circle the number between 1 and 7 that best applies to you						
29 . How would you rate your <u>overall health</u> during the past week?						
1	2	3	4	5	6	7
(Very poor)						(Excellent)
30. How would you rate your <u>overall quality of life</u> during the past week?						
1	2	3	4	5	6	7
(Very poor)						(Excellent)

**EORTC Quality-of-life Questionnaire Core 30 (EORTC QLQ-C30), Chinese version**

**EORTC 生活质量问卷-30 (QOL-30)**

我们想了解有关您和您的健康的一些情况，请您亲自回答下面所有问题，这里的答案并无“对”与“不对”之分，只要求在最能反映您情况的那个数字上画圈。您所提供的资料我们将会严格保密。

条目	没有	有点	相当	非常
1. 您从事一些费力的活动有困难吗, 比如说提很重的购物袋或手提箱?	1	2	3	4
2. <u>长距离行走</u> 对您来说有困难吗?	1	2	3	4
3. <u>户外短距离行走</u> 对您来说有困难吗?	1	2	3	4
4. 您白天需要待在床上或椅子上吗?	1	2	3	4
5. 您在吃饭、穿衣、洗澡或上厕所时需要他人帮忙吗?	1	2	3	4
<u>在过去一个星期内</u>	没有	有点	相当	非常
6. 您在工作 and 日常活动中是否受到限制?	1	2	3	4
7. 您在从事您的爱好或休闲活动时是否受到限制?	1	2	3	4
8. 您有气短吗?	1	2	3	4
9. 您有疼痛吗?	1	2	3	4
10. 您需要休息吗?	1	2	3	4
11. 您睡眠有困难吗?	1	2	3	4
12. 您觉得虚弱吗?	1	2	3	4
13. 您食欲不振 (没有胃口) 吗?	1	2	3	4
14. 您觉得恶心吗?	1	2	3	4
15. 您有呕吐吗?	1	2	3	4
16. 您有便秘吗?	1	2	3	4
17. 您有腹泻吗?	1	2	3	4
18. 您觉得累吗?	1	2	3	4
19. 疼痛影响您的日常活动吗?	1	2	3	4
<u>在过去一个星期内</u>	没有	有点	相当	非常

20. 您集中精力做事有困难吗, 如读报纸或看电视?	1	2	3	4		
21. 您觉得紧张吗?	1	2	3	4		
22. 您觉得忧虑吗?	1	2	3	4		
23. 您觉得脾气急躁吗?	1	2	3	4		
24. 您觉得压抑 (情绪低落) 吗?	1	2	3	4		
25. 您感到记忆困难吗?	1	2	3	4		
26. 您的身体状况或治疗影响您的家庭生活吗?	1	2	3	4		
27. 您的身体状况或治疗影响您的社交活动吗?	1	2	3	4		
28. 您的身体状况或治疗使您陷入经济困难吗?	1	2	3	4		
对下列问题, 请在 1-7 之间选出一个最适合您的数字并画圈。						
29. 您如何评价在过去一星期内您总的健康情况?						
1	2	3	4	5	6	7
(非常差)						(非常好)
30. 您如何评价在过去一星期内您总的生命质量?						
1	2	3	4	5	6	7
(非常差)						(非常好)



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