AN EXPLORATION OF THE FACTORS AND NEEDS ASSOCIATED WITH THE DEVELOPMENT OF A PALLIATIVE CARE PROGRAMME INTO THE PALESTINIAN HEALTHCARE SYSTEM FROM DIFFERENT KEY STAKEHOLDERS' PERCEPTIONS

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An Exploration of the Factors and Needs Associated with the Development of a Palliative Care Programme into the Palestinian Healthcare System from Different Key Stakeholders' Perceptions

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CERTIFICATE OF ORIGINALITY

I hereby declare that this thesis is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written, nor material that has been accepted for the award of any other degree or diploma, except where due acknowledgement has been made in the text.

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ABSTRACT

Background

Due to a transitional demographic change in population growth globally and an increase in life expectancy, the need for palliative care (PC) has increased, and this approach is urgently required for adoption and integration into healthcare systems (HCSs). The integration of PC services into mainstream HCSs and national policies has been identified as a core foundation for PC development. Despite the significant benefits of PC and the successful introduction of PC services in many countries worldwide, there is so much more to be done in low- and middle-income countries (LMICs), where these services are still largely inaccessible or unavailable. There are no PC services provided in Palestine - a country that experiences a significant increase in cancer diagnosis, population density, economic and financial shortages, drug shortages, and fragmented HCS. The unavailability of PC services in most LMICs, including Palestine, seems incongruous and unacceptable, given the importance of PC services. The unavailability of PC services is attributed to multiple challenges that continue to create obstacles to their availability and development. Considering that other countries have successfully developed PC for their HCS, there are lessons to be learned from them on how to integrate PC services into an existing HCS. Palestine may follow the innovations pioneered in other countries that have successfully integrated PC into their HCS. No research studies have been done focusing on the development of PC. It is apparent that high-level documents from governments or large organisations focus on the implementation and evaluation of PC strategies and models.

Aim and objectives

The objective of this doctoral research thesis is to explore the factors and needs associated with the development of a PC programme in the Palestinian HCS from different key stakeholders’ perceptions. Based on the WHO Public Health PC Model and the socioecological, this doctoral thesis is accomplished through three separate specific studies. Study One aimed to identify the unmet service needs of patients with advanced cancer, with the following five objectives: 1) to determine the prevalence of unmet supportive care needs of patients with advanced cancer; 2) to determine the level of emotional/psychological distress, pain, and other symptoms of patients with advanced cancer; 3) to assess the quality of life (QOL) and spiritual well-being of patients with advanced cancer; 4) to assess the sociodemographic and clinical variables that influence unmet needs; and 5) to examine the association between unmet needs and pain, symptoms, QOL, and the spiritual well-being of patients with advanced cancer.

Study Two aimed to assess PC knowledge, attitude, educational needs and HCS-related issues from the perspective of physicians and nurses, with the following six objectives: 1) to assess the physicians' and nurses' knowledge of PC; 2) to explore physicians' and nurses' attitudes about end-of-life-care and care of the dying; 3) to assess the needs for PC educational programmes from the perspective of physicians and nurses; 4) to ascertain how far PC services are available in hospitals from physicians' and nurses' perspectives; 5) to identify the key barriers to the provision of PC into the HCS from the perspective of physicians and nurses, and 6) to determine the factors that influence their knowledge and attitudes toward PC and care of the dying.

Study Three aimed to explore the perspectives of decision- and policy-makers on the provision of PC services, with the following five objectives: 1) to understand the extent to which PC has been identified as a priority from policymakers' perspectives; 2) to discuss with policymakers existing and new policies (strategies, plans, resources) that support the integration of PC into the structure of national HCSs; 3) to explore policymakers' perspectives about policies/work being done regarding strengthening human resources, such as training and education; 4) to identify which essential medicines for pain and symptom management are available in the HCS, their cost, and prescribing related-issues from policymakers' point of view; and 5) to identify the challenges and facilitators to the provision of PC from policymakers' perspective. The findings of these three studies will serve as a point for a discussion on how to move forward in the provision of a PC programme into the HCS of LMICs (Palestine).

Methods

A multi-method research design was employed in this doctoral research study to fulfil the overall study aim through three specific studies. The first two studies adopted a quantitative approach (survey), while the third study adopted a qualitative approach (interviews). In Study One, a hospital-based cross-sectional quantitative design was applied on a convenience sample of 379 patients aged 18 or above who had been diagnosed with advanced-stage cancer. Participants were recruited from two hospitals in the Gaza Strip (Al- Shifa Hospital and the European Gaza Hospital), which provide cancer care services to adult patients. A modified Supportive Care Framework for Cancer Care (SCNF) was adopted to guide the study's design and the selection of the outcome variables. The unmet needs of patients were assessed using the Arabic version of the short form of the Supportive Care Needs Survey (SCNS-SF34). Other instruments were utilised to examine their distress [The Arabic version of the Distress Thermometer (DT)], anxiety and depression [The Arabic version of the Hospital Anxiety and Depression Scale (HADS)], physical symptoms [The Arabic Questionnaire for Symptom Assessment (AQSA)], QOL [The Arabic version of the Functional Assessment of Cancer Therapy (FACT-G)], and spirituality [The Arabic version of the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp)].

In Study Two, a cross-sectional quantitative study design was also applied on a convenience sample of 169 professionals working in medical and oncology departments at one of the abovementioned two hospitals, where cancer patients are more likely to be treated, and follow-up care is provided. The Palliative Care Knowledge Test (PCKT), Bradley attitude questionnaire of end-of-life care, Frommelt Attitudes Towards Care of the Dying (FATCOD Form B), and PC Needs Assessment instrument were utilised for data collection. The WHO steps (forward translation, expert panel Back-translation, pre-testing, and final version) were adopted to translate and adapt all study instruments into Arabic-the mother tongue of study participants. Overall, all instruments' item-level content validity index and scale-level content validity index showed a high content validity. The Cronbach’s α coefficient for all instruments was also acceptable.

In Study Three, a descriptive, exploratory qualitative design was employed on a purposive sample of 12 decision and policymakers. Participants were identified as having a policy-making role in the HCS and were responsible for making executive and legislative decisions about matters related to services (including PC). These policymakers had prior experience, either clinical and/or managerial positions in health services developments. Face-to-face, semi-structured interviews were employed to collect the data.

The Statistical Package for the Social Science (SPSS) software version 25 was used to enter and analyse data of the first two studies. Missing data were replaced with multiple imputations. Descriptive statistics were utilized to summarise the personal characteristics of the participants as well as all instruments and their domains. A generalised linear regression analysis was employed to test the relationship between the variables. All statistical tests were two-tailed, and *p* values of less than 0.05 were treated as significant. A qualitative content analysis approach was adopted for analysis of the interview data of Study Three.

Results

Of the 379 advanced cancer patients recruited in Study One, 96.8% stated they had at least one ‘moderate to high’ level of unmet service needs. The most frequent unmet needs were those in the physical aspects of daily living (Mean 58.94; SD ± 20.93) and psychological (Mean 58.84; SD ± 19.49) domains. Most of the patients (91%) were physically ill and reported experiencing physical symptoms. About 86.3% had a high level of distress. Almost 90% reported signs of depression and anxiety. Although they felt that their spiritual well-being was good, their QOL was poor. Regression analyses identified that educational level, age, gender, marital status, cancer stage, cancer type, physical symptoms, depression, anxiety, distress, QOL, and spirituality were independently associated with unmet service needs.

A total of 169 healthcare professionals (137 nurses and 32 physicians) participated in Study Two. Professionals had insufficient knowledge of PC (Mean 42.8; SD±11.02), but had positive attitudes towards end-of-life-care (Mean 3.32; SD±0.38). Nurses had significantly higher scores on attitudes towards the care of dying than physicians (t= -4.980, *p* <0.001). A total of 75.1% of professionals would like to learn more about PC. Patients'/families’ avoidance of discussing issues around dying and a lack of training for staff related to PC were the two significant barriers in providing PC. Educational level and previous training were found to be associated significantly with knowledge and attitudes towards PC.

For Study Three, 12 decision and policymakers participated in the semi-structured interviews. The participants' ages ranged from 35 to 57 years. Most had more than 20 years of experience at the Ministry of Health. Four primary categories were identified from the interviews: 1) nature of current PC healthcare services; 2) potential benefits of PC; 3) challenges to PC provision; and 4) considerations for PC integration into the HCS. Each category had two or more subcategories. The current PC healthcare services provided to Palestinian patients with life-threatening illnesses and their families are not comprehensive and limited to symptomatic management. There is a Palestinian national strategic plan for developing PC; however, the goals of development are not clearly defined in the plan, and capabilities to implement the plan are inadequate. Education and training-related challenges were frequent challenges in the GS, followed by funding allocation and medication availability.

Conclusion

Palestinian advanced cancer patients exhibited a significantly high prevalence of unmet needs. Increasing unmet needs have contributed negatively to patients' physical and psychological well-being, and QOL. The high prevalence supports the argument that there is a need to develop a PC programme within the HCS, which would likely help enhance the care provided in the future. High unmet supportive care needs are attributed to insufficient PC knowledge and training of HCPs. Integration of formal and informal education on PC within care services and health curricula is a priority. Educational and training programmes should be comprehensive, covering PC's basic and advanced principles. The findings also help policymakers to build and implement the PC programme in the Palestinian HCS. Although PC is clearly stated in the Palestinian national strategic plan, the goals of development are not clearly defined in the plan, and capabilities to implement the plan are inadequate. Developing policies and plan to align with national laws could help enhance health services for patients and their families and resolve several challenges. Integration of PC into Palestinian universities’ educational curricula as an obligatory course and establishing advanced degree programmes in PC to overcome the shortage of PC specialists is required. The Palestinian government should collaborate with national and international partners to overcome the challenges of PC provision and implement PC into the Palestinian HCS.

PUBLICATION AND PRESENTATIONS ARISING FROM THE PHD STUDY

Referred journal articles arising from the thesis

1- Abu-Odah H, Molassiotis A, Liu J. Challenges on the provision of palliative care for patients with cancer in low- and middle-income countries: a systematic review of reviews. *BMC Palliat Care*. 2020 Apr 22;19(1):55. DOI: 10.1186/s12904-020-00558-5. [Chapter 3 of this thesis.]

2- Abu-Odah H, Molassiotis A, Liu J. Lessons learned from countries that have introduced palliative care services into their national health system: a narrative review. *J Palliat Care*. 2021 Feb 2:825859721989557. DOI: 10.1177/0825859721989557. [Chapter 4 of this thesis.]

Refereed journal articles and book chapters arising from other research training or collaborations with others during the PhD study

1- Abu-Odah H, Molassiotis A, Liu JWY. Global palliative care research (2002-2020): bibliometric review and mapping analysis. *BMJ Support. Palliat. Care.* DOI. 10.1136/bmjspcare-2021-002982

2- Molassiotis A, Chunlan G, Abu-Odah H, Caryn W, Loke L. Evolution of disaster nursing research in the past 30 years (1990 -2019): A bibliometric and mapping analysis. *Int. J. Disaster Risk Reduct.* 2021 Mar 30:102230. DOI.org/10.1016/j.ijdrr.2021.102230

3- Abu-Odah H., Mikati D., Arawi T. Deconstructing palliative care in areas of armed conflict: needs, challenges, and concerns. *In: Laher I. (eds) Handbook of Healthcare in the Arab World. Springer,* Cham. 2021 https://doi.org/10.1007/978-3-319-74365-3_225-1.

4- Abu-Odah H, Ramazanu S, Saleh E, Bayuo J, Abed Y, Salah MS. COVID-19 pandemic in Hong Kong and Gaza Strip: lessons learned from two densely populated locations in the world. *Osong Public Health Res Perspect*. 2021 Feb;12(1):44-50. DOI: 10.24171/j.phrp.2021.12.1.07.

Under review articles

1- Abu-Odah H, Molassiotis A, Liu J. Analysis of the unmet needs of Palestinian palliative cancer patients and their relationship to emotional distress: results from a cross-sectional study. *BMC Palliat Care* (Minor revision) [Chapter 7 of this thesis.]

2- Abu-Odah H, Molassiotis A, Liu J. Assessment of the educational and healthcare system-related issues from physicians and nurses' perspectives before developing a palliative care program within the Palestinian healthcare system: a cross-sectional study. *The Journal of Hospice and Palliative Nursing* (Accepted) [Chapter 8 of this thesis.]

3- Abu-Odah H, Molassiotis A, Liu J. Gathering policymakers' perspectives as an essential step in planning and implementing palliative care services at a national level: an example from a limited resourced country. *BMC Palliat Care* (Under review) [Chapter 9 of this thesis.]

4- Abu-Odah H, SU JJ, Wang M, Lin R, Bayuo J, Musa S, Molassiotis A. Palliative care landscape in the COVID-19 era: a bibliometric network analysis of global research. *J Palliat Care*. (Under review)

5- Abu-Odah H, SU JJ, Musa SS. Unwillingness or reluctance of Palestinians to get COVID-19 vaccine: the reasons behind it and how to persuade them? *International Journal of Infectious Diseases* (Under review)

6- Abu-Odah H, Said B N, Nair CS, Allsop JM, Currow D, et al. Identifying barriers and facilitators of translating research evidence into clinical practice: a systematic review of reviews. *Health & Social Care in the Community* (Under review)

7- Bayuo J, Abu-Odah H, Owusuaa Koduah A. Components, models of integration, and outcomes associated with palliative/ end-of-life care interventions in the burn unit: A scoping review. *J Palliat Care* (Under review)

8- SU JJ, Abu-Odah H, Bayuo J, Lin R, LUO X, Szeto S, Molassiotis A. Monetary obligation and reciprocity in caregiving relationship for stroke care: A false dichotomy from hired caregivers' view. *Health & Social Care in the Community* (Under review)

9- SU JJ, Paguio J, Abu-Odah H, Zhou H. Acceptability of a nurse-led eHealth cardiac rehabilitation program for patients with coronary heart disease. *The Journal of Cardiovascular Nursing* (Under review)

10- Bayuo J, Agbeko A, Acheampong E, Abu-Odah H, Davids J. Palliative care interventions for adults in the emergency department: a review of components, delivery models, and outcomes. *Academic Emergency Medicine* (Under review)

11- Musa SS, Yusuf A, Zhao S, Abu-Odah H, Saad FT, Adamu L, He D. COVID-19 Pandemic: Modeling the Impacts of Possible Relapse and Reinfection in Saudi Arabia. *Bulletin of Mathematical Sciences* (Under review)

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1- Abu-Odah H, Molassiotis, A and Liu J. Challenges on the provision of palliative care for patients with cancer in low- and middle-income countries: a systematic review of reviews. [Oral Presentation]. *The 23rd East Asian Forum of Nursing Scholars*. (January 10 –11, 2021), Chiang Mai, Thailand

2- Abu-Odah H, Molassiotis, A and Liu J. Assessing educational and healthcare system-related issues before developing a palliative care program within the Palestinian healthcare system. [Poster Presentation]. *Oceanic Palliative Care Virtual Conference 2021| 21OPCC*. (September 7–10, 2021), Australia

Newsletters have mentioned doctoral student activities

1-International Association for Hospice & Palliative Care (IAHPC). Members' Impact. Volume 22, No 10, October 2021. https://hospicecare.com/what-we-do/publications/newsletter/2021/10/membership-matters/

2- European Association for Palliative care (EAPC). Palliative care in the Palestine-Gaza Strip. Posted on June 10, 2020.
https://eapcnet.wordpress.com/2020/06/10/palliative-care-in-the-palestine-gaza-strip/

3- School of Nursing-The Hong Kong Polytechnic University. PhD student lays the foundation for palliative care in Palestine. Feature Story. Posted on October 30, 2020.

https://sn.polyu.edu.hk/en/news_events/features/PhD_student_lays_the_foundation_for_palliative_care_in_Palestine/index.html

4- School of Nursing-The Hong Kong Polytechnic University. PhD project contributes to palliative care in Palestine. Annual report 2020, Page 52-53.

https://sn.polyu.edu.hk/filemanager/common/publication/annual_report_2020.pdf

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Hammoda ABU-ODAH

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LIST OF ABBREVIATIONS

An abbreviation	**Full-term**
AMSTAR	Assessment of Multiple Systematic Reviews
AQSA	Arabic Questionnaire for Symptom Assessment
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DT	Distress Thermometer
EGH	European Gaza Hospital
EOL	End-of-Life
EoLC	End-of-Life-Care
ESAS	Edmonton Symptom Assessment System
FACIT	Functional Assessment of Chronic Illness Therapy
FACIT-Sp	Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being
FATCOD	Frommelt Attitudes Towards Care of the Dying
GS	The Gaza Strip
HADS	Hospital Anxiety and Depression Scale
HCPs	Healthcare Professionals
HICs	High-Income Countries
INSA	International Narrative Systematic Assessment
LMICs	Low-and Middle-Income Countries
MECs	Middle East Countries
MeSH	Medical Subject Heading
MOH	Ministry of Health
NGOs	Non-Governmental Organizations
PC	Palliative Care
PCKT	Palliative Care Knowledge Test
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QOL	Quality of Life
SCNF	Supportive Care Framework for Cancer Care
SCNS-SF34	Supportive Care Needs Survey Short Form 34
SEM	Socio-Ecological Model
UK	United Kingdom
USA	The United States of America
WHO	World Health Organization

CHAPTER (1): INTRODUCTION

1.1 Introduction

This chapter will present an introduction of this doctoral study that covers the background and statement of the research problem and the organisation of this doctoral research thesis.

1.2 Background and statement of the research problem

Palliative care (PC) is considered one of the most holistic and appropriate approaches to provide specialised medical and nursing care for patients with chronic illness at end-of-life (EOL) (Gomez-Batiste et al., 2013). PC has received growing attention from the World Health Organization (WHO), which has defined PC as “an approach that improves the quality of life of patients and their families through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Stjernsward, Foley, & Ferris, 2007; World Health Organization, 2002, p.84; 2017). PC is intended to relieve symptoms that appear when the disease progresses and allows patients to live comfortably rather than cure the disease (Kaye et al., 2015; World Health Organization, 2018a). Due to a transitional demographic change in population growth globally and an increase in life expectancy, the need for PC has increased, and the application of this approach is urgently required to be adopted and integrated into the healthcare system (Centeno, Lynch, Donea, Rocafort, & Clark, 2013).

The integration of PC services into mainstream healthcare systems (HCSs) and national policies are identified as a core foundation for PC development (Worldwide Hospice Palliative Care Alliance, 2014). It has attracted increasing attention and interest from the WHO due to its benefits. In 2014, the WHO called on countries to implement policies to ensure the integration of PC into national health services globally (World Health Organization, 2014). Many countries have responded to this call by using different strategies, such as facility-based hospices or community-based services with home care; however, others are still struggling with the development of PC services in their HCS. For instance, the United States of America (U.S.A.), the United Kingdom (UK), and Australia responded to the WHO's call and have been recognised as leaders in PC development in terms of the quality of PC services. In addition, Malaysia and Uganda, both low-and middle-income countries (LMICs), have striven towards improvements in PC and have been ranked at the top of the list of countries with a high Quality of Death Index, compared to other LMICs (The Economist Intelligence Unit, 2015). Regardless of the successful implementation of PC services in many countries, there is so much more to be done in countries where these services are still largely inaccessible or unavailable (Connor & Sepulveda Bermedo, 2014).

Despite the significant benefits of the PC approach, only about 5.6 million out of 40 million patients with a life-threatening illness receive PC services worldwide (World Health Organisation, 2020b). Most of these services are available and provided in high-income countries (HICs) (Connor & Sepulveda Bermedo, 2014). In many LMICs, PC services are not available, and this is attributed to multiple challenges that continue to create obstacles to their availability and development. For instance, most PC models that exist are developed and implemented in Western countries (Sachedina, 2005; Sarhill, LeGrand, Islambouli, Davis, & Walsh, 2001) and may not be congruent with some cultural issues (e.g., religion, beliefs, and norms) in other countries. Healthcare professional (HCP)-related issues, such as lack of training and education, are other obstacles preventing the adoption of PC in LMICs (Abu-Odah, Molassiotis, & Liu, 2020, 2021; Hawley, 2017). In addition, related administrative matters, such as access to opioids (Abdel-Razeq, Attiga, & Mansour, 2015; Hawley, 2017) and the unwillingness of patients and families to be referred to specialised PC units may also prevent the adoption of PC services.

The WHO has undertaken some action measures to promote and implement PC in the HCS of LMICs (World Health Assembly, 2014); however, these measures have faced many obstacles during implementation. LMICs are experiencing a significant gap between demand and supply of PC services, and therefore, immediate actions are required to overcome these impediments (Saini & Bhatnagar, 2016). The urgency is heightened by the fact that the burden of non-communicable diseases is escalating in LMICs, including cancer (World Health Organization, 2018a). Most cancer patients are diagnosed during the late stage of the disease and, therefore, they are in desperate need of adequate PC (Knaul, Frenk, & Shulman, 2011). Furthermore, cancer being the largest group, countries often focus on developing their PC programmes before introducing PC to other groups of patients with EOL and PC needs (Connor & Sepulveda Bermedo, 2014).

The unavailability of PC services in most LMICs seems incongruous and unacceptable, given the importance of PC services to patients and their families, HCPs, and HCSs. For this importance, the issue has received the focused attention of a doctoral researcher. Several systematic reviews have been done to identify the challenges to the provision of PC; most of these studies generally focused on patients with life-threatening diseases, with limited attention given to cancer patients. Furthermore, no systematic overview focused on LMICs. Therefore, the doctoral researcher applied a systematic review to identify the challenges in the provision of PC in LMICs (Abu-Odah et al., 2020). This systematic review demonstrated that the main challenges of personal and HCSs included knowledge deficits and misunderstandings on the part of patients, their families, the public, and HCPs about PC, and inadequate numbers of trained workers. Further, limited physical infrastructure, insufficient drugs for symptom relief and a lack of a comprehensive national plan for developing PC were recognised as the core organisational and policy-level challenges. This review concluded that understanding the challenges, from policy and organisation down to the individual (patients and HCPs) levels could help in the development of PC pathways in LMICs, and it could be used as a guide to developing a model for the provision of PC services. Considering that other countries have successfully developed PC into their HCS, there are lessons to be learned from each other on how to integrate PC services into an existing HCS. LMICs may follow the innovations pioneered in other countries that have successfully integrated PC into their HCS.

It is of the essence to learn from countries demonstrating enhanced PC practices before the development of a new PC programme in a given country. Such practices could be used as a guide and address barriers that may hinder the development of PC at a national level. Hence, the doctoral researcher conducted another review to gain a broad overview of national approaches to PC implementation into HCSs in countries with PC identified within their national policies and strategies (Abu-Odah et al., 2021). Findings underscored that education and appropriate policies were the most frequent strategies covered by all of the countries that were included. Under education, information about training HCPs was needed for the effective introduction of a PC programme. Reviewing standards of care required to deliver PC effectively and financial support for PC service development were considered the central policies needed. Furthermore, partnerships and collaboration across health systems, as well as providing care based on patient needs, were required for the provision of a PC programme. The review concluded that best practices could be achieved by focusing on educational and policy-based strategies by identifying patients' needs, HCPs' knowledge and training, and incorporating stakeholders' perspectives.

Notwithstanding the importance of the PC programme as mentioned above, no research studies have been done focusing on PC development. It is apparent that high-level documents from governments or large organisations and non-governmental organisations (NGOs) have focused on implementing and evaluating PC strategies. Therefore, this doctoral research study has addressed this gap by exploring the factors and needs associated with developing a PC programme into the Palestinian HCS from different key stakeholders' perspectives. This study focuses on Palestine-Gaza Strip (GS), where the situation in terms of religion, finances, the economy, the HCS, and access to services often differs greatly from that in other countries. Most of the Palestinian people are Muslims who believe in Allah (God) and in the inevitability of death, which is Allah's responsibility (Iranmanesh, Razban, Tirgari, & Zahra, 2014a). This beliefs and norms help patients to cope and accept illness and die in peace (Wing & Handzo, 2014). Financial resources in Gaza are scarce, poverty levels are high, financial and administrative coordination are poor, and healthcare resources are in short supply (Abu Hamad, Skaik, & Abu-Odah, 2016). Healthcare services, such as PC, targeted cancer therapies, and bone-marrow transplantation are limited or fragmented in the GS (World Health Organization, 2019a). Furthermore, there is a shortage of specialist physicians, and limited availability of drugs (World Health Organization, 2019a).

A multi-method research design was adopted in this doctoral research study because it is considered the best way to fulfil the overall study aim through three specific studies. The first two studies adopted a quantitative approach (survey) to identify the unmet service needs of patients with advanced cancer (Study 1) and to assess the educational and HCS-related issues that HCPs may face, and how these affect the development of PC services (Study 2). The third study adopted a qualitative stance (interviews) to explore the perspectives of decision and policymakers on the provision of PC services. The findings of these three studies will serve as a point for a discussion on how to move forward in the provision of a PC programme into the HCS of LMICs (Palestine).

1.3 Thesis organisation

This doctoral research thesis comprises 10 chapters, including this introductory chapter. Chapter Two displays detailed narrative literature about PC related-concepts and the Palestinian context. Chapters Three and Four present the two reviews conducted by the doctoral researcher and end by identifying the research gap that needs further attention. Chapter Five illustrates the conceptual framework. The details of the doctoral thesis research methodology, including research design, aim, objectives, and research method, are presented in Chapter Six. The three studies' background, objectives, methods, results, discussion, and implications are presented separately in Chapters Seven, Eight, and Nine, respectively. Discussion and conclusion of the entire doctoral project are presented in Chapter Ten.

CHAPTER (2): LITERATURE REVIEW OF PC RELATED-CONCEPTS AND THE PALESTINIAN CONTEXT

2.1 Introduction

This chapter displays narrative literature relevant to the current thesis. It provides general information about PC definition, history, and significance. The chapter also covers a detailed description of the global burden of cancer, focusing on LMICs, including Palestine.

2.2 Definition and evolution of the concept of palliative care

Palliative care is a multidisciplinary approach to providing specialised care for patients with life-threatening illness to alleviate the physical, social, spiritual, and psychological symptoms accompanying their illness (Gomez-Batiste et al., 2013). It evolved in England in the 1960s, which witnessed meaningful development of modern PC, with its roots in the hospice philosophy. Dame Cicely Saunders (1918-2005) is considered the mother of hospice development and established St Christopher's Hospice in England in 1967. During the 20th century, the hospice movement and philosophy agreed on the use of medical technology to prolong life. The hospice movement shed light on the quality of patient life during the disease trajectory. This philosophy focused on achieving a good QOL and better conditions for patients with chronic disease by providing comprehensive care for them and their families. To achieve a better QOL, Saunders brought the concept of "total pain" to the surface, including physical, psychological, social, and spiritual dimensions. Saunders stressed that embracing relatives in the care of patients at the EOL is of utmost importance (Lutz, 2011). The success story and achievement of Christopher's Hospice led to hospice development across the globe. During the 1970s, the hospice ideal occupied other settings in the UK (Clark, 2007). Hospice services started in the rest of Europe in the 1980s.

In 1989, the WHO defined PC as a global concept embedded from Saunders' concept of "total pain". The definition was updated and revised in 2002, such that it now reads: "PC is an approach that improves the quality of patients' lives as well as their families through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, 2002, p. 84). The revised definition covers all patients with life-threatening illnesses, rather than cancer alone. All concepts/definitions of PC that arose after 2002 are embedded from the WHO's definition today. For example, the European Association for Palliative Care (EAPC) describes PC as comprehensive and active care. This means improving the quality of a patient's life and his relatives socially, psychologically, and existentially, particularly when looking after terminally ill patients (Van der Steen et al., 2014).

The definition of PC was redefined in 2018 by the Lancet Commission on Global Access to Palliative Care and Pain Relief, which focuses on the relief of serious health-related suffering (Radbruch et al., 2020). "The global burden related suffering" was described as a new construct by the Lancet commission for PC and pain relief. It is defined as suffering associated with PC. Thus, burden-related suffering was then estimated using the mortality data of 20 conditions adjusted according to physical and psychological suffering, instead of focusing only on number of deaths in the population. The new definition is comprehensive, which includes family members and caregivers as the unit of care (Radbruch et al., 2020).

The term “PC” is often used synonymously with “end-of-life care”, “hospice care”, and “terminal care” - terms that convey the same topic in the literature. The European guidelines use the three terms (PC, end-of-life care and hospice care) interchangeably, referring to the care provided to patients with life-threatening illnesses. In contrast, the term “terminal care” is linked with a patient’s condition in the last days/hours of life (Radbruch & Payne, 2010).

2.3 Significant of palliative care

Palliative care is the most holistic and appropriate approach, which helps patients with chronic illnesses at EOL live comfortably for as long as possible (Kaye et al., 2015; World Health Organization, 2018a). The critical principle of PC is to help patients and their families live decently (World Health Organisation, 2013a). PC’s purpose is to enhance patient QOL with effective pain relief and other distressing symptoms, as much as possible. It emphasises that PC can be applied as early as possible in the course of any chronic, ultimately fatal illness (World Health Organization, 2002). Several studies have shown the significant benefits of PC on patients and their family life and satisfaction (Bernard, Berchtold, Strasser, Gamondi, & Borasio, 2020; Kristanti, Setiyarini, & Effendy, 2017) and how this contributes to reducing health care usage (May et al., 2018) and enhances resource utilisation (May et al., 2018; Shugarman et al., 2004).

2.4 Global burden of cancer and its consequences

Cancer includes more than 100 different diseases of unknown aetiology (American Cancer Society, 2018). It is an increasingly significant reason for morbidity and mortality worldwide (Bray et al., 2018). In 2020, approximately 19.3 million new cancer cases were diagnosed globally (Sung et al., 2021). Cancer accounts for about

10 million deaths; 70% of deaths are registered in LMICs (Sung et al., 2021; World Health Organization, 2018a).

LMICs are countries whose gross national income ranges from $996 and $3,895 (World Bank Group, 2017). These countries are experiencing an increase in the burden of non-communicable diseases, including cancer (World Health Organization, 2018a). By 2035, about two-thirds of new cancer cases will be diagnosed in LMICs (Tefferi et al., 2015). This will put enormous pressures and strain on the HCSs of LMICs (International Atomic Energy Agency, 2019) as most of these countries are not well-prepared or organised to manage this growing burden, and suffer from insufficient budget allocation and limited resources (Prager et al., 2018). Treating such diseases places high demands on health services in countries with scarce resources, resulting in high direct and indirect care costs.

The consequences of cancer and its treatments have negative impacts on the QOL of patients and their families (Surbone et al., 2010). The diagnosis of cancer frequently results in a complex set of issues that patients and their families must confront (Holland, 2003). Alleviating the consequences of cancer and providing high-quality care, including symptom management, handling side effects, and providing social, psychological, spiritual and emotional support, are recognised as high priority aspects that should be considered (Pérez-Cruz et al., 2019).

2.5 Why focus on cancer in palliative care development

Almost all cancer patients in LMICs are diagnosed at a late stage, making them more inclined to experience severe pain and distress (Abu Hamad et al., 2016), respiratory and gastrointestinal problems, and loss of consciousness, all related to disease progression (Mercadante, Masedu, Valenti, Mercadante, & Aielli, 2016). Considering that, patients with cancer are in a high priority in need of PC at the end-stage-of-life. Furthermore, being the largest group, countries often focus on developing their PC programmes before introducing them to other groups of patients with EOL and PC needs (Connor & Sepulveda Bermedo, 2014). While it is acknowledged there is an ethical imperative to provide PC for all patients with incurable and life-limiting illnesses and that PC priorities, particularly on the African continent, may be more related to treating patients with HIV/AIDS and related comorbidities and co-diseases, the focus is on cancer patients for two reasons. First, cancer rates, particularly in Africa, are expected to grow by 400% over the next 50 years (Morris, 2003), 70% of cancer deaths take place in LMICs, and 70% of patients diagnosed with cancer in LMICs are diagnosed at an advanced stage (Bray et al., 2018; World Health Organization, 2018a). Second, in the Palestinian context, cancer is the second leading cause of death (at 14%), with an expected significant increase in the cancer burden that will create challenges in the delivery of care to patients, who are mostly diagnosed at a late stage of the disease (Palestinian Ministry of Health, 2019). The African Palliative Care Association has also recently advocated for more PC to be provided to cancer patients, along with more access to opioids and other essential medicines (Ddungu, 2011).

2.6 Palestinian context

2.6.1 Cancer population in Gaza Strip

The GS is a narrow band of land populated by 2,018,000 people (Palestinian Central Bureau of Statistics, 2017). It is 45 kilometres long and 6-12 kilometres wide, covering 378 square kilometres (Palestinian Central Bureau of Statistics, 2017). The Palestinian Ministry of Health (MOH) report indicates an increasing trend of cancer cases among the Gazan people. Cancer is currently the second major cause of morbidity and mortality after cardiovascular disease (Palestinian Ministry of Health, 2019). Breast, colorectal, lymphoma, leukaemia, and lung are the most common cancers among adults (Palestinian Ministry of Health, 2019). The reported number of new cancer cases in 2005 was 32.7 per 100,000 in the GS; 45% of all cases were in men and 55% in women (Husseini et al., 2009). Between 2006 and 2010, cancer increased from 567 index cases in 2006 to 934 cases in 2010 (Palestinian Ministry of Health, 2013b). In 2015, the crude cancer incidence rate for the entire population reached 87.9 per 100,000 persons. It is apparent that the number of cases increases over time (Palestinian Ministry of Health, 2016).

The latest cancer report shows that the total number of registered cancer cases from 2011-2015 was 6,813 cases, with an incidence ratio range from 64.2 to 87.9/100,000. Cancer was more common in women than men (55% vs 45% respectively) (Figure 1). For males, the most common cancer is colorectal cancer, which forms 11.7% of all male cancers (Palestinian Ministry of Health, 2019). For females, and as expected, breast cancer is the most common cancer, forming 34.8% of cancers among women.

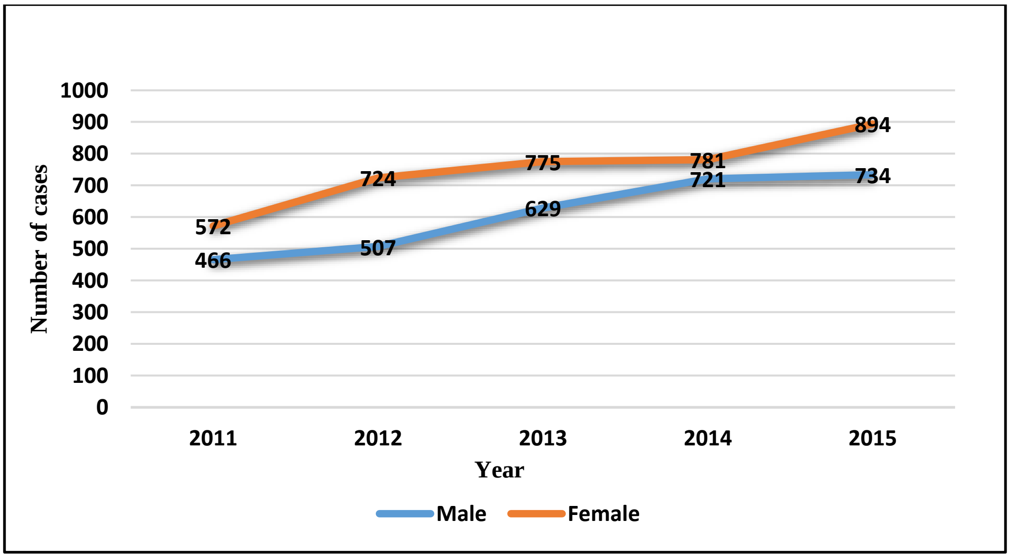


Figure 1: Incidence of cancer in the Gaza Strip (2011-2015)

2.6.2 Cancer and palliative care services in the Gaza Strip

The context of Palestine has differed from that of other countries in the world, as Palestine faces many challenges, such as scarce financial resources, high poverty levels, limited infrastructure, and political divisions, since 2007 (Abu Hamad et al., 2016; Maziak, 2009). Despite these challenges, primary health care services rank as the best among neighbouring Arab countries; however, tertiary health care services need improvements, particularly cancer care (Halahleh & Gale, 2018). Different health sectors deliver healthcare services to Palestinian citizens, including MOH, United Nations Relief and Works Agency for Palestine Refugees in the Near East, NGOs, and private for-profit service providers. The MOH provides most of the healthcare services (primary, secondary and tertiary). The MOH purchases advanced medical services through referring patients to neighbouring countries, other private institutions and NGOs' healthcare facilities, including local Palestinian facilities.

Oncology services are provided by the three MOH hospitals: Al-Shifa, European Gaza Hospital (EGH), and El-Rantisi Hospital (Palestinian Ministry of Health, 2020). The total number of oncology beds in the three hospitals is around 75. Cancer care is improving in Palestinian hospitals. However, services like PC, targeted cancer therapies, and bone-marrow transplantation is limited or unavailable (Halahleh & Gale, 2018; World Health Organization, 2019a). Furthermore, the shortage of specialist physicians has limited the availability of chemotherapy (World Health Organization, 2019a). Political divisions also play a role in the chronic lack of medication, suboptimal financial and administrative coordination, inadequate infrastructure, and limited human healthcare resources (Halahleh & Gale, 2018; World Health Organization, 2011).

The national healthcare strategy clearly stated the importance of cancer services. They should be given priorities at different levels, including prevention, control, management, and follow-up (Palestinian Ministry of Health, 2013a). Despite the importance, gaps in the cancer control strategy were reported (Abo Ammer, 2012); these gaps are mainly related to poor financial and administrative coordination, shortages in human healthcare resources, and inadequate staffing (Abu Hamad et al., 2016). In addition, oncology departments are housed in inappropriately designed buildings, and there are shortages of necessary equipment and supplies (Abo Ammer, 2012). Cancer diagnostic services have faced many barriers leading to delays in the diagnosis of the disease. Delayed diagnosis of patients and inadequate treatments necessitate PC in the GS to help patients to live comfortably and alleviate their pain and distress. There is a desperate need to fill gaps in the diagnosis of cancer (Histopathology), promoting lab services pertaining to oncology (Fluro-cytology, cytogenetic analysis, molecular analysis/Karyotyping). Furthermore, the PC services provided to patients with cancer within government hospitals are limited or unavailable (Halahleh & Gale, 2018; Khleif & Imam, 2013), an area that requires considerable investment.

2.7 Chapter summary

This chapter presents a comprehensive literature review of PC and its development, the burden of cancer worldwide, and LMICs. It also focuses on Palestinian content, and how Palestinians suffer from shortages in human healthcare resources, inadequate staffing, and unavailability of PC services within government and private hospitals in the GS. The following two chapters will present both reviews conducted by the doctoral researcher to identify the research gap and present the crucial constructs that should be focused on before the development of a PC programme at a country level.

CHAPTER (3): SYSTEMATIC REVIEW: IDENTIFICATION OF THE CHALLENGES TO PALLIATIVE CARE PROVISION IN LMICS

3.1 Introduction

This chapter presents the systematic review conducted by the doctoral researcher to identify challenges to the provision of PC in LMICs. It presents the review in detail, including the research gap, aim and objectives, methods, findings, discussion, and conclusion. The chapter ends with a summary highlighting the main findings that need to be addressed. This review has already been published in an international peer-reviewed journal (Abu-Odah et al., 2020). Minor modifications have been applied to this published review in terms of citation styles and reference lists, to adhere to the structure and guidelines of this doctoral thesis. Permission to use the article in this doctoral thesis has been granted by the publisher (Abu-Odah H, Molassiotis A, and Liu J, Challenges on the provision of PC for patients with cancer in low- and middle-income countries: a systematic review of reviews, BMC Palliat Care. 2020 Apr 22;19(1):55. DOI: 10.1186/s12904-020-00558-5), as this is “an open-access article distributed under the Creative Commons Attribution 4.0 International License, which permits use, adaptation, distribution, and reproduction in any medium or format, provided the original work is properly cited”.

3.2 Review gap, aim, and questions

Several studies have been conducted worldwide to assess the challenges in the provision of PC services. Donkor, Luckett, Aranda, and Phillips (2018) assessed challenges in LMICs, Fadhil, Lyons, and Payne (2017) focused on similar issues in the Eastern Mediterranean region, and Aldridge et al. (2016) dedicated the challenges to integrating PC in the U.S. These studies generally focused on patients with life-threatening diseases, with limited attention given to cancer patients. In addition, no systematic overview synthesising the challenges and possible facilitators on the provision of PC in LMICs has been reported. Therefore, this current review synthesises evidence from previous literature and provides a comprehensive mapping of the existing literature about challenges and possible facilitators in the provision of PC for cancer patients in LMICs. The identification and the synthesis of the key challenges and possible facilitators was based on the socio-ecological model (SEM) (McLeroy, Bibeau, Steckler, & Glanz, 1988). This model is widely used across studies (Golden & Earp, 2012; Ma, Chan, & Loke, 2017). It has four levels: personal level, organisational level, health system level, and policy/payment level (Figure 2). This paper seeks to answer the following questions: (1) What are the challenges associated with the provision of PC for cancer patients in LMICs? and (2) What are the possible facilitators that can overcome these challenges?

Figure 2: A modified socioecological framework
(McLeroy et al., 1988).

3.3 Methods

3.3.1 Study design

This is a systematic review of reviews aimed at providing a broad overview of the field and mapping the current body of work on the challenges of providing PC services to cancer patients. This review is reported in accordance with the PRISMA (preferred reporting items for systematic reviews and meta-analyses) guidance (Moher, Liberati, Tetzlaff, & Altman, 2009).

3.3.2 Search sources and strategies

Searches were performed on seven electronic databases: PubMed, EMBASE, SCOPUS, PsycINFO, Web of Sciences, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Cochrane Database of Systematic Reviews. The search was specific to review articles published in the English language in or after 2000 to capture information more relevant to current HCSs, and given that PC was defined by the WHO in 1998 and optimised in 2002 (World Health Organization, 2017).

The search strategy of this systematic review was based on the PCC (population, concept, and context) framework (Hannes & Macaitis, 2012; Ng et al., 2014) and was as follows: Population: adult patients with cancer; Concept: challenges and possible facilitators; and Context: LMICs. The following terms were included in the search strategy; first, terms for “challenges”, such as “barriers”, “problems”, “limitations”, and “obstacles” were included. Second, words synonymous to “provision”, such as ‘bringing”, and “access” were also added in the search. Third, terms like “palliative care”, such as “palliative medicine”, “hospice care”, “supportive care”, “terminal care”, and “end-of-life care” were further added. Fourth, terms for “cancer”, such as “tumor”, “neoplasms”, “terminal cancer”, “metastatic cancer” and “malignant” were included. Finally, expressions for “review*” were included. All of these terms were linked using the Boolean operator "AND", and Medical Subject Heading (MeSH) terms were used. Table 1 shows the detailed search terms for PubMed and CINAHL databases adjusted appropriately for the other databases.

3.3.3 Criteria for considering studies in this review

Inclusion criteria

- Review articles only to synthesise the highest level of evidence, to make better decisions
- Review focusing on patients diagnosed with cancer;
- Review focusing on LMICs;
- Review focusing on patients aged at least 18 years, or the word ‘adults’ is used by authors in the description of the samples;
- Published in journals in or after 2000 to capture information more relevant to PC updated definition; and
- Written in English.

Exclusion criteria

- Informal literature review (review does not have defined research questions and does not have defined search process) or discussion papers;
- Studies with non-cancer diseases or mixed populations without provision of separate results for cancer patients; and
- Protocols, editorial comments, conference abstracts, guidelines, and policies

Table 1: Selected search strategies for review articles

Search	Search Term	Hits
PubMed		
S1	Search ((((challenges[Title/Abstract]) OR obstacles[Title/Abstract]) OR limitations[Title/Abstract]) OR problems[Title/Abstract]) OR barriers[Title/Abstract]	1051391
S2	Search ((provision[Title/Abstract]) OR bringing[Title/Abstract]) OR access[Title/Abstract]	350573
S3	Search (((((palliative care[MeSH Terms]) OR palliative medicine[Title/Abstract]) OR hospice care[Title/Abstract]) OR supportive care[Title/Abstract]) OR terminal care[Title/Abstract]) OR end of life care[Title/Abstract]	72182
S4	Search (((((cancer[Title/Abstract]) OR tumor[Title/Abstract]) OR neoplasms[Title/Abstract]) OR terminal cancer[Title/Abstract]) OR metastatic cancer[Title/Abstract]) OR malignant[Title/Abstract]	2462108
S5	Search review*[Title/Abstract] Sort by: Best Match	1878924
S6	S1 AND S2 AND S3 AND S4 AND S5	88
S7	S1 AND S2 AND S3 AND S4 AND S5 (Limiters - Date of Publication: 20000101-20190110; English Language)	79
CINAHL		
S1	TI challenges OR TI barriers OR TI problems OR TI limitations OR TI obstacles	68,419
S2	AB challenges OR AB barriers OR AB problems OR AB limitations OR AB obstacles	373,747
S3	AB provision OR AB bringing OR AB access	110,926
S4	TI provision OR TI bringing OR TI access	30,549
S5	TI palliative care OR TI palliative medicine OR TI hospice care OR TI supportive care OR TI terminal care OR TI end of life care	22,990
S5	AB palliative care OR AB palliative medicine OR AB hospice care OR AB supportive care OR AB terminal care OR AB end of life care	25,576
S7	AB cancer OR AB tumor OR AB neoplasms OR AB terminal cancer OR AB metastatic cancer OR AB malignant	270,124
S8	TI cancer OR TI tumor OR TI neoplasms OR TI terminal cancer OR TI metastatic cancer OR TI malignant	252,261
S9	TI review*	176,934
S10	AB review*	366,746
S11	S1 OR S2	416,347
S12	S3 OR S4	130,606
S13	S5 OR S6	37,837
S14	S7 OR S8	392,676
S15	S9 OR S10	473,045
S16	S11 AND S12 AND S13 AND S14 AND S15	74
S17	S11 AND S12 AND S13 AND S14 AND S15 (Limiters - Date of Publication: 20000101-20190110; English Language)	71

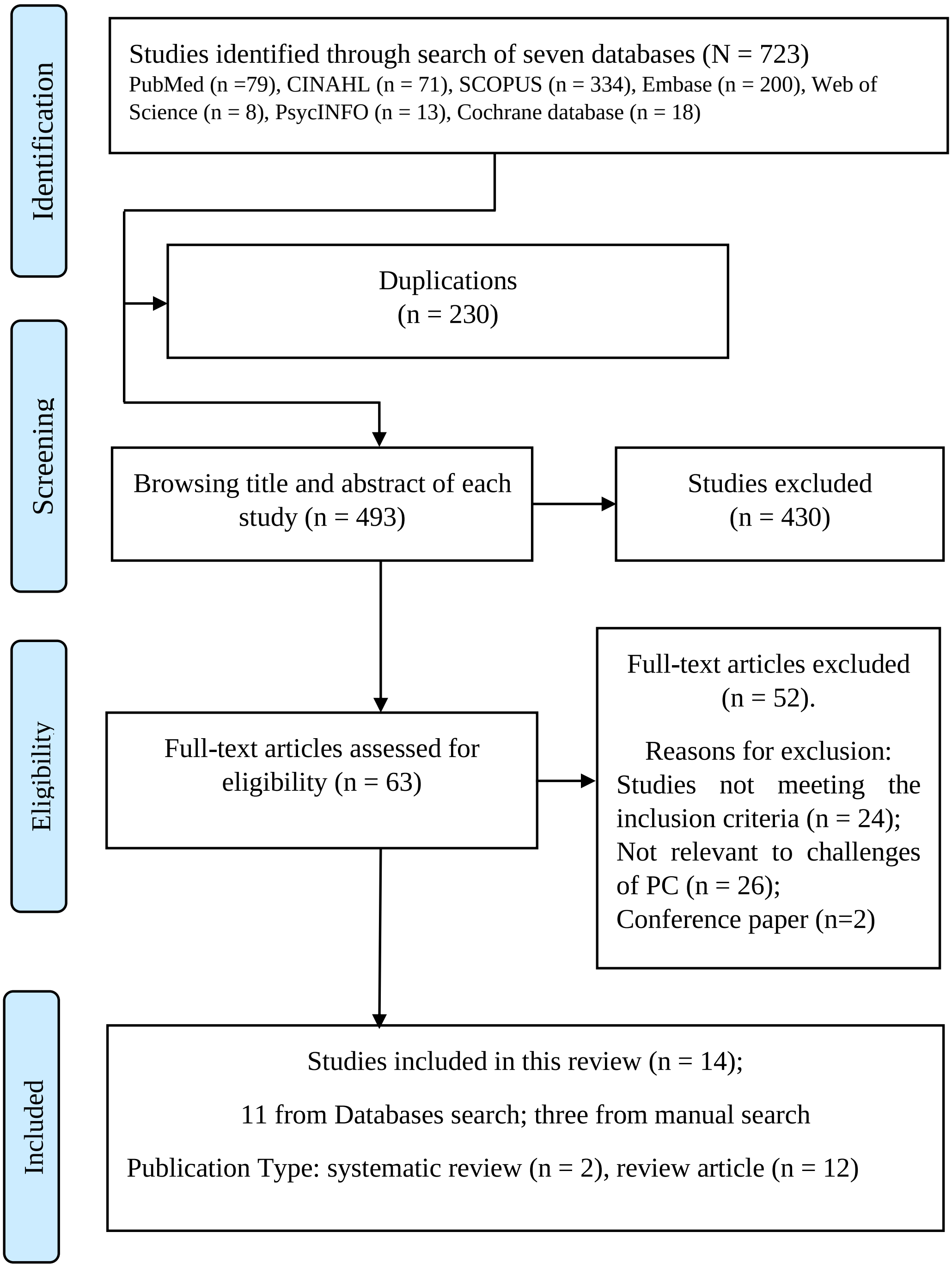
Explanation of abbreviations: S = Search; MeSH = Medical Subject Headings; AB = Abstract; TI = Title

3.3.4 Study selection and data extraction

The retrieved studies were exported into Endnote version X9, which was subsequently used to remove duplicates. Titles and abstracts of the remaining studies were screened by the first author (HAO) for eligibility against the inclusion and exclusion criteria. The full text of potentially eligible studies was then located for further screening. The second author (AM) was responsible for making the final decision on any uncertainty that the first author encountered during the assessment of full-text papers. Reasons for excluding reviews were identified and documented (Figure 3).

Data were extracted by one author (HAB) for each included study and reviewed by a second author (AM) if needed. A data extraction sheet was utilised to record the following data; (1) citation details: authors, year of publication, and country of the first author; (2) number of studies included and sample descriptions; (3) aim (s) of the review; (4) results (main findings) summarised based on the SEM; (4.1) category of challenges; personal, system, policy and organisational factors, (4.2) category of possible facilitators; personal, system, policy and organisational factors (Table 2).

Figure 3: Flow diagram of the identification of papers



3.3.5 Quality assessment of the reviews

Two authors independently used the Assessment of Multiple Systematic Reviews (AMSTAR-2) tool for systematic review articles or the International Narrative Systematic Assessment (INSA) tool for narrative review articles (La Torre, Backhaus, & Mannocci, 2015) to assess the quality of all included review articles. AMSTAR-2 has 16 items; each item is rated ‘yes’ for a positive result or ‘no’ for no information provided or ‘partial yes’ response in some cases; we consider it useful to determine partial compliance with the standard. The overall quality of a systematic review was rated ‘high’, ‘moderate’, ‘low’ and ‘critically low’ (Shea et al., 2017). High quality means that the paper provides a comprehensive summary of the available studies' results; moderate quality indicates that the review paper has more than one weakness but no critical flaws (Shea et al., 2017). Low quality indicates that the paper has a critical flaw and may not provide an accurate and comprehensive summary of the available studies (Shea et al., 2017). INSA contains seven items: clarity of background, objective, conclusion, description of the selection of studies, study characteristics, results, and conflict of interest. Each item is graded ‘yes’ or ‘no’, and one point is given for each of the seven criteria. A review with a total INSA score of ≥5 points is considered a ‘good’ quality review (La Torre et al., 2015).

3.3.6 Data analysis

As aforementioned, the SEM was selected as an analytical framework for data analysis (Figure 2). The McLeroy et al. model generated from the SEM was adopted to align the context and conceptualise the review findings (McLeroy et al., 1988). This is done to remove the distinction between intrapersonal and interpersonal domains and, in its place, differentiate between HCP, patient, and caregiver domains. Furthermore, the model is appraised to identify community domains as health system domains (McLeroy et al., 1988). Therefore, the final modified model has four levels; 1) personal level; 2) organisational level; 3) health system level; 4) policy/payment level. The personal level focuses on patients, families, and HCPs, while the organisational level deals with the organisation's culture and infrastructure. The health system level describes workforce and training, and finally, the policy/payment level relates to legislation and funding.

3.4 Results

3.4.1 Characteristics of the included reviews

The review yielded 723 articles, and 11 met the inclusion criteria. Each review reference list was further assessed to see if any relevant review had been omitted. Through this, an additional three reviews were added. Consequently, 14 reviews are included for analysis (Figure 3).

The majority of the included studies (n = 12) were narrative reviews (Abdel-Razeq et al., 2015; Ali, 2016; Basu, Mittag-Leffler, & Miller, 2013; Bingley & Clark, 2009; Elcigil, 2011; Fadhil et al., 2017; Hannon et al., 2016; McDermott, Selman, Wright, & Clark, 2008; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah, Al-Kindi, & Hassan, 2013b), and the remaining two were systematic reviews (Donkor et al., 2018; Rochmawati, Wiechula, & Cameron, 2016). Concerning the geographical focus of the reviews, four reviews originated from Middle Eastern countries (Bingley & Clark, 2009; Fadhil et al., 2017; Silbermann et al., 2012; Zeinah et al., 2013b) and three reviews were from LMICs (Basu et al., 2013; Donkor et al., 2018; Hannon et al., 2016). The other seven reviews focused on specific countries, including Jordan (Abdel-Razeq et al., 2015), Latin America (Soto-

Perez-de-Celis et al., 2017), Indonesia (Rochmawati et al., 2016), Turkey (Elcigil, 2011), India (McDermott et al., 2008), Palestine (Shawawra & Khleif, 2011), and Kenya (Ali, 2016).

With regards to the author origins, seven authors were from LMICs (Basu et al., 2013; Bingley & Clark, 2009; Donkor et al., 2018; Hannon et al., 2016; McDermott et al., 2008; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017); two from the U.S. (Basu et al., 2013; Soto-Perez-de-Celis et al., 2017), two from the UK (Bingley & Clark, 2009; McDermott et al., 2008), and one each from Australia (Donkor et al., 2018), Canada (Hannon et al., 2016), and Israel (Silbermann et al., 2012). As for publication year, the number of publications increased significantly in the last four years (Abdel-Razeq et al., 2015; Ali, 2016; Donkor et al., 2018; Fadhil et al., 2017; Hannon et al., 2016; Rochmawati et al., 2016; Soto-Perez-de-Celis et al., 2017). Only two reviews were published before 2010 (Bingley & Clark, 2009; McDermott et al., 2008).

In terms of disease category, 13 reviews focused on patients diagnosed with cancer (Abdel-Razeq et al., 2015; Ali, 2016; Basu et al., 2013; Bingley & Clark, 2009; Donkor et al., 2018; Elcigil, 2011; Fadhil et al., 2017; Hannon et al., 2016; McDermott et al., 2008; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b), and one review focused on mixed chronic diseases, including cancer (Rochmawati et al., 2016). Only two reviews included the number of studies in their reviews (Donkor et al., 2018; Rochmawati et al., 2016); one included nine studies (Rochmawati et al., 2016), and the other included 18 studies (Donkor et al., 2018). Table 2 displays the characteristics and main findings of all included reviews.

3.4.2 Quality of the included studies

Generally, the methodological quality of the narrative reviews was good. Nine narrative reviews scored ≥5 points on the INSA tool, reflecting good quality reviews (Abdel-Razeq et al., 2015; Basu et al., 2013; Bingley & Clark, 2009; Fadhil et al., 2017; Hannon et al., 2016; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b). The rest of the reviews (n = 3) had a score equal to 4 points on the INSA tool (Ali, 2016; Elcigil, 2011; McDermott et al., 2008). Half of the narrative reviews did not report a conflict of interest (Ali, 2016; Basu et al., 2013; Bingley & Clark, 2009; Elcigil, 2011; McDermott et al., 2008; Shawawra & Khleif, 2011). The methodological quality of the systematic reviews (Donkor et al., 2018; Rochmawati et al., 2016) was high, suggesting a paper presenting an accurate and comprehensive summary of the results of the available studies that address the question of interest.

3.4.3 Challenges to palliative care provision

3.4.3.1 Personal challenges

Personal challenges focused on the knowledge, attitudes, beliefs, skills, and culture of patients and their families, the general public, and HCPs. Seven reviews (Bingley & Clark, 2009; Elcigil, 2011; Fadhil et al., 2017; McDermott et al., 2008; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Zeinah et al., 2013b) showed that HCP knowledge deficits about PC and the use of opioid analgesics were the most common challenges affecting the provision of PC for cancer patients. Additionally, some patients could not distinguish between PC and hospice care (Bingley & Clark, 2009; Elcigil, 2011; Rochmawati et al., 2016; Zeinah et al., 2013b). Five other reviews indicated that HCPs, families, and the general public were not aware of PC and its benefits to patients and HCSs (Bingley & Clark, 2009; Elcigil, 2011; Fadhil et al., 2017; Shawawra & Khleif, 2011; Zeinah et al., 2013b). Further, four reviews pointed to negative attitudes and beliefs among HCPs as obstacles in the provision of PC services (Abdel-Razeq et al., 2015; Basu et al., 2013; Hannon et al., 2016; Silbermann et al., 2012).

3.4.3.2 Healthcare system challenges

Healthcare system challenges included workforce development issues, education, service delivery, and access issues across organisations. Thirteen reviews discussed the HCS as a barrier to the provision of PC (Abdel-Razeq et al., 2015; Basu et al., 2013; Bingley & Clark, 2009; Donkor et al., 2018; Elcigil, 2011; Fadhil et al., 2017; Hannon et al., 2016; McDermott et al., 2008; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b). A shortage of workers, or an inadequately trained PC workforce, was the most critical barrier to the provision of PC (Abdel-Razeq et al., 2015; Basu et al., 2013; Elcigil, 2011; Hannon et al., 2016; Zeinah et al., 2013b). This includes a shortage of nursing staff (Elcigil, 2011), especially the shortage of trained female nurses (Abdel-Razeq et al., 2015), and specialised ancillary personnel (Abdel-Razeq et al., 2015). Moreover, there was a lack of professional training programmes for HCPs (Elcigil, 2011; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017), including the failure to offer basic training to staff (Abdel-Razeq et al., 2015) and little collaboration/partnership between health organisations (Fadhil et al., 2017).

Drug restrictions were also identified as one of the HCS challenges, as reported in seven reviews. These restrictions included inadequate access to essential pain-relief medications (Basu et al., 2013; Fadhil et al., 2017; Hannon et al., 2016; Rochmawati et al., 2016; Silbermann et al., 2012), interruption of opioid supply and availability (Abdel-Razeq et al., 2015; Basu et al., 2013), and cumbersome drug importation processes (Donkor et al., 2018).

3.4.3.3 Organisational challenges

Organisational level issues shed light on structure, organisational culture, policies, and procedures of the organisation. Four reviews reported organisational-related issues as a barrier to the provision of PC in LMICs (Donkor et al., 2018; McDermott et al., 2008; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b). Facilities infrastructure constitutes one of the major components of the HCS, and this must be estimated and planned before the provision of any services. Limited physical infrastructure (i.e., buildings, equipment and supplies, beds, chairs, etc.) were reported as critical challenges to the provision of PC (Donkor et al., 2018; Soto-Perez-de-Celis et al., 2017). In addition, the geography of the country (McDermott et al., 2008; Rochmawati et al., 2016) (i.e., people living in a rural or remote area) could preclude access to PC services (McDermott et al., 2008).

3.4.3.4 Policy/payment challenges

Twelve reviews reported key policy challenges (funds, legislation, and research) as factors impeding the provision of PC for cancer patients (Abdel-Razeq et al., 2015; Basu et al., 2013; Bingley & Clark, 2009; Donkor et al., 2018; Elcigil, 2011; Fadhil et al., 2017; Hannon et al., 2016; McDermott et al., 2008; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b). Across five reviews, a shortage or lack of funding was recognised as the most critical barrier to the provision of PC (Basu et al., 2013; Bingley & Clark, 2009; Donkor et al., 2018; McDermott et al., 2008; Zeinah et al., 2013b). Several other studies acknowledged that lack of a comprehensive national PC plan (Fadhil et al., 2017; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017), inadequate or inappropriate legislation and policy (McDermott et al., 2008; Shawawra & Khleif, 2011; Soto-Perez-de-Celis et al., 2017), fragmented or weak HCS (Donkor et al., 2018; Fadhil et al., 2017), and lack of government support (Bingley & Clark, 2009; Zeinah et al., 2013b) negatively impacted the delivery of PC to cancer patients. Collectively, these identified challenges were influenced by limited political commitment (Donkor et al., 2018), complicated political situations (Fadhil et al., 2017), restrictive pharmacovigilance laws and regulations (Donkor et al., 2018), or the absence of a state-sponsored social security system (McDermott et al., 2008).

3.4.4 Possible facilitators for the provision of palliative care

Of the 14 reviews, 13 mentioned facilitators for overcoming challenges associated with the provision of PC. Personal facilitators were discussed in 11 review articles (Abdel-Razeq et al., 2015; Bingley & Clark, 2009; Donkor et al., 2018; Elcigil, 2011; Hannon et al., 2016; McDermott et al., 2008; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b). HCS facilitators were also presented in 11 reviews (Abdel-Razeq et al., 2015; Ali, 2016; Bingley & Clark, 2009; Elcigil, 2011; Hannon et al., 2016; McDermott et al., 2008; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b). Policy facilitators were enumerated in 12 reviews (Abdel-Razeq et al., 2015; Ali, 2016; Bingley & Clark, 2009; Donkor et al., 2018; Elcigil, 2011; Hannon et al., 2016; McDermott et al., 2008; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-

Perez-de-Celis et al., 2017; Zeinah et al., 2013b), while organisational facilitators were discussed in only one review (Soto-Perez-de-Celis et al., 2017).

3.4.4.1 Personal facilitators

Reviews indicated that adequate and continuous education is needed for both HCPs and patients and the wider general public (Abdel-Razeq et al., 2015; Bingley & Clark, 2009; Donkor et al., 2018; Elcigil, 2011; Hannon et al., 2016; McDermott et al., 2008; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b) to change their attitude to PC and improve their awareness of PC (Bingley & Clark, 2009; Elcigil, 2011; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Zeinah et al., 2013b). Adequate education of the general public and family were covered in 10 reviews (Abdel-Razeq et al., 2015; Bingley & Clark, 2009; Donkor et al., 2018; Elcigil, 2011; Hannon et al., 2016; McDermott et al., 2008; Rochmawati et al., 2016; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b), appropriate education of HCPs in four reviews (Abdel-Razeq et al., 2015; Hannon et al., 2016; Shawawra & Khleif, 2011; Zeinah et al., 2013b), improving public and HCPs attitudes on opiophobia in two reviews (Silbermann et al., 2012; Zeinah et al., 2013b), and enhancement of cultural aspects and providing PC that valued the patient's preferences and beliefs were described in one review (Soto-Perez-de-Celis et al., 2017).

3.4.4.2 Healthcare system facilitators

Facilitators related to the HCS were mentioned in 12 reviews (Abdel-Razeq et al., 2015; Ali, 2016; Bingley & Clark, 2009; Donkor et al., 2018; Elcigil, 2011; Hannon et al., 2016; McDermott et al., 2008; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b).

Adequate training of HCPs was also identified as a critical HCS facilitator that could not only improve the quality of care, but also increase the workforce (Abdel-Razeq et al., 2015; Ali, 2016; Bingley & Clark, 2009; Hannon et al., 2016; Shawawra & Khleif, 2011; Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b). Moreover, workforce quality can be enhanced through increasing national and international professional programmes (Ali, 2016; Bingley & Clark, 2009; Shawawra & Khleif, 2011; Silbermann et al., 2012), providing informal training to medical oncologists (Zeinah et al., 2013b), creating a supportive learning environment for HCPs and developing information management systems (Donkor et al., 2018), and integrating PC into curricula and practice (Ali, 2016; Elcigil, 2011; McDermott et al., 2008; Shawawra & Khleif, 2011; Silbermann et al., 2012). Other facilitators identified included changing legislation that inappropriately restricts access to opioid medications (Bingley & Clark, 2009; Hannon et al., 2016; McDermott et al., 2008; Soto-Perez-de-Celis et al., 2017) and improving access to and the availability of narcotic drugs (McDermott et al., 2008; Soto-Perez-de-Celis et al., 2017).

3.4.4.3 Organisational facilitators

Improving the physical infrastructure of healthcare settings can play a crucial facilitative role in the development and provision of PC, as reported in two reviews (Shawawra & Khleif, 2011; Soto-Perez-de-Celis et al., 2017).

3.4.4.4 Policy/payment facilitators

Policy/payment issues were the main facilitators to the provision of PC for cancer patients, as described in 12 reviews (Abdel-Razeq et al., 2015; Ali, 2016; Bingley & Clark, 2009; Donkor et al., 2018; Elcigil, 2011; Hannon et al., 2016; McDermott et al., 2008; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Silbermann et al., 2012;

Soto-Perez-de-Celis et al., 2017; Zeinah et al., 2013b). Designing and implementing a national PC policy was the main facilitator discussed in nine reviews (Ali, 2016; Bingley & Clark, 2009; Donkor et al., 2018; Hannon et al., 2016; McDermott et al., 2008; Rochmawati et al., 2016; Shawawra & Khleif, 2011; Silbermann et al., 2012; Soto-Perez-de-Celis et al., 2017). These can be achieved through the involvement of stakeholders (Donkor et al., 2018), budget support (Ali, 2016; Donkor et al., 2018; Elcigil, 2011; Hannon et al., 2016; Zeinah et al., 2013b), and negotiating for secure government or health insurance funding provision (Bingley & Clark, 2009). Enhancing and increasing research on PC was also identified as an essential policy facilitator (Abdel-Razeq et al., 2015; Elcigil, 2011; Shawawra & Khleif, 2011; Soto-Perez-de-Celis et al., 2017), which helps in identifying the needs and gaps in PCprovision.

Table 2: Summary of aims and key findings of the included reviews

Author (Year), Implementation Year(s), Country/Region	Review aim	Setting/ Population	Findings Barriers	Possible facilitators/recommendations for improvement
Donkor et al. (2018), 1990-2017 Australia Systematic review, included 18 studies	To identify the facilitators and barriers to the implementation of cancer treatments and PC.	LMICs Cancer	***Health system:*** • Drug importation process ***Policy:*** • Lack of financial support • Limited political commitment • Restrictive pharmacovigilance laws and regulations • Fragmented health system ***Organization/ structure:*** • Limited physical infrastructure	***Personal:*** • Education • Community sharing ***Health system:*** • Creating a learning environment • Information management system ***Policy:*** • Payment support • Stakeholder sharing • Political commitment • Positive relationships with international organizations • Strategy aligned with national policy
Soto-Perez-de-Celis et al. (2017) 2017 USA	To identify the existing deficiencies and providing a framework for the improvement of PC.	Latin America Cancer	***Personal:*** • Cultural barriers ***Health System:*** • Lack of opportunities for clinical training ***Policy:*** • Inadequate or inappropriate legislation • Lack of comprehensive national PC plans • Unreliable reporting of data ***Organization/ Structure:*** • Insufficient infrastructure	***Personal:*** • Improve education • Enhance cultural aspects • Individualized care for patient's preferences and beliefs ***Health System:*** • Increase the availability of pain medication • Training to all HCPs • Enhance, expand access to medication ***Policy:*** • Design comprehensive PC plans • Integrate end-of-life care into national health care laws • Enhance research ***Organization/ Structure:*** • Improve infrastructure

Author (Year), Implementation Year(s), Country/Region	**Review aim**	**Setting/ Population**	**Findings**	
			Barriers	**Possible facilitators/recommendations for improvement**
Fadhil et al. (2017) 2017 Egypt	To identify barriers to the development of PC.	Eastern Mediterranean Region Cancer	***Personal:*** • Poor awareness of policymakers about PC • Poor awareness of HCPs about PC • Poor public awareness ***Health System:*** • Little partnership working • Insufficient PC education for HCPs • Gaps in access to essential pain-relief medicines ***Policy:*** • Scarcity of national plans and policies • Complicated political situations • Weak health-care systems • Absence of PC in national policies	-
Ali (2016) 2016 Kenya	To assess the integration of PC services into the public healthcare system.	Kenya cancer	-	***Health system:*** • Training HCPs • A higher diploma in PC ***Policy:*** • The government budget for PC services • Include PC in local health strategies and plans. • National PC guidelines
Hannon et al. (2016) 2015 Canada	To overcome barriers that continue to affect the availability of PC in LMICs.	LMICs cancer	***Personal:*** • Negative attitudes about PC and death and dying ***Health System:*** • Limited access to opioid medication • Lack of training of HCPs and volunteers ***Policy:*** • Lack of investment in health systems	***Personal:*** • Education of HCPs • Shifts in societal norms to PC • Shifts in HCPs norms to PC ***Health System:*** • Changes in legislation restricting access to opioid medications • Training of health professionals. ***Policy:*** • A health policy that supports the integration of PC • Investment in systems of health care delivery • Development of rigorous data and research • International partnerships

Author (Year), Implementation Year(s), Country/Region	**Review aim**	**Setting/ Population**	**Findings**	
			Barriers	**Possible facilitators/recommendations for improvement**
Rochmawati et al. (2016) 1990-2015 Indonesia Systematic review, includes 9 studies	To identify facilitators and barriers to the provision of PC.	Indonesia Cancer, HIV/AIDS	***Personal:*** • Knowledge deficit and misunderstanding of HCPs ***Health System:*** • Difficult access to narcotic drugs ***Organization/ Structure:*** • Geography	***Personal:*** • Family and community support ***Policy:*** • Policy and organization support ***Health System:*** • Volunteering
Abdel-Razeq et al. (2015) 2014 Jordan	To discuss challenges and offer suggestions for the improvement of cancer management.	Jordan Cancer	***Personal:*** • Negative professional attitudes • Negative public attitudes ***Health System:*** • Lack of specialized human resources • Lack of adequate training of responsible staff • Interrupted opioids supply and availability • Shortage of trained female nurses • Few specialized ancillary support personnel ***Policy:*** • Not available outcome data at a national level	***Personal:*** • Increase HCPs knowledge ***Health System:*** • Structured training programs for HCPs ***Policy:*** • Integration of both clinical care and clinical research
Zeinah et al. (2013b) 2012 Qatar	To outline current PC at Middle Eastern countries. To address major challenges hindering the development of PC.	Middle East countries Cancer	***Personal:*** • Lack of education and awareness ***Health System:*** • Shortage of specialized PC teams ***Policy***: • Political issues • Scarcity of resources • Shortage or lack of funding • Lack or deficiency governmental support ***Organization/ Structure:*** • No application of service (including opioid use and expertise)	***Personal:*** • Raising awareness of the public on opiophobia. • Raising awareness of the HCPs on opiophobia. ***Health System:*** • Informal training to medical oncologists in PC. • Providing formal education to HCPs ***Policy***: • Adequate funding for training programs.
Basu et al. (2013) 2013 USA	To provide an overview of the progress in providing PC in low- and medium-resource countries. To present the development of PC in Ethiopia.	LMICs Cancer	***Personal:*** • Negative cultural attitudes and beliefs of patients • Negative cultural attitudes of physicians ***Health System:*** • Lack of a trained workforce. • Lack of availability of opioids or restricted in their use	-

Author (Year), Implementation Year(s), Country/Region	**Review aim**	**Setting/ Population**	**Findings**	
			Barriers	**Possible facilitators/recommendations for improvement**
			Policy: • Lack of funding	
Silbermann et al. (2012) 2012 Israel	To address the accomplishments and challenges of palliative cancer care in Middle Eastern countries.	Middle East countries Cancer	***Personal:*** • Families' feeling of alienation and isolation • Families' fear of neglect by the primary physician ***Health System:*** • Lack of relevant training of HCPs • Poor accessibility to essential PC drugs • Delay in referrals ***Policy:*** • Lack of health policies and plans	***Personal:*** • Education of physicians and nursing PC principles • A community-based orientation ***Health System:*** • Introduce PC principles into the curricula • Develop postgraduate training programs for physicians and nurses. ***Policy:*** • Public policy
Elcigil (2011) 2011 Turkey	To assess the status of PC in Turkey.	Turkey Cancer	***Personal:*** • Lack of PC education • Lack of public awareness • Limited knowledge of opioid analgesics ***Health System:*** • Lack of training programs • Shortage of nursing staff • Lack of certification for PC Nursing ***Policy:*** • Very limited research	***Personal:*** • Increase public awareness channels ***Health System:*** • Disseminate information on certification of PC nurses to agencies. ***Policy:*** • Establish interdisciplinary research on PC concepts • Increase funding for research • Evidence-based curriculum to strengthen the teaching of PC concepts
Shawawra and Khleif (2011) 2011 Palestine	To conduct a needs assessment survey within facilities that provide care for oncology patients in the West Bank.	Palestine Cancer	***Personal:*** • Lack of community awareness on PC ***Health System:*** • No presence of educational resources for PC, • No training programs in PC, ***Policy:*** • An absence of organizational strategic planning, • No standards for PC service • An absence of national standards on PC.	***Personal:*** • The need for public awareness. ***Health System:*** • The need for training of HCPs • Introduce PC principles into the curricula ***Policy:*** • Networking between the national NGO's and the MOH. • National policy and standards on PC and opioids legislations. • Baseline data and research. • Interdisciplinary teamwork.

Author (Year), Implementation Year(s), Country/Region	**Review aim**	**Setting/ Population**	**Findings**	
			Barriers	**Possible facilitators/recommendations for improvement**
Bingley and Clark (2009) 2008 UK	To review PC development in six Middle East countries.	Middle East countries Cancer	***Personal:*** • Opioid phobia in the public • Opioid phobia in professionals • Lack of public awareness of PC • Lack of professional-level awareness ***Health System:*** • Inadequate professional training programs ***Policy:*** • Lack of funds • Lack of government support.	***Personal:*** • Public education programs • Raising awareness about the need for PC ***Health System:*** • Increasing national and international training • Improving opioid legislation ***Policy:*** • Improving health care policies • Negotiating for a secure government or health insurance funding provision
McDermott et al. (2008) 2007 UK	To identify strengths and weaknesses in the state of development across the subcontinent.	India Cancer	***Personal:*** • Limited knowledge of patients about PC ***Health System:*** • Unavailability of opioid • Shortage of workforce ***Policy:*** • Limited national PC policy • Insufficient funding for services • Absence of social security system ***Organization/ Structure:*** • Poverty • Population density • Geography	***Personal:*** • Increase public awareness of PC ***Health System:*** • Improve drug availability and expertise ***Policy:*** • Include PC in medical and nursing curricula • Design and implement a national PC policy

LMICs= Low-income and middle-income countries; UK=United Kingdom; USA=United State America; PC = Palliative care; HCPs = Healthcare professionals

3.5 Discussion

This systematic review adds to the literature on the topic by providing a systematic and more comprehensive mapping of the challenges associated with the provision of PC services in LMICs. This goes further to identify common facilitators to overcome these challenges in LMICs. Fourteen reviews have highlighted that the provision of PC for cancer patients in LMICs are affected by a wide range of challenges. Personal and HCS-related issues have been highlighted as key challenges to the provision of PC. One interesting finding was that although the included reviews focused on LMICs, seven authors who conducted these reviews were from HICs, indicating the interest from HICs in PC in countries with minimal resources and developing economies.

Overall, insufficient knowledge, poor awareness, negative attitudes, and the beliefs of patients, families, the general public, and HCPs are crucial personal challenges to the provision of PC in LMICS. Four reviews that were conducted in HICs reported similar findings (Aldridge et al., 2016; Dalgaard, Bergenholtz, Nielsen, & Timm, 2014; Davies & Prince-Paul, 2012; LeBlanc, Roeland, & El-Jawahri, 2017). Furthermore, a population-based study suggested that a low level of awareness and knowledge deficits common among adults are part of the challenges (Shalev et al., 2018). Another study linked insufficient knowledge and low levels of awareness on the part of patients, families, the public, and HCPs, to PC services and their benefits (Lane, Ramadurai, & Simonetti, 2019) to these challenges, potentially contributing to delayed patient referrals to PC services (Ryan & Ingleton, 2011; Torke et al., 2010). Therefore, PC education has been recommended as the first step (World Health Organization, 2014) to increase awareness, promote positive attitudes, and improve knowledge of these services among the general public and HCPs (Dalberg, McNinch, & Friebert, 2018;

Zelko, Selic, & Malacic, 2017). This can be realised by integrating core competencies of PC into the curricula of universities (Stjernsward et al., 2007; World Health Organization, 2014), and cultivating more positive attitudes in the public through the media or public engagement programmes.

This review indicates that workforce shortages or an inadequately trained workforce and poor accessibility and availability of pain-relief medication are essential HCS challenges to PC provision. There is a significant shortage of specialised HCPs in the PC world (Canadian Medical Association, 2015; Kamal, Maguire, & Meier, 2015). This shortage will affect the quality of the PC services provided and the fulfilment of cancer patient expectations (Lupu & American Academy of Hospice and Palliative Medicine Workforce Task Force, 2010). Investment in terms of time and resources in training a PC workforce is a recommended facilitator in addressing workforce shortages. Also, volunteers can play crucial roles in supporting the health of cancer patients and overcoming workforce shortages (Carrasco et al., 2015; Centeno, Bolognesi, & Biasco, 2015). There are benefits in involving and utilising volunteers in healthcare settings. They can be used for caring for and delivering support and services to patients and the overall economy of the HCS (Frick et al., 2004; International Labour Organization, 2011). Using volunteers to improve psychosocial health, education, and engagement might be an effective way to lower costs and the economic burden of delivering PC services in LMICs (Sales et al., 2013). Volunteers, however, require effective and appropriate training to enhance their performance and the quality of care provided to patients (Knaul et al., 2018; Knaul et al., 2011). This has been successfully implemented in some LMICs (Steedman et al., 2014).

Poor accessibility to pain-relieving medications is a unique barrier to accessing PC in LMICs, with 80% of people having little or no access to such medication (Knaul et al., 2011). Despite the fact that the availability of pain-relieving medications as a basic component of HCSs, false perceptions of patients and their families (Bagçivan, Tosun, Kömürcü, Özet, & Akbayrak, 2009; Jemal, Center, DeSantis, & Ward, 2010; Kim et al., 2015; Krakauer, Wenk, Buitrago, Jenkins, & Scholten, 2010) and HCPs (De Lima, Pastrana, Radbruch, & Wenk, 2014; Peker et al., 2008) can be major challenges to the provision of PC. Many patients avoid using pain-relieving medication because of their beliefs and fears that using this type of medication will lead to addiction (Bagçivan et al., 2009; Jemal et al., 2010; Kim et al., 2015; Krakauer et al., 2010). While HCPs may not prefer to prescribe these medications because of their lack of adequate pain assessment skills and their belief that the use of opioids can cause addiction (De Lima et al., 2014; Peker et al., 2008). Besides the perceptions of patients and HCPs about opioid use, it is further acknowledged that LMICs constitute 80% of the world population, but receive only 6% of the available morphine (Bond, 2009). The European Society of Medical Oncology, through its Global Opioid Policy Initiative project, has identified a range of issues impacting the use of opioids in LMICs, and these include not only a lack of availability of opioids, but also outdated policies that discourage access, limited awareness and unnecessary administrative obstacles, and inadequate HCP education and empowerment (Cherny, Cleary, Scholten, Radbruch, & Torode, 2013). Often it is a combination of all of the above factors that impede the use and uptake of opioids in LMICs, making access to such medication a complex issue. Several authors recognise the worldwide lack of access to opioids (Cleary, Baselga, de Conno, & Radbruch, 2010; Cleary, Radbruch, Torode, & Cherny, 2013; Husain, Brown, & Maurer, 2014) as a factor affecting the provision of PC to cancer patients. Furthermore, for PC to become readily available, restrictions on the access to opioid drugs in LMICs should be removed (Dalal & Bruera, 2013). This is because opioid therapy requires both availability and affordability for cancer patients receiving PC, as pain management is one of the critical components in PC services (De Lima et al., 2014; World Health Organization, 2014). A few authors opine that the availability and affordability of opioids is essentially part of "human rights" (Brennan, 2007; Radbruch, Payne, de Lima, & Lohmann, 2013), and the WHO has developed a list of essential medicines for a basic HCS, including opioids and medicines for other common symptoms in PC (World Health Organization, 2019b). Legal restrictions, such as national laws, often restrict opioid use or prohibit access to narcotics (Cleary et al., 2010; Cleary, Powell, et al., 2013; Cleary, Radbruch, et al., 2013; Manjiani, Paul, Kunnumpurath, Kaye, & Vadivelu, 2014). These impediments, nonetheless, have negative consequences for patients and their families (Reville & Foxwell, 2014). Reviewing or changing related legislation and policies is needed to overcome these impediments. This can be carried out at the national level by analysing legislation and policy documents (Bosnjak, Maurer, Ryan, Leon, & Madiye, 2011; Cleary et al., 2010; Cleary, Powell, et al., 2013).

Limited physical infrastructure, in addition to the geography of the country, poverty, and population density, are the main organisational challenges to the provision of PC. LMICs experience financial/funding challenges and poverty, which negatively affect the development of their HCSs (Moore, 2015). Therefore, it is recommended that policymakers collaborate with national and international organisations to secure funding for improving healthcare provision.

Most people in need of PC are at home due to transportation difficulties or limited income to access care or buy medications (World Health Organization, 2018b). Integrating PC into primary care services is a recommended strategy to improve access to PC for patients living in remote areas (Recoche et al., 2014). This integration will help patients and their families, who are living in remote areas, to receive comprehensive care without being overwhelmed by personal cost issues (McCormick, Chai, & Meier, 2012).

Shortage of funding and lack of a comprehensive national plan on implementing PC identified in this review are complex and overlapping. Lack of national plans and policies on PC services are common in most LMICs (Ddungu, 2011). LMICs should develop national PC plans and integrate these plans within their strategy for non-communicable diseases. This should align with the local context and health care needs, and can be achieved through the engagement of policymakers and budget estimations (World Health Organization, 2016a). There was also a lack of cost data available in the included reviews and previous literature, which is also considered a barrier to introducing and estimating PC costs. In the reviews that were assessed, most LMICs only briefly highlighted insufficient funding and limited resources, although funding availability is of paramount importance in the development of PC services.

To overcome policy challenges, policymakers should understand the processes involved in PC implementation, and factors that affect implementation and the introduction of solutions to overcome these obstacles (Nilsen, 2015). Credible setting of policy agendas, realistic policy formulation, timely policy implementation, and policy monitoring and evaluation (Exworthy, 2008) remain pressing needs on the part of LMICs to overcome these impediments. Involving policymakers in this process is essential and has a significant positive effect on defining their priorities, diagnosing their challenges, and implementing appropriate solutions for service improvement (Bate & Robert, 2006).

Challenges that preclude the provision of PC differ significantly in HICs and LMICs in terms of scope, context, culture, and religious beliefs. However, there are some similarities in challenges to PC provision. The main common obstacles to the provision of PC in both HICs and LMICs include lack of a properly trained workforce (Aldridge et al., 2016; Davies & Prince-Paul, 2012; LeBlanc et al., 2017), fear among HCPs (Bhadra et al., 2015), lack of awareness about PC (Alkhudairi, 2019; Lane et al., 2019; McIlfatrick et al., 2013; Shalev et al., 2018; Westerlund et al., 2018), limited funding, and lack of coordination amongst services (Lynch et al., 2010b). However, in LMICs, factors affecting the provision of PC services to cancer patients further include a lack of resources and inadequate physical infrastructure. Others are related to administrative challenges, which are mainly centred on access to opioids and organisational commitment (Hawley, 2017). Furthermore, culture, beliefs, and norms about death and opioid consumption work against PC in LMICs. Compared to HICs, inadequate accessibility and availability of opioids are unique to LMICs.

About 83% of people in LMICs consume only 9% of the world morphine available (Seya, Gelders, Achara, Milani, & Scholten, 2011), in comparison to 7.5% of the countries located in the WHO American and European regions, which have adequate consumption levels of opioids (Duthey & Scholten, 2014). A lower percentage of opioid consumption in LMICs may be tied to legislation in some countries, where patients are required to register to receive opioids. In fact, some

African and European countries even require special registration for hospice patients (Cleary et al., 2010; Cleary, Powell, et al., 2013).

Negative attitudes about PC and death, opioid phobia, and families' feeling of alienation and isolation are the most common challenges in LMICs, while misperceptions equating “PC” with end-of-life care on the part of HCPs and the public are the main challenges in LMICs (Aldridge et al., 2016; Davies & Prince-Paul, 2012; LeBlanc et al., 2017). Furthermore, in HICs, PC provision for cancer patients is relatively good, with most patients enjoying good access to services (Hawley, 2017). Nevertheless, uneven PC coverage (Lynch et al., 2010b) is most common in countries with limited resources.

3.6 Strengths and limitations

A strength of this systematic review is that it covered several databases with up-to-date data to capture information more relevant to current HCSs. However, this review also presents several limitations, such as a limited number of original studies included in the reviews, focusing only on reviews, and the narrative format of most reviews used in the present analysis.

3.7 Conclusion

This review expands the existing knowledge on the challenges and possible facilitators in the provision of PC services to cancer patients in LMICs. Understanding these challenges from each level (from policy and organisation down to individual patient-HCPs) could help develop PC pathways in LMICs. It could be used as a guide to develop a model for PC service provision. Policymakers can use it to understand the implementation of a new PC programme in their countries and the areas they need to focus on and prioritise. NGOs can use it to supplement governmental efforts and cover related gaps. Also, political influence and support are required to ensure sustainability and high-quality PC services. Although PC for patients with cancer is gaining gradual recognition worldwide (Connor & Sepulveda Bermedo, 2014), it still lacks widespread adoption in LMICs. Overall, this detailed analysis of the challenges and possible facilitators offers the opportunity to develop interventions to improve and implement PC into HCSs in LMICs.

Future research efforts are needed to develop a sufficient body of evidence to support effective learning and policy development. Furthermore, other potential challenges that may preclude the provision of PC not covered in this review may form the basis for future studies. For instance, two significant aspects may be considered. The first aspect is the HCPs' voice. As most reviews have focused on knowledge, attitudes, and beliefs, none has investigated communication competencies between professionals and their relationship with their patients, an important aspect for PC successful provision. Communicating professionally with patients improves their attitudes (Brock et al., 2013). The second aspect is the patient/family voice. Most reviews have examined the attitudes of patients and their families towards PC services, but none studied patient priorities, needs, and wishes in terms of PC services in LMICs. For policy development, assessing country readiness for PC provision and integration is an essential step to effective adoption (Helfrich, Li, Sharp, & Sales, 2009).

Despite the aforementioned challenges, other countries have successfully implemented PC into their HCS. Therefore, there are lessons to be learned from one another on mitigating the impediments and integrating PC services into the existing HCS. For the concern, a narrative review has been conducted by the doctoral researcher looking at countries demonstrating good PC practices before the development of a new programme. A detailed description of the narrative review will be presented in the next chapter.

CHAPTER (4): NARRATIVE REVIEW: LESSONS LEARNED FROM COUNTRIES THAT HAVE INTRODUCED PC SERVICES INTO THEIR NATIONAL HEALTHCARE SYSTEM

4.1 Introduction

The chapter presents a narrative review to identify the areas that need to be considered before PC programme development into a country HCS. It includes the study gap, aim and questions, methods, findings, discussion, and conclusion. This review has already been published in an international peer-reviewed journal (Abu-Odah et al., 2021). Minor modifications have been applied to this published review, including citation styles and reference lists to adhere to the structure and guidelines of this doctoral thesis. (Abu-Odah H, Molassiotis A, and Liu J, Lessons learned from countries that have introduced PC services into their national health system: a narrative review, J Palliat Care. 2021 Feb 2;825859721989557. DOI: 10.1177/0825859721989557; SAGE permission under the Green Open Access: SAGE’s Archiving and Sharing Policy).

4.2 Review gap, aim, and questions

Numerous studies have already been conducted discussing national access to PC. Rhee et al. (2017) assessed the development of national PC across African countries and showed increased development of PC services in some of these countries; however, in most countries difficulties in accessing opioids and restrictive laws are common barriers to adequate PC provision. Fraser et al. (2017) compared strategies used to improve PC provision in Uganda and Kenya, and showed that both countries had implemented strategies to integrate PC into their HCS and health curricula. Seymour and Cassel (2017) reviewed PC delivery in the U.S. and England. They found that achieving a comprehensive public health approach in PC required international collaboration and the development of an evidence-based approach for effective partnership between HCPs at all societal levels. All previous studies have focused on PC's problems; however, no study has been carried out to review national policies, strategies, and framework reports of both HICs and LMICs to learn about effective ways of introducing PC. Therefore, this narrative review was conducted to gain a broad overview of national approaches regarding PC implementation, and to understand the process of implementation of a PC programme into HCSs in countries that have identified PC within their national policies and strategies. This review aims to address the following questions: 1) What are the methods used for assessing of PC services before setting up a PC programme? 2) What are the key priority areas that have been linked to the successful development of PC programmes in conjunction with the WHO public health PC dimensions (policies, education and training, medicine availability or service implementation)? and 3) What are the challenges to accessing PC services?

4.3 Methods

This review aimed to gain an overview of national approaches regarding PC implementation into health systems. It is based on the methods suggested by Green, Johnson, and Adams (2006) and Cipriani and Geddes (2003).

4.3.1 Sources of information

Searching and identifying high-level reports such as national policies, strategies, and frameworks can be challenging, as most reports are published in grey literature. Nevertheless, peer-reviewed databases were searched to see whether some reports were available or not. The authors searched three electronic databases from 2000 onwards to cover all reports with PC strategies, including PubMed, EMBASE, and Scopus.

A grey literature search was undertaken via Internet search engines, including Google and Google Scholar, Open Grey, Australian Policy Online, National Institute for Health and Clinical Excellence UK, EAPC in Europe, and reports listed in the Care Search's Review Collection relating to "Service/Systems Issues." Reference lists of articles or reports that met eligibility criteria were also manually searched to identify any additional reports. The review search strategy was conducted with the help of a university librarian, including both Medical Subject Headings (MeSH) and free text keyword searches: "palliative care", "palliative care medicine", OR "hospice care", OR "terminal care", OR "end-of-life care", AND "implementation services", OR "health services". Table 3 shows the detailed search terms from the PubMed database.

4.3.2 Selection criteria

Representative countries (HICs and LMICs), based on their high ranking in the Quality of Death Index and high-quality PC services, were selected to cover different contexts, cultures, and geographic regions (The Economist Intelligence Unit, 2015). The final inclusion criteria were as follows:

1- Governmental reports (guidelines, strategies, and frameworks) were included in this review.
2- First and latest published reports of each selected country were included, because many of these reports are updated every three to five years and repeat similar information.
3- Reports mentioned at least one category of the WHO public health PC strategy.
4- Reports discussed PC services implementation and focused on any life-threatening diseases, regardless of type.

5- Published in English and after 2000, when the first national strategy was enacted in 2000 by the Australian government.

6- It is limited to the following countries, including the UK, Australia, New Zealand, Ireland, Belgium, Malaysia, Lebanon, Morocco, and Uganda.

Table 3: PubMed search strategies for review documents

Search	Search Term	Hits
PubMed		
1	Search "Palliative Care"[Mesh] Sort by: [pubsolr12]	50816
2	Search (Search ((((((palliative care [Title/Abstract]) OR supportive care [Title/Abstract]) OR palliative medicine [Title/Abstract]) OR hospice [Title/Abstract]) OR end-of-life care [Title/Abstract]) OR terminal care [Title/Abstract])) Sort by: [pubsolr12]	2357
3	1 OR 2	52402
4	Search "Health Plan Implementation"[Mesh] Sort by: [pubsolr12]	5385
5	Search (("Health Plan Implementation"[Mesh]) AND (("Palliative Care"[Mesh]) OR ((Search ((((((palliative care [Title/Abstract]) OR supportive care [Title/Abstract]) OR palliative medicine [Title/Abstract]) OR hospice [Title/Abstract]) OR end-of-life care [Title/Abstract]) OR terminal care [Title/Abstract]))))) AND ((((("Australia"[Mesh]) OR "United Kingdom"[Mesh]) OR "Ireland"[Mesh]) OR "New Zealand"[Mesh]) OR "Belgium"[Mesh]) Filters: Journal Article; Government Document Sort by: [pubsolr12]	13
6	4 OR 5	13
7	Search (((("Australia"[Mesh]) OR "United Kingdom"[Mesh]) OR "Ireland"[Mesh]) OR "New Zealand"[Mesh]) OR "Belgium"[Mesh] OR "Malaysia"[Mesh]) OR "Lebanon"[Mesh]) OR "Uganda"[Mesh]) OR "Morocco"[Mesh]) Sort by: [pubsolr12]	546031
8	3 AND 6 AND 7	13
9	3 AND 6 AND 7. Filters: Publication date from 2000/01/01 to 2019/12/31; English Sort by: [pubsolr12]	13

Explanation of abbreviations: S = Search; AB = Abstract; TI = Title

4.3.3 Data selection and extraction

The title and summary reports were screened to confirm that they fit the inclusion criteria. All reports meeting the inclusion criteria were exported into the EndNote program X9. Duplicates were removed afterwards. The title and summary reports were read, and full-text versions were downloaded and further examined. Table 4 displays a list of the final reports included, and organised based on the ranking of PC across the world (The Economist Intelligence Unit, 2015). The descriptive data extraction table included the following information: (i) general characteristics of reports: authors/participants; year in which the reports were published; and country; (ii) document title; (iii) methods used to set up the PC programme; (iv) main findings summarised based on the WHO public health PC model (policies, medication, education, and implementation); and (v) emerging or inherent challenges.

4.3.4 Data analysis

Qualitative content analysis based on the Mayring (2014) seven-step method was adopted for data analysis. It begins with defining the research questions and background. Then it determines the main category based on the WHO public health PC model (Figure 4) (Stjernsward et al., 2007; World Health Organization, 1990). The establishment of a coding technique for presenting similarities and differences between the included articles follows, and then preliminary codes are comprehensively determined. The final two steps, listing the final categories and analysis and interpretation, are based on category frequencies (Mayring, 2014).

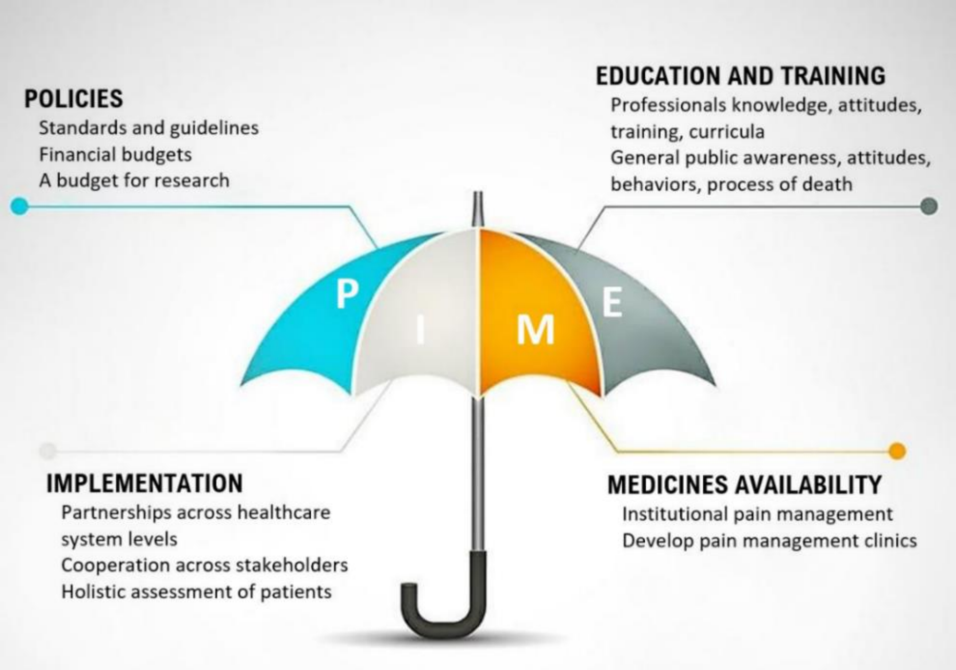


Figure 4: A modified WHO public health PC approach
(Stjernsward et al., 2007)

4.4 Results

4.4.1 Characteristics of the included articles

After screening 1,223 titles and abstracts and 29 full-text articles, 13 met the inclusion criteria, all identified from grey literature sources (Figure 5). The 13 reports were published between 2001 and 2019, with 10 reports published from 2009 onwards (Association Lalla Salma De Lutte Contre Le Cancer, 2009; Department of Health Social Services and Public Safety, 2010; Hospis Malaysia, 2016; Keirse et al., 2009; Ministry of Health, 2013; National Palliative and End of Life Care Partnership, 2015; NSW Ministry of Health, 2019; Palliative Care Association of Uganda, 2017; Soueidan, Osman, & El-Jardali, 2018; Urbis, 2010). Across the nine included countries; two reports each were from the UK (Department of Health, 2008; National Palliative and End of Life Care Partnership, 2015), Australia (NSW Ministry of Health, 2019; Urbis, 2010), New Zealand (Ministry of Health, 2001, 2013), Ireland (Department of Health and Children, 2001; Department of Health Social Services and Public Safety, 2010), and one each from Belgium (Keirse et al., 2009), Malaysia (Hospis Malaysia, 2016), Lebanon (Soueidan et al., 2018), Uganda (Palliative Care Association of Uganda, 2017), and Morocco (Association Lalla Salma De Lutte Contre Le Cancer, 2009).

Enhancing general public awareness and HCP education were the focus of all included reports (Association Lalla Salma De Lutte Contre Le Cancer, 2009; Department of Health, 2008; Department of Health Social Services and Public Safety, 2010; Hospis Malaysia, 2016; Keirse et al., 2009; Ministry of Health, 2001, 2013; National Palliative and End of Life Care Partnership, 2015; NSW Ministry of Health, 2019; Palliative Care Association of Uganda, 2017; Soueidan et al., 2018; Urbis, 2010). Seven countries discussed financial budgets, infrastructure and legislation as a component of policy domain (Association Lalla Salma De Lutte Contre Le Cancer, 2009; Department of Health, 2008; Department of Health and Children, 2001; Department of Health Social Services and Public Safety, 2010; Hospis Malaysia, 2016; Ministry of Health, 2001, 2013; National Palliative and End of Life Care Partnership, 2015; NSW Ministry of Health, 2019; Palliative Care Association of Uganda, 2017; Urbis, 2010). Seven countries focused on PC implementation into the existing public health system (Association Lalla Salma De Lutte Contre Le Cancer, 2009; Department of Health, 2008; Department of Health and Children, 2001; Department of Health Social Services and Public Safety, 2010; Ministry of Health, 2013; National Palliative and End of Life Care Partnership, 2015; NSW Ministry of Health, 2019; Palliative Care Association of Uganda, 2017; Soueidan et al., 2018; Urbis, 2010), while two countries focused on medication availability (Department of Health, 2008; Urbis, 2010). Table 4 displays the characteristics and main findings from all included reports.

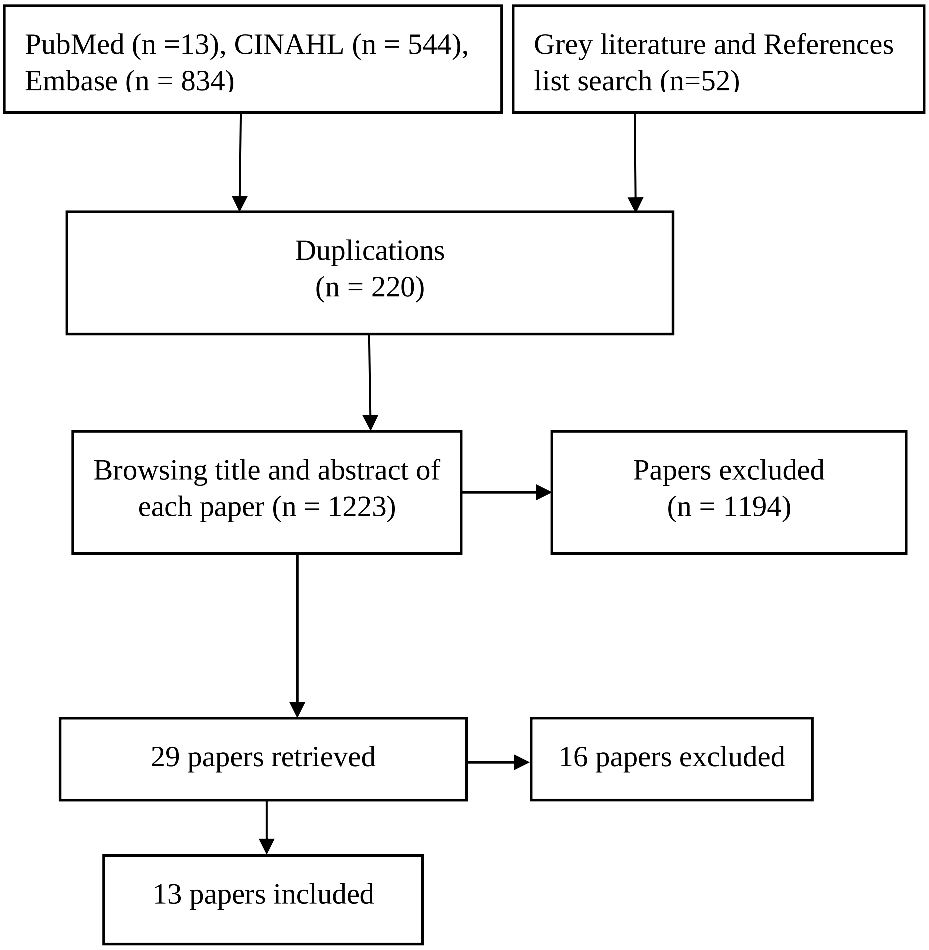


Figure 5: Flow chart of included articles

4.4.2 Methods used prior to setting up a national palliative care programme

Most included countries used different methods to collect information during the preparation phase of the PC programme. Interviews and surveys were the most common methods used for gathering information for planning and implementing the PC programme. Australia (Urbis, 2010), New Zealand (Ministry of Health, 2013) and Uganda (Palliative Care Association of Uganda, 2017) adopted different types of interviews (including in-depth interviews, focus groups, and workshops) for gathering information from policymakers' perspectives related to understanding the policy context, identifying the key barriers and perspectives on success, as well as priorities to be considered in the future.

Surveys were adopted by Australia (NSW Ministry of Health, 2019; Urbis, 2010), New Zealand (Ministry of Health, 2001, 2013), the UK (Department of Health, 2008), Ireland (Department of Health Social Services and Public Safety, 2010), Belgium (Keirse et al., 2009), Morocco (Association Lalla Salma De Lutte Contre Le Cancer, 2009), and Malaysia (Hospis Malaysia, 2016) to gain information about patient and family needs. Morocco and New Zealand also utilised surveys for verifying the level of general public awareness of PC (Association Lalla Salma De Lutte Contre Le Cancer, 2009; Ministry of Health, 2001, 2013). Belgium (Keirse et al., 2009) and New Zealand also used surveys to assess HCPs knowledge and beliefs about PC.

4.4.3 Key priority areas linked to the successful implementation of a PC programme

4.4.3.1 Education and training

Creating a well-educated and trained workforce

All included countries demonstrated a strong focus on education and training (Association Lalla Salma De Lutte Contre Le Cancer, 2009; Department of Health, 2008; Department of Health Social Services and Public Safety, 2010; Hospis Malaysia, 2016; Keirse et al., 2009; Ministry of Health, 2001, 2013; National Palliative and End of Life Care Partnership, 2015; NSW Ministry of Health, 2019; Palliative Care Association of Uganda, 2017; Soueidan et al., 2018; Urbis, 2010). Information on HCP awareness, knowledge, and training are significant strategies of the successful provision of PC mentioned across reports from eight countries, including Australia (NSW Ministry of Health, 2019; Urbis, 2010), the UK (Department of Health, 2008; National Palliative and End of Life Care Partnership, 2015), New Zealand (Ministry of Health, 2001), Ireland (Department of Health and Children, 2001), Belgium (Keirse et al., 2009), Malaysia (Hospis Malaysia, 2016), Morocco (Association Lalla Salma De Lutte Contre Le Cancer, 2009), Uganda (Palliative Care Association of Uganda, 2017), and Lebanon. (Soueidan et al., 2018). Of these countries, Ireland, Malaysia, Lebanon, Morocco, and Uganda focused on integrating PC training into all health curricula as an educational strategy towards the successful provision of PC services. In contrast, Australia focused on ensuring that HCPs have end-of-life conversation skills to assist them in the care planning process. Australia developed a free online course to help HCPs conduct effective conversations with patients and their families. Belgium seemed to be more focused on training curricula on symptom management and communication skills. Ireland focused on HCP education and legislation that seeks to ensure an individualised approach to care. One notable challenge that Australian reports highlighted was the slight increase in the number of PC nurses and doctors and the lack of PC training programmes. The government recommended high awareness and knowledge of the principle of PC across the health workforce, and not only among specialised PC professionals. This could be achieved by providing high-quality continuous training and education to HCPs, particularly the nursing workforce.

Enhancing general public awareness

Enhancement of public awareness, attitudes, and perceptions of PC was another crucial priority area reported by Australia (Urbis, 2010), the UK (Department of Health, 2008), New Zealand (Ministry of Health, 2001), Belgium (Keirse et al., 2009), Lebanon (Soueidan et al., 2018), and Morocco (Association Lalla Salma De Lutte Contre Le Cancer, 2009). Of these countries, the UK focused on enhancing positive attitudes and behaviours on the part of the general public towards dying and death. The Australian reports highlighted one notable challenge regarding the education and training strategy, which showed that a lack of public awareness and understanding of the death process continue to be a challenge for people at the EOL. The Australian government suggested community-led initiatives, such as social marketing and health promotion campaigns, as a means of raising public awareness.

4.4.3.2 Policies

Setting up PC standards and guidelines

Seven countries, including Australia, the UK, Ireland, New Zealand, Malaysia, Uganda, Morocco, and Lebanon, focused heavily on the policy component of the

WHO public health PC model in their national strategy. Of these countries, Australia (Urbis, 2010), the UK (Department of Health, 2008; National Palliative and End of Life Care Partnership, 2015), New Zealand (Department of Health and Children, 2001), and Ireland (Department of Health Social Services and Public Safety, 2010) have emphasised the integration of PC across all health settings as a leading policy towards the provision of PC programmes. In contrast, LMICs did not demonstrate any activities regarding this integration across settings.

Developing PC standards, guidelines, and supportive legislation have been recognised as a critical component of the policy, identified in New Zealand reports focusing on ensuring the quality of PC provided (Department of Health and Children, 2001), and in reports in Malaysia focusing on mapping the level of services available in the community for equal distribution of PC services across cities, and informing future directions and improvement of services (Hospis Malaysia, 2016).

Identifying financial budgets

Identifying financial budgets (funding model) for PC service development was reported in five countries, including Morocco (Association Lalla Salma De Lutte Contre Le Cancer, 2009), Uganda (Palliative Care Association of Uganda, 2017), Ireland (Department of Health and Children, 2001), New Zealand (Ministry of Health, 2001), and Australia (Urbis, 2010). Supporting research into PC has also been identified as an essential policy component for PC development. For instance, the UK recommended a separate budget for research (Department of Health, 2008), while Morocco and Uganda have encouraged researchers to focus their research on PC without, however, dedicating specific funding (Association Lalla Salma De Lutte Contre Le Cancer, 2009; Palliative Care Association of Uganda, 2017).

4.4.3.3 Medicine availability

Information on medicines availability was mentioned only in the reports from the UK and Morocco. The UK focused on providing medication to minimise pain and suffering for people with all life-limiting diseases across healthcare settings (Department of Health, 2008). Morocco, however, focused on institutional pain management at all health system levels, developing pain management clinics, and creating pain management committees in hospitals (Association Lalla Salma De Lutte Contre Le Cancer, 2009).

4.4.3.4 Service implementation

Activating partnerships across healthcare system levels

PC implementation is the fourth main component discussed by all included countries, with the exception of Belgium and Malaysia. All countries demonstrated evidence towards the implementation of PC in their initial national strategy. Australia (NSW Ministry of Health, 2019), UK (Department of Health, 2008; National Palliative and End of Life Care Partnership, 2015), New Zealand (Ministry of Health, 2013), Ireland (Department of Health and Children, 2001), Morocco (Association Lalla Salma De Lutte Contre Le Cancer, 2009) and Uganda (Palliative Care Association of Uganda, 2017) emphasised activating partnerships and sharing ideas with aged, community, and primary health sectors to develop consistent approaches for advance care planning. Whereas, Australia (NSW Ministry of Health, 2019) and Morocco (Association Lalla Salma De Lutte Contre Le Cancer, 2009) placed attention on ensuring active cooperation across all stakeholders within the HCS, including between professionals, policymakers, clinicians, and programme managers. Australia prioritised working with

PC interest groups to consider national objectives for enhancing consistency across the country.

Holistic patient assessment

In addition to activating partnerships, four countries, including Australia (NSW Ministry of Health, 2019; Urbis, 2010), New Zealand (Ministry of Health, 2001, 2013), the UK (Department of Health, 2008), Ireland (Department of Health Social Services and Public Safety, 2010) have focused on PC care that should be based on patients' and families' unique needs and preferences.

Regardless of the successful implementation of PC across countries, some of these countries faced challenges in implementing optimal PC services across all levels of society. For instance, Australia (NSW Ministry of Health, 2019), the UK (Department of Health, 2008), and New Zealand (Ministry of Health, 2013) are experiencing a growing ageing population, resulting in high pressure on the HCS. Australia also reported that geographic location (i.e. living in remote areas) hindered people from reaching PC services, and socioeconomic needs and cultural background could be obstacles in the implementation of PC across all settings (NSW Ministry of Health, 2019). The Australian government made progress towards enhancing PC in a culturally appropriate way for Aboriginal and Torres Strait Islander peoples. Developing culturally specific activities to address a targeted group's needs may help improve access to services when needed.

Table 4: Key priority area for successful provision of palliative care services in conjunction with WHO public health PC model

Authors/ participants, Years Country	**Title/document**	**Key priority areas** **(E)= Education; (I)= Implementation; (M)= Medicines; (P)= Policies**
Urbis, 2010 Australia (Urbis, 2010)	"Evaluation of the national PC strategy 2010 final report"	- Enhance the capacity of all relevant sectors **(P)** - Identify a financial budget (Funding model) to meet the patients and their family's needs **(P)** - Establish firm policy, legislative and regulatory frameworks for the provision of pharmaceuticals **(P)** - Develop a public (and patient) awareness strategy to promote death as a normal part of living **(P, E)** - Encourage integration of PC training within health undergraduate and postgraduate curricula **(P, E)** - Enhance the general public's awareness of PC benefits **(E, P)** - Develop a pharmaceutical benefits schedule **(M)** - Undertake research on testing drug efficacy **(M)** - Provide PC for people living in a remote area **(I)** - Deliver care based on patients' needs and preferences **(I, E)** - Develop infrastructure for delivering excellent quality PC in any setting **(I)**
Ministry of Health, 2019 Australia (NSW Ministry of Health, 2019)	"End of Life and PC Framework 2019-2024" 5-year plan	- Ensure people with more complex needs access the care provided by specialist PC services **(P)** - Enhance HCPs skills and knowledge of PC **(E)** - Support people to have conversations about what is essential in living and dying well **(E)** - Provide care for people, their families, and carers based on their unique needs and preferences **(I, E)** - Work with partners to develop consistent approaches for advance care planning **(I)** - Ensure an effective collaboration and coordination effort across the health system, including between service (professionals, policymakers, clinicians, and programme managers **(I)**
National Health Service England, 2008. UK (Department of Health, 2008)	"End of Life Care Strategy: Promoting High-Quality Care for All Adults at the End of Life"	- Ensure PC services are available in all health settings **(P)** - Enhance research funding through health research institutions **(P)** - Review the need for ongoing continuing professional education **(P, E)** - Ensure all health care professionals have received training in communication skills to start conversations and support people approaching the end-of-life **(P, E)** - Ensure that health care professionals at all levels are provided with the necessary education and training skills **(P, E)** - Promote public education and awareness about PC through changing attitudes and behaviours toward dying and death **(E, P)** - Ensure the availability of opioid drugs for people approaching the end of life **(M, P)** - Ensure local partnerships to consider how best to engage PC with the community **(I)** - Deliver information on how to access comprehensive and culturally appropriate bereavement **(I)** - Ensure that individuals have received care based on their needs, priorities, and preferences **(I, E)**

Authors/ participants, **Years** **Country**	**Title/document**	**Key priority areas** **(E)= Education; (I)= Implementation; (M)= Medicines; (P)= Policies**
National Palliative and End of Life Care Partnership, 2015 UK (National Palliative and End of Life Care Partnership, 2015)	"Ambitions for Palliative and End of Life Care: A national framework for local action 2015 – 2020". 5-year plan	- Support people with rapid access to needs-based social care **(P, I)** - Ensure people are well-informed about dying, death and bereavement **(E, P)** - Ensure that health care professionals providing palliative and end of life care understand and comply with legislation that seeks to ensure an individualised approach **(E, P**) - Activate partnerships, particularly between the National Health Service, social care, and the voluntary sector **(I)** - Make partnerships between different faith groups and cultural communities **(I)** - Ensure people receive the care they need **(I, E)**
Ministry of Health, 2001 New Zealand (Ministry of Health, 2001)	"The New Zealand PC strategy" 5 –10-year	- Develop standards and guidelines to ensure the quality of PC provided **(P)** - Ensure hospitals have PC teams **(P, I)** - Ensure all districts have general and specialised PC services **(P, I)** - Promote public education and awareness about what is PC, requirements, and expectations from PC **(E, P)** - Develop workforce and training programs for general and specialised health care professionals **(E,P)** - Identify the patients' and their family's physical, social, and spiritual needs **(I, E)**
Ministry of Health, 2013 New Zealand (Ministry of Health, 2013)	"Resource and Capability Framework for Integrated Adult PC Services in New Zealand"	- Collaborate with other partners **(I, P)** - Support collaboration between primary PC professionals in all settings and specialist PC professionals **(I)** - Identify the population needs **(I)**
Department of Health and Children, 2001 Ireland (Department of Health and Children, 2001)	"Report of the National Advisory Council on PC"	- Develop a separate budget for PC **(P)** - Provide adequate funding for delivering PC services **(P)** - Ensure partnerships with voluntary service professionals **(I)**
Department of Health, Social Services and Public Safety 2010 Ireland (Department of Health Social Services and Public Safety, 2010)	"Living Matters Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland" 5-year plan	- Ensure that PC is applicable across all conditions and all care settings **(P, I)** - Ensure that PC presents people with options for choice by whom, how and where their care can be delivered **(E)** - Acknowledge the effects of illness on the person, family, carers, and staff **(E)** - Provide clear information on the best standards of practice **(I)** - Confirm that patient needs are based on a holistic assessment that identifies the social, spiritual, financial, physical and psychological needs of patients and their families **(I, E)**
Keirse et al. 2009 Belgium (Keirse et al., 2009)	"Organisation of PC in Belgium-supplement"	- Ensure general health care professionals have sufficient education **(E)** - Integrate necessary PC training courses in the curriculum including control of symptoms, communication skills, and addressing social problems and spiritual needs **(E, P)**

Authors/ participants, **Years** **Country**	**Title/document**	**Key priority areas** **(E)= Education; (I)= Implementation; (M)= Medicines; (P)= Policies**
Hospis Malaysia 2016 (Hospis Malaysia, 2016)	"PC Needs Assessment, Malaysia: 2016"	- Implement guidelines and standards to define the level of service and standards of care required to deliver PC **(P, I)** - Enhance community awareness, perceptions, and expectations **(E)** - Engage health care professionals in diverse specialities and general practitioners through education and training **(E, P)** - Provide education and training at undergraduate and speciality training level for all health care professionals **(E, P)**
PC Association of Uganda 2017 (Palliative Care Association of Uganda, 2017)	"PC for all in need in Uganda Strategic Plan 2017 -2021" 5-year plan	- Establish adequate financing and related resources **(P)** - Enhance PC research **(P)** - Ensure policymakers awareness and understanding of PC **(P, E)** - Focus on training, mentorship, and support supervision **(E, P)** - Disseminate information to improve PC services **(E)** - Integrate PC services into all health settings **(I)**
Association Lalla Salma De Lutte Contre Le Cancer 2009 Morocco (Association Lalla Salma De Lutte Contre Le Cancer, 2009)	"National cancer prevention and control plan: 2010-2019"	- Provide secure paid-for transport from the hospital to the home and from the home to the hospital **(P)** - Promote research in the PC field **(P)** - Develop pain management reference centres **(P)** - Provide training to health professionals and medical social workers **(E,P)** - Ensure medical social workers' awareness about their role in oncology centres **(E,P)** - Provide patients and their families with relevant information and consultation support **(E)** - Develop a model for pain management education **(I, P)**
Faculty of Health Sciences, American University of Beirut (Soueidan et al., 2018)	"Integrating PC into the Health System in Lebanon"	- Undertake public awareness campaigns on PC aims and resources **(E)** - Ensure adequate education and training of health professionals in core PC knowledge and skills **(E, P)** - Integrate PC services within health care facilities **(I)** - Provide PC to patients' home **(I)**

E=Education; I= Implementation; M= Medicines; PC=Palliative care; P= Policies

4.5 Discussion

This is the first review to provide a broad overview of national approaches regarding PC implementation into HCSs in countries that have identified PC within their national policies. Implementation of PC services accelerated in the past decade, as most reports have been published since 2010. The findings are supported and correlate well with other international publications on the global development of PC (Connolly, 2015; Connor & Sepulveda Bermedo, 2014). This reflects the interest and concern of governments to build strategies towards improving PC.

Surveys and interviews were common methods used for evaluating PC services before setting up a PC programme. Surveys were the most frequent tool adopted by governments for assessing patients, the general public, and HCPs knowledge and awareness. Different studies have adopted surveys for assessing HCPs knowledge and awareness (Abudari, Zahreddine, Hazeim, Assi, & Emara, 2014; Ayed, Sayej, Harazneh, Fashafsheh, & Eqtait, 2015; Budkaew & Chumworathayi, 2013; Kassa, Murugan, Zewdu, Hailu, & Woldeyohannes, 2014), patients' needs (Aslakson et al., 2017; Lo et al., 2011), and general public awareness (Al-Drees, AlHubail, & Elzubair, 2019; Alkhudairi, 2019; Benini et al., 2011; Hirai et al., 2011; McIlfatrick et al., 2013; Westerlund et al., 2018). Adopting survey methods produces a large amount of data and can, therefore, be generalised to the population (Kelley, Clark, Brown, & Sitzia, 2003). Interviews were a convenient method adopted to understand policymakers' perspectives. Interviewing and involving policymakers and experts in the process of PC implementation is vital for understanding the processes and factors that affect PC implementation, and is vital for sorting priorities, solving challenges and implementing appropriate solutions for service improvement (Bate & Robert, 2006).

Discussion with policymakers from the beginning of PC services is required to help governments measure the value of PC to the health system.

Education and training are the most frequently covered topics by all included country reports. Promoting general public awareness and ensuring HCPs knowledge have been identified as an essential step towards the successful provision of a PC programme (Hannon et al., 2016). Educating the general public about the concept of PC and its benefits is a continuous process in developing PC (Callaway, Connor, & Foley, 2018), which can enhance referral to services and increase accessibility (Cagle et al., 2016; Wilson, Avalos, & Dowling, 2016). A lower level of general public awareness has affected the quality of care, leading to negative perceptions and impacts on PC services (Fadhil et al., 2017; McIlfatrick et al., 2013). A European qualitative study has shown that misunderstanding on the part of the community towards PC services was a crucial challenge in the development of PC services (Lynch et al., 2010a). Development of health promotion activities (Abel, Bowra, Walter, & Howarth, 2011; Kellehear & O’Connor, 2008; Kumar, 2007) and social media campaigns can be used as a tool for improving public awareness about PC (Gauvin, Abelson, & Lavis, 2013).

Ensuring that HCPs have adequate knowledge and training in PC is a crucial step for effective PC implementation. This is consistent with other studies that have shown that insufficient knowledge on the part of HCPs and lack of training are considered significant challenges in the development of PC (Aldridge et al., 2016; Khoshnazar et al., 2016). Insufficient knowledge might be caused by inadequate PC content PC in health curricula and training programmes (Paice et al., 2006; Wallace et al., 2009). Enhancement of HCP training can be achieved by different tools, such as modifying curricula and including PC in undergraduate and postgraduate medical and nursing programmes (Centeno & Rodriguez-Nunez, 2015; Ddungu, 2011) and classroom-based PC training (Pulsford, Jackson, O'Brien, Yates, & Duxbury, 2013). Hence, assessing HCPs knowledge and training is valuable and fruitful for gaining information that will help the development of PC strategies and guidelines.

Development of national PC policies, standards, and strategies, identifying financial budgets and enhancing research funding are the main policy areas that have been highlighted for PC development. Policies play a significant role in providing guidance to the PC development process and entrenching sustainability of services (Luyirika et al., 2016). Supportive policies through adequate funding were required for effective integration of PC into the HCS (Fraser et al., 2017; The Economist Intelligence Unit, 2015) because without policies that support the provision of PC, it will be difficult for any PC to be introduced (Stjernsward et al., 2007). Sharing and involving policymakers with the process of implementation is crucial towards designing standards and setting budgets for providing PC services (Ansari, Rassouli, Akbari, Abbaszadeh, & Akbarisari, 2018), also considering that every country has different contexts and views on PC services (Higginson, Hart, Koffman, Selman, & Harding, 2007).

Developing PC standards and guidelines is also recognised as an important step in the effective implementation of PC. Lack of practical guidelines has been recognised as a barrier to improving the quality of care (Temkin-Greener et al., 2015). Guidelines are intended to guide healthcare facilities and HCPs across all health settings on how to perform best practices in managing patients with life-limiting illnesses (National consensus project for quality palliative care, 2018). Appropriate guidelines and standards not only can guide HCPs on how to communicate and work together to achieve optimal patient care (African Palliative Care Association, 2010), but also allow policymakers to monitor the progress of PC implementation (World Health Organisation, 2016).

Development of financial budgets for PC services is another key priority area before introducing an effective PC programme. Developing funding and resource-allocation models are required for the sustainable provision of high-quality care (Groeneveld et al., 2017). Estimating the cost of service provision with outcomes is an effective method for service cost-estimation and resource allocation (Kaplan & Porter, 2011). A cost-effective method on PC implementation is important in light of the limited resources that countries may have (Smith, Brick, O'Hara, & Normand, 2014). Hence, developing a funding model based on the availability of resources in a country is a priority before the implementation of a PC programme.

Integration of PC services across all care settings is also a leading policy strategy towards the provision of PC programmes. Integration of PC services into a country's HCS is recommended internationally as a critical component of the HCS (Hasselaar & Payne, 2016; World Health Organisation, 2014). To effectively integrate these services requires greater collaboration between agencies to meet patients' needs (Higginson et al., 2014). Information sharing about patients among HCPs is the central area of successful PC integration, which allows continuity of care (Bone et al., 2016; den Herder-van der Eerden et al., 2017). Sharing information requires excellent communication and training skills, and well-organised information systems, as well as support from policy leaders. Hence, ensuring key stakeholders' willingness to share information and develop information systems before implementing PC is a priority.

Little information on medication availability was noted in most of the countries that were included. This point is reflected in work by the Economist Intelligence Unit, which states that the included countries had a good HCS and ranked at the top worldwide in terms of the quality of PC services for adults (The Economist Intelligence Unit, 2015); consequently, they may have already established an appropriate pain management programme and already considered it to be one of the central pillars in the health system. Therefore, these countries did not focus on pain medication in their strategies. In 2013, the WHO classified morphine as a widely accepted potent opioid of choice in addressing moderate to severe pain. Morphine is included in the WHO Essential Medicines List as an analgesic for PC (World Health Organisation, 2016), and it is also included in the International Association for Hospice and Palliative Care List of Essential Medicines in PC for the treatment of moderate to severe pain (World Health Organisation, 2013b). However, access to opioids requires clear and appropriate legislation, availability of and funding for opioids, and clinicians' confidence in the effectiveness of opioid management. Hence, ensuring the availability of painkillers in the HCS before implementing a PC programme is another priority.

Our findings highlighted that providing PC based on patients and their family's preferences is an important strategy to be considered before the successful implementation of a PC programme. Planning based on patients' needs has been portrayed in different studies, for example, improving QOL (All Ireland Institute of Hospice and Palliative CARE, 2017; Richardson, Sitzia, Brown, Medina, & Richardson, 2005) or reducing hospital admissions and re-admissions (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Khandelwal et al., 2015). Our findings also mentioned that talking about death and what is essential in living and dying well are considered challenges to accessing PC programmes. These findings are in line with other studies, which have shown that talking openly about death is a contentious issue in some countries because of cultural values and religious beliefs, and this is considered a challenge in PC provision (Abu Seir & Kharroubi, 2017; Long, 2011; Manalo, 2013). Therefore, assessment of patients and their families has many benefits; including helping recognise patients in need of PC, helping to inform the planning of PC programmes and setting up interventions, helping HCPs in the management of health care problems and source allocation, and help in identifying gaps and setting up priorities in PC provision. Hence, for the enhancement of PC integration into a country's HCS, various activities should be considered at the level of patients and their families, community, institutions, and systems.

4.6 Limitations

There were several limitations in this review that should be highlighted. We sourced the information only from governmental reports; other relevant information may be available in dissertations/thesis and conference papers that were not included. The information extracted is from narrative reports instead of scientific research studies; thus, there is a lack of evidence to show the effectiveness of the suggested strategies. The language restriction to English was also a limitation.

4.7 Conclusion

It is necessary to learn from countries demonstrating effective practices in PC before the implementation of a new programme at a national level. Such practices could be used as a guide and a meaningful way of addressing barriers that stand in the way of the development of PC services. Holistic assessment of patients, increasing public awareness, and creating a well-trained educational and specialised workforce are the first steps required before implementing a PC programme. Lobbying of policymakers about the significance of PC and involving them within all development processes are also vital steps before the systematic implementation of PC services. In addition, setting up PC standards and guidelines and working in partnership between HCS levels, specialist interest groups, and stakeholders is essential for the successful provision of PC services.

Despite the significance of the provision of PC programmes into the HCS, no research studies have been done focusing on need assessment and planning before the development of PC. It is apparent that high-level documents from governments or large organisations and NGOs focused on the development of PC strategies. This doctoral research study will address this research gap by identifying the key stakeholders (patients, HCPs, and decision and policymakers) perspectives of PC that will contribute to the development of PC programmes in the Palestinian HCS by using different methods. This doctoral research project will serve as a point for discussion about moving forward towards introducing PC services into the health system.

The next chapter will present the conceptual framework of this doctoral research study, which was constructed based on the findings of the previous two reviews (Abu-Odah et al., 2020, 2021).

CHAPTER (5): CONCEPTUAL FRAMEWORK

5.1 Introduction

A conceptual framework is a map used to display the relationship between the study variables and clarify the interpretation of the study results (Maxwell, 2005). It is defined as a set of concepts that are interrelated, which creates a comprehensive understanding of the topic studied (Jabareen, 2009). To understand the relationship between the different components in this thesis, a conceptual framework has been constructed based on the findings of the preceding reviews (Abu-Odah et al., 2020, 2021), the WHO Public Health PC Model (Stjernsward et al., 2007; World Health Organization, 1990), and the Socioecological model (SEM) (McLeroy et al., 1988). The chapter presents a description of each model and the rationale for adopting them and ends with a discussion of the proposed conceptual framework of the research study.

5.2 The WHO Public Health PC Model

The WHO Public Health PC model was formulated by the World Health Organization (1990) and was updated by Stjernsward et al. (2007). It was developed as a tool for providing guidance and advice to countries on implementing PC programmes into their HCSs and across levels of care (Fraser. et al., 2018; Stjernsward et al., 2007). Governments have widely used it to integrate PC programmes into their national policies (All Ireland Institute of Hospice and Palliative CARE, 2017; Hospis Malaysia, 2016; Palliative Care Association of Uganda, 2017).

The WHO Public Health PC model covers four components: 1) appropriate policies, 2) education of HCPs and the general public, 3) the availability of medicines and 4) services implemented across all levels of society (Stjernsward et al., 2007). The four components interact with and dynamically influence each other. For instance, patients respond to the system in which they receive treatment, and the healthcare organisation responds to policies that, in turn, influence patients' care. These components provide an effective strategy towards establishing a PC programme into a country's HCSs (Figure 4).

5.3 The Socioecological Model (SEM)

The socioecological model (SEM) was initially identified in 1970 (Bronfenbrenner, 1977) and was formulated as a theory in 1980 for understanding the multifaceted and interactive effects between personal factors, environmental factors, and organisational leverage points for health enhancement within a health organisation (McLeroy et al., 1988). It has been a widely recognised model used to better understanding individuals' health behaviours (Golden & Earp, 2012).

The SEM is composed of five levels: 1) intrapersonal concerns about knowledge, attitudes, behaviour, self-concept, and skills of individuals, 2) interpersonal focuses on the family, workgroup, and friendship networks, 3) organisational focuses on rules and regulations for operation, 4) community focus on the relationships between organisations, institutions, and informal networks, and (5) policy level, emphasising national laws and policies (McLeroy et al., 1988). All of these factors are interrelated and can affect health enhancement through enhancing an individual's behaviour (Sallis & Owen, 2008). A minor modification on SEM was generated by Haines, Frost, Kane, and Rokoske (2018) by removing the distinction between intrapersonal and interpersonal levels and differentiating between the roles of HCPs, patients and caregivers, and identifying the roles of community in contributing to the health system.

The final modified model (Figure 2) has four levels: 1) the personal level, which focuses on patients, families, and HCPs, 2) the organisational level deals with the organisation's culture and infrastructure, 3) the HCS level describes workforce and training issues, and 4) the policy level relates to legislation and funding (Haines et al., 2018).

5.4 The rationale of choice of the WHO Public Health PC model and SEM

The rationale for choosing the models mentioned above for the current research is that they have been utilised to enhance outcomes for patients with chronic conditions and provide a comprehensive, evidence-based conceptual framework for integrated care into HCSs in LMICs for many years (Callaway et al., 2018; McLeroy et al., 1988; Stjernsward et al., 2007; World Health Organization, 1990). Further, they are proactively focused on policymakers, HCPs, along with the general public and patients, while at the same time acknowledging and respecting the social and cultural realities of a country. The interaction at multi-level dimensions improves healthcare service outcomes and can create a positive environment for implementing PC programmes. They also suggest a framework guiding changes in health systems, improving the process of decision making and strategic planning, and providing a solid base for policy development (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004), which is essential for PC development in LMICs.

Notwithstanding the robustness of the WHO Public Health PC model in terms of components, it does not cover the emerged variables that may play a role in developing PC, such as cultural and religious issues and attitudes towards death. Thus, the doctoral researcher sees that merging both models will provide a solid framework covering all factors that may affect the successful implementation of PC programmes. The WHO model is recommended for PC implementation care (Fraser. et al., 2018; Stjernsward et al., 2007) and combined with SEM helps in conceptualising the multilevel factors of the provision of a PC programme (Bronfenbrenner, 1977; McLeroy et al., 1988).

5.5 The proposed study conceptual framework

Based on the previous information discussed, a combination of both models will provide a complete understanding of components that play crucial roles in developing PC services. This section merges the components and provides a detailed discussion and connection of each component with others supported by previous reviews (Abu-Odah et al., 2020, 2021). It ends with the study conceptual framework map (Figure 6).

5.5.1 Policy

The development of policies is the essential construct required for the successful provision of PC services. Without policies that support the provision of PC, it is difficult for any PC to be introduced (Stjernsward et al., 2007). Policies play a significant role in providing guidance to the PC development process and entrenching the sustainability of services (Luyirika et al., 2016). According to both models, the policy can take many forms, whether standalone or integrated with a national plan (Maetens, Cohen, & Harding, 2019). Both models and reviews agreed that appropriate policies should cover the following elements: policies, funding supporting PC delivery, resources, and essential medicine (Haines et al., 2018; Maetens et al., 2019; McLeroy et al., 1988; Stjernsward et al., 2007).

Supportive policies (strategies, guidelines, and standards) backed by adequate funding are in need of a useful integrated PC into the HCS (Ddungu, 2011; Fraser et al., 2017; The Economist Intelligence Unit, 2015). The setting of clear and appropriate guidelines and standards is necessary for the provision of PC services, improved access to quality PC for all citizens, and mitigating barriers (Fraser et al., 2017; Maetens et al., 2019; Stjernsward et al., 2007). Lack of guidelines has been recognised as a barrier to improving the quality of care (Temkin-Greener et al., 2015). Appropriate guidelines and standards help policymakers measure progress towards implementing PC services and how to enhance the quality of services (World Health Organization, 2016b).

The involvement of policymakers, leaders, and experts in the process of PC implementation is, therefore, a priority for understanding the processes and factors that affect PC implementation (Ansari et al., 2018). It is also vital to sort priorities, identify resources, set budgets, solve challenges, and implement appropriate solutions/facilitators for service improvement (Ansari et al., 2018).

Essential medications are needed for PC provision, particularly pain management, one of the central issues in the HCSs. Morphine is one of the essential medicines, a widely accepted potent opioid of choice in moderate to severe pain. Morphine is included in the WHO Essential Medicine Lists as an analgesic for PC (World Health Organization, 2016b). Access to opioids requires sufficient, transparent and appropriate legislation, availability and funding for opioids, and clinician confidence in opioid management. Ensuring the availability of painkillers in the HCSs before the implementation of a PC programme is a priority. Hence, the setting of appropriate policies in discussion with policymakers from the beginning of PC services is required to help governments to measure the value of PC to the HCSs and helps HCPs on how to work together for achieving optimal care to patients.

5.5.2 Education/Healthcare system

Education is an essential component of a comprehensive strategy for developing a PC programme (Stjernsward et al., 2007). Staff training for enhancing knowledge has been identified as an essential step towards the successful provision of a PC programme (Hannon et al., 2016; Stjernsward et al., 2007). In addition to education and training, other factors, such as HCP attitudes and beliefs, should be considered and assessed from the perspective of health care organisations (Silbermann et al., 2015). Insufficient knowledge on the part of HCPs is considered a significant barrier to the development of PC (Aldridge et al., 2016; Khoshnazar et al., 2016). Insufficient knowledge of HCPs may be attributed to a lack or inadequate content about PC in the curricula (Paice et al., 2006; Wallace et al., 2009). Increasing knowledge and skills helps HCPs communicate and interact effectively with patients, which positively affects the provision of a PC programme—gaining such information about HCP knowledge, and attitudes regarding PC in a preparatory stage helps develop PC services.

Negative HCP attitudes are a crucial challenge in the provision of PC (Aldridge et al., 2016; Dalgaard et al., 2014; LeBlanc et al., 2017). Therefore, PC education has been recommended as the first step (World Health Organization, 2014) to increase awareness, promote positive attitudes and improve knowledge of these services among professionals (Dalberg et al., 2018; Zelko et al., 2017). Enhancing knowledge and attitudes can be realised by integrating core competencies of PC into university curricula (Stjernsward et al., 2007; World Health Organization, 2014).

Workforce shortages or inadequate workforce is also a significant HCS challenge in the provision of PC. This shortage affects the quality of the PC services provided to cancer patients, resulting in mismatched expectations (Lupu & American Academy of Hospice and Palliative Medicine Workforce Task Force, 2010). Therefore, investment in time and resources in workforce training is recommended in addressing workforce shortages. The quality of the workforce can be enhanced through increasing national and international professional programmes (Ali, 2016; Shawawra & Khleif, 2011), and providing informal training to medical oncologists (Zeinah, Al-Kindi, & Hassan, 2013a). It also can be enhanced by creating a supportive learning environment and developing information management systems (Donkor et al., 2018), and integrating PC into curricula and practice (Ali, 2016; Elcigil, 2011; Shawawra & Khleif, 2011; Silbermann et al., 2012).

5.5.3 Services implementation

Implementation of PC services is the core part of a comprehensive PC strategy (Stjernsward et al., 2007). Maetens et al. (2019) highlighted that it is crucial to identify the unmet service needs of patients before implementing PC services. Maetens et al. (2019) reported that the needs should cover physical, social, spiritual, psychological, financial, emotional, and cultural, as well as patients' values and preferences. They also reported that services needs include managing pain that disrupts functional/daily life activities, breathlessness, and other clinical indicators for further PC assessment (Maetens et al., 2019). In addition to the needs mentioned above, others retrieved from the literature include practical and informational needs (Fitch, 1994). Influencing factors also should be considered when identifying patients' needs, including socioeconomic-demographic factors (age, gender, marital status, educational level, and monthly income) and clinical-related factors (diagnosis/type, grade, current treatment, and duration since diagnosis).

Identifying unmet services needs assists HCPs and leaders in recognising what types of needs patients might have and how these needs might be approached. Understanding how well and how much their needs have been satisfied will help in designing and implementing a PC programme. Establishing feedback systems for collecting information from different stakeholders, including patients' further help to refine and develop services and influence health care outcomes.

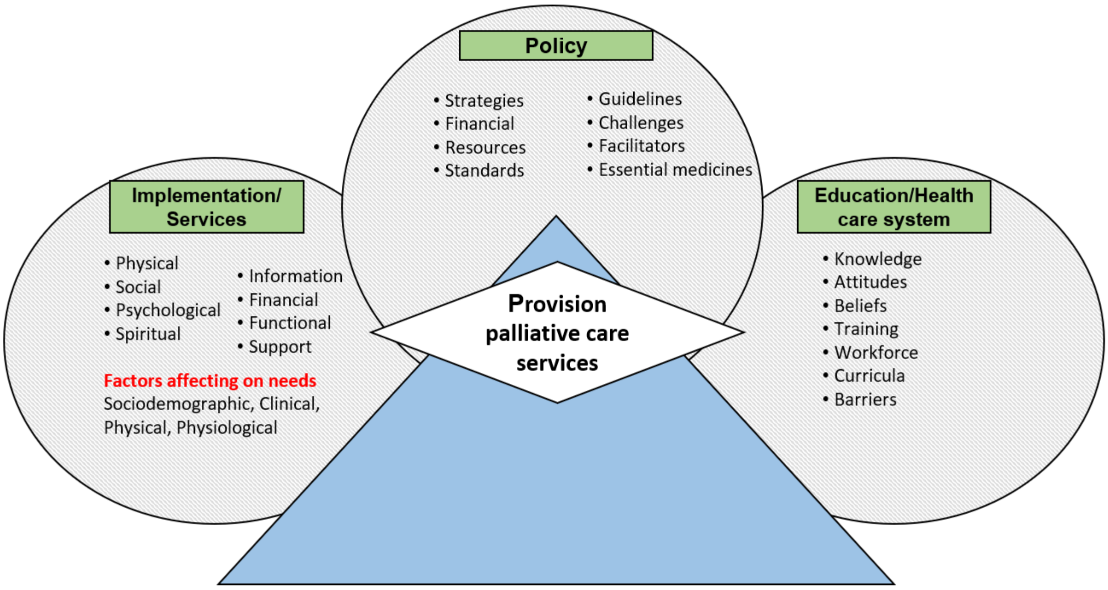


Figure 6: The proposed conceptual framework for the current doctoral study

5.6 Summary

Based on the proposed conceptual framework and the issues highlighted, before developing a PC programme it seems crucial to focus on assessing the unmet patient service needs, HCP education, and policy issues. The next chapter will present the doctoral research study aims and the methodological approaches that address the specific aims.

CHAPTER (6): METHODOLOGY AND PROCEDURES

6.1 Introduction

This chapter illustrates the methodological and theoretical approaches and research methods used to address the study purpose. It covers the study aims and objectives and gives an overview of a multi-method research design adopted in this study. A distinction between multi-method and mixed-method approaches and the rationale for choosing the multi-method study design is presented. The chapter ends with a figure presenting the overall research methods of this doctoral thesis.

6.2 Research objectives

As presented in the first chapter, the long-term goal of this doctoral thesis is to contribute to developing a PC programme into the HCSs of LMICs (Palestine). This doctoral thesis aimed to explore the factors and needs associated with developing a PC programme into the Palestinian HCS from key stakeholders' perspectives. Findings from different key stakeholders' perspectives will provide a comprehensive understanding before the development of the PC programme. This study will serve as a point for a discussion on how to move forward in the provision of a PC programme in Palestine. The specific objectives of the three studies in this doctoral thesis are the following:

(1) To identify the unmet supportive care service needs of patients with advanced cancer.

(2) To assess the educational and healthcare system-related issues or needs that physicians and nurses may face, and how these affect the development of PC services.

(3) To explore the perspectives of decision and policymakers on the provision of PC services.

6.3 Methodological and theoretical approaches

6.3.1 Research design

The multi-method research design was adopted to identify key stakeholder perspectives on PC that will contribute to implementing PC programmes into the HCSs. The multi-method research design involves quantitative and qualitative studies that are relatively complete on their own and then used together to form an essential component of the research phenomenon. Each study is planned and conducted separately to answer particular questions, and the results of all questions are transformed to form a comprehensive whole (Morse, 2003).

6.3.2 The philosophical orientation of research design

Research is a systematic process that the researcher follows to find new knowledge (Creswell, 2012). It is conducted for different reasons, including describing, predicting, explaining, evaluating, or understanding a phenomenon. Research design is critical to research, because it provides a plan to follow during the research process (Grove, Burns, & Gray, 2012). Research design is defined as "the overall plan for obtaining answers to the research questions and for handling challenges that can undermine the study evidence" (Polit & Beck, 2014, p. 51).

Fundamentally, any research design is guided by a paradigm. The paradigm is defined as a set of beliefs regarding ontology, epistemology, and methodological questions on the nature of reality (Broom & Willis, 2007; Lincoln, Lynham, & Guba, 2011). The two communal paradigms are positivist and constructivist; each has different beliefs.

The positivism paradigm assumes that knowledge exists in the real world, and we can learn by acquiring this knowledge, meaning that reality is objective and can be quantified (Broom & Willis, 2007). The constructivist paradigm proposes that humans can construct the knowledge they hold because of experience, culture, and meaning that differs from each other, and all knowledge is created by the individuals or society. The methods used in each paradigm are also different. For example, in positivist (quantitative) research, the methods range from randomised controlled trials to surveys, while in constructivist (qualitative) research, they range from an interview, observation to case study, etc. (Broom & Willis, 2007).

The third pragmatist paradigm was identified in 1980 (Johnson, Onwuegbuzie, & Turner, 2007) aimed to collect, analyse, and mix both quantitative and qualitative methods (Teddlie & Tashakkori, 2009) and provide the best approach to comprehend a phenomenon (Creswell, 2002; Creswell & Clark, 2011). A mixed-methods approach is a tradition based on pragmatism, combined between the different approaches to finding a workable solution (Creswell & Clark, 2011).

6.3.3 The distinction between mixed methods and multimethod designs

There are debatable issues around the meaning of mixed methods and multi-method approaches, which have generated blurring and confusion in academia (Bryman, 1984; Creswell & Tashakkori, 2007). Although some researchers have drawn a clear distinction between mixed methods and multi-method, others make no distinction between those terms. The failure to differentiate between both approaches was prevalent around the turn of the early 20th century (Anguera, Blanco-Villaseñor, Losada, Sánchez-Algarra, & Onwuegbuzie, 2018). Caracelli and Greene (1993) described a category of mixed methods research as conducting separated analyses of quantitative and qualitative data, and then engaging in the integration of findings during the interpretation phase of the research (Caracelli & Greene, 1993). Morse (2003) defined a multi-method research design as “qualitative and quantitative projects that are relatively complete, but that are used together to form essential components of one research program”. While Stange, Crabtree, and Miller (2006) stated that mixed methods research is identified as a multimethod and includes integrating quantitative and qualitative approaches to generating new knowledge. The lack of clarity of the distinction between both designs has negative consequences for the methodological discipline.

Johnson et al. (2007) listed and analysed 19 definitions of mixed-methods research, in particular, to find the distinction with multimethod research. Johnson and colleagues contacted 19 leaders in the field of research design to provide a clear distinction between the two designs in terms of meaning. A transparent clarification provided by Pat Bazeley as ‘‘Multimethod research is when different approaches or methods are used in parallel or sequence but are not integrated until inferences are being made’’ (Johnson et al., 2007, p. 119). While Burke Johnson and Anthony Onwuegbuzie define mixed-methods design as “research in which the researcher is mixing/combining both quantitative and qualitative research questions, methods, approaches, concepts or language into a single study or set of related studies” (Johnson et al., 2007, p. 120).

The above view of multimethod research is supported by the explanation presented in *Sage Handbook of Mixed Methods in Social & Behavioral Research* that elucidates multimethod research as research involving multiple types of qualitative methods or multiple types of quantitative methods (Tashakkori & Teddlie, 2010), while mixed methods research as research mixing both quantitative and qualitative approaches

(Morse, 2003). Based on all previous descriptions of both designs, it is apparent that the confusion does not just surround the term, but is also around the methodological orientation. The authors agreed that integration is essential in mixed-method studies (Bazeley, 2012; Sandelowski, 2014; Teddlie & Tashakkori, 2009), but it is not needed in multimethod design (Plano Clark & Ivankova, 2016).

To sum up, the mixed method as a term was identified in 1980 (Johnson et al., 2007) after 20 years of first discussions on multi-methods by Campbell and Fiske (1959) in a multitrait-multimethod matrix article, which was supported by several scholars who identified mixed method as one category of multi-method approaches. There are three categories of multi-methods inquiry that revolve around the basic distinction that has been constructed between quantitative and qualitative approaches and involve: 1) two or more qualitative approaches, 2) two or more quantitative approaches, or 3) combining at least one qualitative and quantitative method. The third multi-method category is like mixed-method design, but the distinction between both approaches lies in mixing the data.

6.3.4 The rationale for using the multi-method approach

The multi-method approach was chosen to fulfil the study phenomenon. Using a multiple method research approach for this study provides an opportunity to study a multitude of variables associated with PC from different key stakeholders' perspectives (Mertens, 2014). A multiple methods approach is more frequently used in PC disciplines because it resonates with the complexity of the care (Seymour, 2012), which needs knowledge from multiple sources to improve the care provided (Evans, Harding, & Higginson, 2013). Using multiple methods to study a complex phenomenon is recommended by several scholars from different disciplines due to its advantages (Brewer & Hunter, 1989; Creswell, 2003; Newman, Benz, & Ridenour, 1998). Multiple methods increase the robustness of our understanding of a phenomenon (Mingers, 2001), help the researchers to expand their knowledge and study scope (Tashakkori & Teddlie, 1998), provide an opportunity to look for corroboration in the results from different methods (Brewer & Hunter, 1989; Greene, Caracelli, & Graham, 1989), and provide a comprehensive, in-depth and broad understanding of the phenomenon. Time limitations reinforce the researcher to select this strategy, because both types of data will be collected simultaneously, and they are not dependent on each other. Unlike mixed-method designs, the data are not integrated, but are used to better understand the phenomena. Therefore, this strategy will be efficient and feasible for the circumstances of this research.

6.4 Research methods

As discussed in the previous section, a multi-method strategy is selected because it is considered the best way to fulfil the overall study aim through three specific separated studies. The first two studies adopted a quantitative approach (survey) to identify the unmet service needs of patients with advanced cancer (Study 1) and to assess the educational and HCS-related issues that HCPs may face, and how these affect the implementation of PC services (Study 2). The third study adopted a qualitative stance (interviews) to explore the perspectives of decision and policy-makers on the provision of PC services. Each study was set as a standalone piece of work covering all methodological techniques (Figure 7).

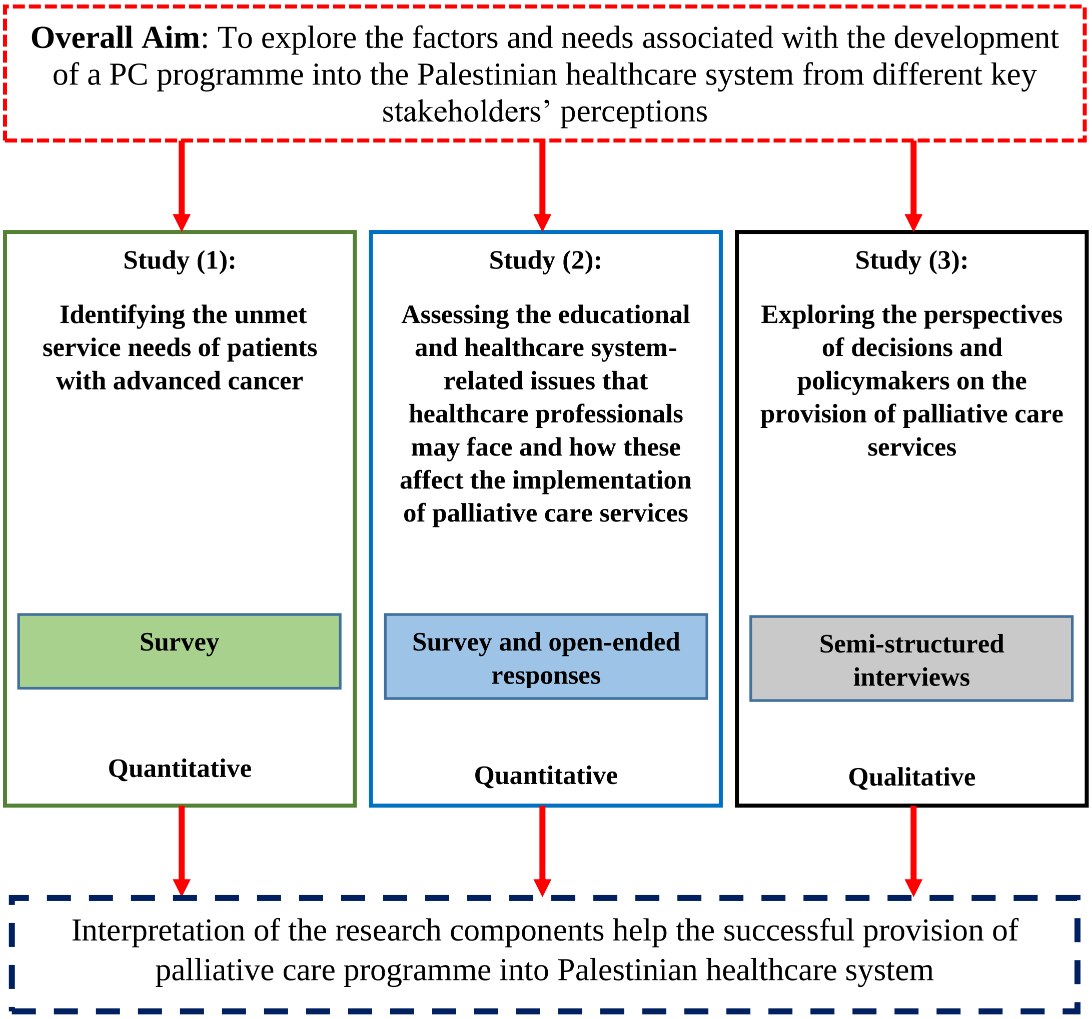


Figure 7: Overall research methods

6.5 Chapter summary

This chapter provided a clear distinction between mixed methods and multimethod designs. The multi-method research design is the best adapted to fulfil the overall study aim through three specific studies. The rationale for using the multi-method approach is clearly discussed. A detailed presentation of each study method will be presented in the following three chapters.

CHAPTER (7): STUDY ONE-IDENTIFICATION OF THE UNMET SERVICE NEEDS OF PATIENTS WITH ADVANCED CANCER: A CROSS-SECTIONAL STUDY

7.1 Introduction

The chapter illustrates the first cross-sectional study that has identified the unmet service needs of patients with advanced cancer in Palestine. This study was conducted at the two main hospitals in the GS, where cancer care services are provided to adult patients. Several scales were used in this study to provide comprehensive information on the supportive care needs of advanced cancer patients. A modified Supportive Care Framework for Cancer Care (SCNF) was adopted to guide the study design and selection of the outcome variables. The study's background, unmet needs of advanced cancer patients, instrument utilised for assessing needs, methods, results, discussion, and study implication are also discussed in this chapter. This study is under review in an international peer-reviewed journal (Abu-Odah H, Molassiotis A, and Liu J, Analysis of the unmet needs of Palestinian palliative cancer patients and their relationship to emotional distress: results from a cross-sectional study, BMC Palliat Care. 2021). The paper has been slightly modified with regard to the citation styles and reference lists to adhere to the structure and guidelines of this doctoral thesis.

7.2 Background

Cancer is a devastating disease imposing a significant influence on patients' lives and affects their well-being (Nayak et al., 2017). The diagnosis of cancer often results in a complex set of issues that patients and their families must confront (Woźniak & Iżycki, 2014). Caring for advanced cancer patients is, therefore, not an easy task, requiring continuous follow-up to ensure their needs are met and their lives are improving

(Verhoef et al., 2020). Such patients make up the largest group of patients with life-threatening illnesses in need of support and follow-up (Connor & Sepulveda Bermedo, 2014).

Advanced cancer patients are the largest group of patients with life-threatening illnesses in need of support and follow-up (Connor & Sepulveda Bermedo, 2014). They have more unmet needs than patients in earlier stages of cancer (Au et al., 2013; Hwang et al., 2004). The most frequent unmet needs are classified into psychological issues, communication, information about diagnosis, prognosis and treatment, symptom management needs, and relationship needs (Edib, Kumarasamy, Binti Abdullah, Rizal, & Al-Dubai, 2016; Lisy, Langdon, Piper, & Jefford, 2019). Cancer patients often experience severe pain, distress (Abu Hamad et al., 2016), and fatigue- all related to the progression of the disease (Mercadante et al., 2016). They are vulnerable and in need of appropriate care in the last stages of their life. Identifying the unmet needs of patients with advanced cancer can help to improve their QOL (All Ireland Institute of Hospice and Palliative CARE, 2017; Richardson et al., 2005) and reduce hospital admissions (Brinkman-Stoppelenburg et al., 2014; Khandelwal et al., 2015). Therefore, they are vulnerable and in need of appropriate care at the last stage of their lives.

Appropriate care means providing care that meets the needs of patients and alleviates the symptoms that accompany their illness (Rachakonda, George, Shafiei, & Oldmeadow, 2015). Needs are defined as “the requirement of individuals to enable them to achieve, maintain or restore an acceptable level of social independence or QOL, as defined by particular care agency or authority” (Department of Health, 1992). Therefore, healthcare authorities should assess the desires of the patients and take them into consideration to change current healthcare services (Hawe, 1996). Unmet needs around healthcare services refers to needs that are not addressed nor supported by HCSs (Harrison, Young, Price, Butow, & Solomon, 2009) or to the gap between a patient's needs or expectations for those services and the actual experience of receiving them (Gauld, Raymont, Bagshaw, Nicholls, & Frampton, 2014).

The gap between the healthcare services delivered to patients' and their expectations of such services can increase the burden on HCSs, leading to a surge in healthcare expenditures, and result in harmful effects (Wen & Gustafson, 2004). Thus, identifying patient needs is the first step that needs to be taken to enhance the services that are provided to them (Rainbird, Perkins, Sanson-Fisher, Rolfe, & Anseline, 2009). These include pain and symptom management along their disease trajectory and the extension of physical, psychological/emotional, and spiritual assistance (Wang, Molassiotis, Chung, & Tan, 2018). These needs are categorised under the term PC (World Health Organization, 2002, 2017). Recognising the gaps in needs can provide the impetus for resource allocation and redesign of services (Harrison et al., 2009). Their assessment should be applied before designing and developing a PC programme (Maetens et al., 2019; Valery et al., 2015). Such information gained can inform service planning/redesign (Harrison et al., 2009; Ndiok & Ncama, 2018), and can identify areas that require progress and enhancement in healthcare services provision.

7.3 Unmet needs of advanced cancer patients

Several studies in the literature have focused on the unmet needs of cancer patients. A systematic review conducted by Harrison et al. (2009) explored the unmet needs of patients with cancer. Findings identified that 75 out of 95 articles quantified the prevalence of unmet needs; the most common unmet needs included the activities of daily living, and psychological, informational, psychosocial, and physical needs. This review limited literature searches to only four databases, and the inclusion criteria did not focus on patients with advanced cancer. Two recent systematic reviews have focused on advanced cancer patients (Moghaddam, Coxon, Nabarro, Hardy, & Cox, 2016; Wang et al., 2018). The first systematic review analysed 23 studies and identified informational, psychological, and physical needs as the most common unmet needs (Moghaddam et al., 2016). Despite this study focusing on advanced cancer patients, the definition of advanced cancer was not clearly presented in the review, and the search was limited to only four databases. The second review, conducted by Wang et al. (2018), analysed 50 studies extracted from 10 electronic databases, identifying 12 unmet needs. Results showed that the main unmet needs were psychological, physical, and healthcare service-related and informational needs. The two recent reviews endorsed that physical, psychological, spiritual, and informational were the most frequent unmet needs of patients with advanced cancer (Moghaddam et al., 2016; Wang et al., 2018). The forgoing three reviews (Harrison et al., 2009; Moghaddam et al., 2016; Wang et al., 2018) reported some similarities in the unmet needs (i.e. physical, spiritual, emotional/psychological, and informational), while others showed differences (i.e. communication, symptoms, side effects) in unmet needs.

To minimise differences in the unmet needs across previous studies and to have a better understanding of advanced cancer patient needs, and to guide the design of the study and the selection of the outcome variables for this cross-sectional study in a more evidence-based approach, the Supportive Care Framework for Cancer Care (SCNF) was adopted (Fitch, 1994) and linked with the findings of previous reviews (Moghaddam et al., 2016; Wang et al., 2018). The framework, which covers seven domains, has been used internationally to assess cancer and stroke care (MacIsaac, Harrison, & Godfrey, 2010). The framework also includes factors affecting the needs of patients (Fitch, 1994). Based on the SCNF (Figure 8) and subsequent reviews (Moghaddam et al., 2016; Wang et al., 2018) supporting that, physical, spiritual, emotional/psychological, informational, social, and practical needs, in addition to influencing factors, need to be considered while assessing patients with advanced cancer to develop PC services. Each of these domains and influencing factors are highlighted below.

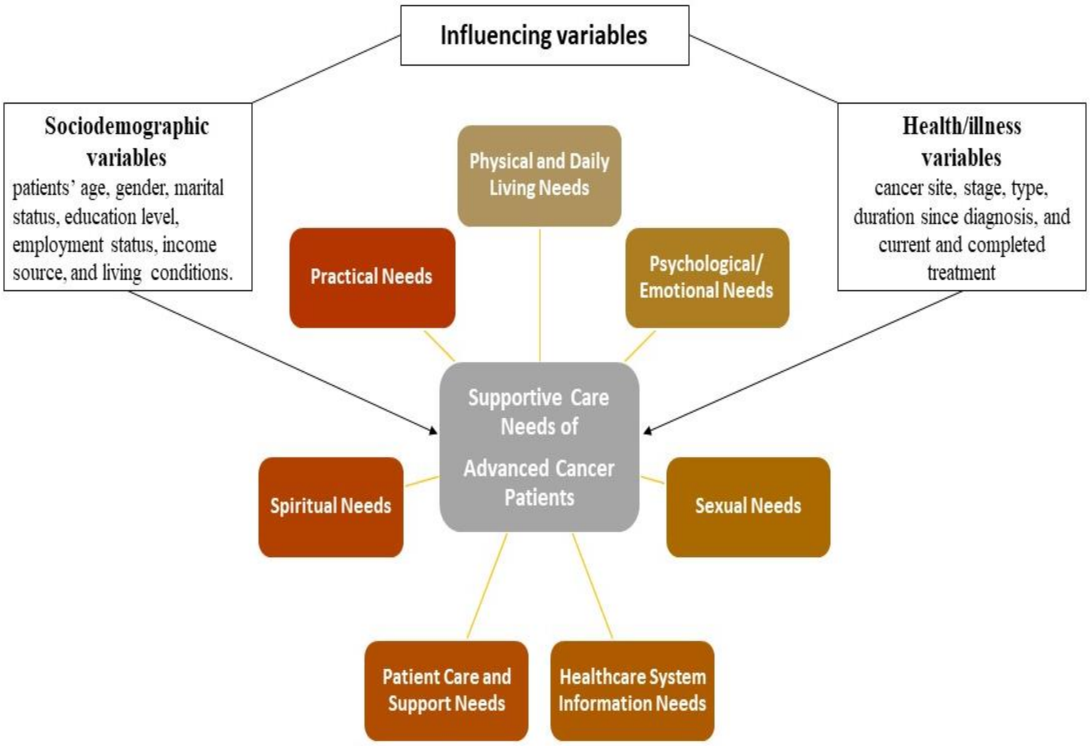


Figure 8: A modified Supportive Care Framework for Cancer Care

(Fitch, 1994; Fraser. et al., 2018; Moghaddam et al., 2016)

7.3.1 Physical needs

Physical needs are critical for cancer patients and should be identified while assessing their needs. Most cancer patients experience physical challenges resulting from the disease and treatment (Lang-Rollin & Berberich, 2018; Weis, 2015). These discomforts include pain, fatigue, weakness, nausea and vomiting, morbidity, and shortness of breath (Fitch, 1994). Management of pain and fatigue are the most common physical unmet needs among advanced cancer patients (Uitdehaag et al., 2015; Van Den Beuken-Van, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). The prevalence of pain is 50.7% in all cancer stages, while it is 66.4% in advanced stages (Van Den Beuken-Van et al., 2016). Meanwhile, pain intensity among those in the advanced stages of cancer would be higher (Van Den Beuken-Van et al., 2016). If patient pain cannot be relieved or poorly managed, it would worsen their general physical condition, compared with early-stage cancer patients (Jacobson et al., 2008; Van Den Beuken-Van et al., 2007). It also would worsen their QOL and is linked with several psychosocial responses (Porter & Keefe, 2011; Rief et al., 2011). Measurement of unmet physical needs, such as pain, is an important research area in cancer services development (Henoch & Lövgren, 2014).

A considerable amount of literature has been published on unmet physical needs among cancer patients. A recent systematic review by Van Den Beuken-Van et al. (2016) reported a high prevalence level of pain among advanced metastatic patients (66.4%). It also revealed that 38% of all patients experience moderate to severe pain. Other original papers were undertaken with the same aim. For example, Rief et al. (2011) assessed long-term pain among breast cancer patients and identified a slight but significant increase in pain over a four-year course. Brown, Cooley, Chernecky, and

Sarna (2011) examined 196 women with lung cancer and reported that 98% of them suffered three or more symptoms. The common symptoms were fatigue, shortness of breath, anorexia, cough, and pain. While Spichiger, Müller-Fröhlich, Stoll, Hantikainen, and Dodd (2011) assessed cancer patients symptoms under chemotherapy, they identified that fatigue was prevalent and frequently the most common symptom among advanced cancer patients. Despite the significant findings of these studies, all have focused only on a specific type of cancer such as lung, colorectal, lymphoma, and breast, excluding other cancer types. Meanwhile, the inclusion criteria for the second paper (Brown et al., 2011) were not clear and were limited to women six months to five years after non-small cell lung cancer diagnosis. In the Arab context, a study conducted by Ghosn et al. (2011) determined the experiences of patients with advanced cancer with PC needs at a tertiary hospital in Lebanon. They identified that 95.3% of patients were suffering from pain and 76.7% experienced severe pain. The findings also reported that fatigue was reported as the second most common symptom after pain (88.4%). These patients were affected with symptoms of anxiety and depression, among others.

7.3.2 Spiritual needs

Spiritual concerns have been defined as the degree to which a cancer patient’s spirituality and existential concerns, such as fear of death, and death and dying, can affect their lifeand health status (Bredle, Salsman, Debb, Arnold, & Cella, 2011; Paterson, Robertson, Smith, & Nabi, 2015). There has been growing interest in spiritual care over the past 15 years as a dimension of PC (Cohen, Mount, Strobel, & Bui, 1995). Religion and spiritual beliefs have been found to be necessary for patients with severe illness (Conway, 2010), particularly patients with advanced cancer, due to the confrontation with death (Edwards, Pang, Shiu, & Chan, 2010; Winkelman et al., 2011). Spirituality is an essential component of care, as described in the National Consensus Project for Quality PC (National Quality Forum, 2006). It is vital to patient health and the essential domain of quality of care, and necessary to demonstrate efficiency and effectiveness of care (Borneman, Ferrell, & Puchalski, 2010). It is also an essential factor providing a context for patients with cancer to deliver hope to cope with their disease trajectory (Puchalski, 2012; Puchalski, King, & Ferrell, 2018).

Individuals who are living at the end-stage of life, such as patients with advanced cancer, may be vulnerable to spiritual distress/pain such as hopelessness, anger, inability to find meaning, asking “why”, and struggling with life (Cheng, Xu, Liu, Mao, & Chen, 2018; Delgado-Guay et al., 2016). Spiritual pain is defined as pain deep in the soul that is not physical or physiological (Delgado-Guay et al., 2013; Mako, Galek, & Poppito, 2006). A spiritual assessment as part of the PC process is recommended towards incorporating spirituality into health practice (Anandarajah & Hight, 2001) and could be a crucial aspect of psychological functioning (Mystakidou et al., 2008).

More recent studies have reported the association between spiritual pain and lower QOL. A recent systematic review conducted by Chen, Lin, Yan, Wu, and Hu (2018) examined the effect of spiritual care on terminally ill patients’ QOL and spiritual well-being. Nineteen studies with 1,584 participants were identified; most studies reported that spiritual care positively affected patients' QOL and spiritual well-being. In addition, recent original research conducted by Pérez-Cruz et al. (2019) reported that most patients with cancer (67%) experienced spiritual pain. Findings also showed that spiritual pain was associated with lower QOL. While this study included a large sample size and specified an application to patients with advanced cancer, spiritual well-being was assessed by a single question item to evaluate religious coping, religiosity, and spirituality, which is not adequate to determine spiritual concerns. Another study by Delgado-Guay et al. (2016) reported that more than 40% (n=292) of advanced cancer patients experienced spiritual pain, and it was correlated with physical and psychological distress. Although the study included a sufficient sample size and covered different types of cancers, it only focused on cancer survivors, without any comparison among different cancer stages.

In Arab countries, two studies have been conducted in Jordan assessing the spiritual well-being of cancer patients. Al-Natour, Al Momani, and Qandil (2017) assessed 150 Jordanian women with breast cancer using the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp scale). Results showed that the women who reported good spiritual wellbeing tended to have better QOL. Lazenby, Khatib, Al-Khair, and Neamat (2013), who assessed 205 cancer patients who completed the FACIT-Sp scale, found that spiritual well-being was significantly associated with social and functional well-being. Despite the significant findings of these two studies, the first study (Al-Natour et al., 2017) focused only on breast cancer, and the second (Lazenby et al., 2013) had included 25 patients with advanced stage cancer out of a total of 205 patients, which weakened the comparison across cancer stages. The findings from these studies may not represent other types of advanced cancer.

7.3.3 Emotional/ psychological needs

As with physical and spiritual well-being, emotional/psychological aspects should be considered during an assessment. Throughout the cancer journey, patients face numerous psychological/emotional symptoms, such as fear, coping with isolation, worry, loss, anxiety, depression, and independence (Mental Health Foundation, 2018; Paterson et al., 2015). Emotional/psychological distress has been recognised as the "sixth vital sign" in cancer care (Bultz & Carlson, 2005; Bultz & Johansen, 2011). It is an essential outcome, which can be associated with reduced treatment compliance (Greer, Pirl, Park, Lynch, & Temel, 2008), and can increase the risk of health deterioration and death (Pinquart & Duberstein, 2010; Satin, Linden, & Phillips, 2009).

Anxiety and depression are two of the most common types of emotional distress experienced by people diagnosed with cancer (Pitman, Suleman, Hyde, & Hodgkiss, 2018; Walker et al., 2013). Anxiety and depression negatively impact patient QOL (Nikbakhsh, Moudi, Abbasian, & Khafri, 2014). Evidence has underscored that levels of anxiety, depression, and physical symptoms are interrelated, with increased depression associated with unmet needs (Newell, Sanson-Fisher, Girgis, & Ackland, 1999). A recent systematic review by Brandenbarg et al. (2019) analysed symptoms of depression, anxiety, and distress level in cancer. Eighteen out of 20 studies reported high depressive symptoms with prevalence ranging between 5.4% and 49.0%, and anxiety was detected in seven studies with prevalence ranging from 3.4% to 43.0%. While, a meta-analysis conducted by Krebber et al. (2014) included 211 studies and identified that the prevalence of depression ranged between 8% and 24% and differed by cancer type, treatment phase, and scale used (Krebber et al., 2014). The review was limited by the literature search in only four databases, and the inclusion criteria were not focusing on patients with advanced cancer. Meanwhile, it had limited information on the majority of the included studies.

Furthermore, a study conducted by Harding et al. (2011) assessed the prevalence and burden of symptoms among 122 patients with advanced cancer in African countries. Findings revealed that the most frequent problems among advanced cancer patients were lack of energy, sadness, feeling drowsy, and worry. In the Arab context, Alosaimi et al. (2018) determined distress among cancer patients in Saudi Arabia and identified that 70% of the patients experienced significant distress. The most frequent problems were sleeplessness, nervousness, loss of interest in usual activities, and pain. In India, Tiwari (2019) evaluated the prevalence of distress among cancer patients. The study included 401 patients and found that 43% were profoundly depressed, while 60% were either highly/mildly anxious. While Nikbakhsh et al. (2014) assessed Iranian cancer patients identified that 29.3% of patients had mild anxiety while 16.7% had symptomatic anxiety. This study included a small sample size that was limited in covering different types of cancer and made generalisation and comparison across types of cancer impossible.

7.3.4 Informational needs

Unmet informational needs were identified as one of the highest prominent needs among cancer patients and should be considered among all other unmet needs. Cancer patient informational needs range between process, communication with caregivers, help with decision making, how to manage side effects, and educational process (Fitch, 1994). Information about cancer progress, side effects, and treatment were the most frequent and important requests by patients and their families (Lam et al., 2014; Rachakonda et al., 2015).

A recent survey conducted by Nair et al. (2018), which aimed to identify the unmet supportive care needs of advanced cancer patients in the United Arab Emirates, found that information needs were the third primary concern among patients, after the psychological and physical aspects. About 17% of patients sought information about sexuality (sexual relationships). This study recruited a large sample covering different types of advanced cancer patients and utilised a valid and reliable questionnaire. Fang et al. (2012) conducted a pilot study to assess patients' informational needs, identified that the majority of respondents desired information about treatment options, how to manage swallowing and speaking difficulties, and keeping healthy after treatment. Findings also reported that advanced cancer patients were less concerned about health status-related information than patients with early-stage cancer. The results also stated that younger patients were interested in receiving information on sexuality. Walsh et al. (2010) administered a questionnaire to 1,784 cancer patients to determine the information sources of cancer and factors associated with the use of information. They found that 69% of patients obtained information from other sources than medical staff, such as family members, the Internet, books, and friends.

Although the body of literature that previously assessed unmet informational needs, inconsistent findings were reported among patients attributed to disease stage, cancer type, instrument used, and country. Some Arabic patients seek information about sexuality, while others ask about treatment options and swallowing difficulties. Most literature focused on either head, neck, breast, colorectal, lung, or prostate cancer (Abi Nader et al., 2016; Kassianos, Raats, & Gage, 2016; Kowalski, Lee, Ansmann, Wesselmann, & Pfaff, 2014; Papadakos et al., 2018; Wieldraaijer, Duineveld, Bemelman, van Weert, & Wind, 2019); the level of unmet needs across different types of advanced cancer remains unclear. This creates a gap to assess unmet informational needs across patients with different types of cancer using an appropriate and suitable instrument.

7.3.5 Social needs

Social needs are defined as the needs related to family and social relationships, interpersonal communication, social supports, etc. (Fitch, 2008, 2012). Cancer and the consequences of its treatment may evoke social changes in patients with cancer. Dealing with these changes produces a myriad of challenges (reduced social support, loneliness, and social isolation) that patients with cancer and their families may confront (Paterson et al., 2015). Thus, it is crucial to overcome these challenges by supporting them socially, as evidence documented that effective social support was related to higher patient QOL after diagnosis (Kroenke et al., 2013).

Lower social support is strongly linked with future depression (Patten, Williams, Lavorato, & Bulloch, 2010). A qualitative description study conducted by Carter, Bryant-Lukosius, DiCenso, Blythe, and Neville (2011) reported that advanced prostate cancer patients withdraw from social activities, such as hobbies or attending social events, due to urinary symptoms and incontinence. Other patients experienced a sense of loneliness, and were dealing with their disease without support. Kamau, Osoti, and Njuguna (2007) conducted a study to determine how disease and treatment affect cervical cancer patients receiving radiotherapy. It showed that between 33% and 44% of the total of 152 patients had the perception that friends had withdrawn social support.

7.3.6 Practical needs

Practical needs included situations of transportation, how to access healthcare services, travel to and from the health centre, financial issues, childcare, day-to-day living, and employment issues (Fitch, 1994, 2008; Paterson et al., 2015). Cancer treatments may have a long-term impact on patient health, resulting in daily practical difficulties (O’Connor, Drummond, O’Donovan, & Donnelly, 2019).

Most studies reported that loss of income/financial support was the most common unmet practical need among survivor cancer patients (Hanly, Maguire, Ceilleachair, & Sharp, 2018; O'Brien et al., 2017). Financial constraint was reported across cancer types. A study conducted by Drummond et al. (2015) reported significantly higher financial constraint among prostate cancer patients who were treated by radical prostatectomy than those who were treated by brachytherapy (Drummond et al., 2015).

7.4 Influencing factors associated with advanced cancer patients’ unmet needs

Based on the SCNF model (Fitch, 1994) and previous evidence, many factors should be considered during a comprehensive assessment of patients with advanced cancer, which may influence their needs. Sociodemographic characteristics, health/illness-related, physical, and psychological variables affect the needs perceived by cancer patients.

7.4.1 Sociodemographic factors

Numerous studies have reported a significant association between demographic-related variables with the unmet needs of advanced cancer patients’ (Akechi et al., 2011; Hasegawa et al., 2016; Morasso et al., 1999; Schmid-Buchi, Halfens, Muller, Dassen, & van den Borne, 2013). Older patients tend to have experienced more physical unmet needs (Teunissen, de Haes, Voest, & de Graeff, 2006). Females were experiencing more physical and psychological unmet needs (Hasegawa et al., 2016; Morasso et al., 1999). At the same time, younger female patients have more psychological needs (Griesser et al., 2011; Schmid-Buchi et al., 2013). Again, patients living alone experienced high psychological needs (Hasegawa et al., 2016), and patients who were married experienced unmet needs in sexuality, psychologically and psychosocially (Akechi et al., 2011; Bernardes et al., 2019; Schmid-Buchi et al., 2013). Educational attainment has also been associated with unmet physical (Liao et al., 2011), informational (Voogt, Van Leeuwen, Visser, Van der Heide, & Van der Maas, 2005), and sexuality related-issues (Au et al., 2013). Other sociodemographic variables, such as income level (Hwang et al., 2004) and employment status (Fong & Cheah, 2016), have also influenced patients with advanced cancer unmet needs.

7.4.2 Clinical factors

For health/illness-related aspects of patients with advanced cancer, a significant relationship was reported between cancer site and unmet patient needs (Houts et al., 1988); however, others showed opposite results (Hwang et al., 2004; Morasso et al., 1999). Studies have pointed out that higher levels of unmet needs were reported among patients diagnosed with prostate and lung cancer (Duke, Treloar, & Byles, 2001; Li & Girgis, 2006; Lintz et al., 2003) in comparison with other cancer types.

Concerning cancer stages, several studies have observed unmet needs of cancer patients during the treatment time (Gozum & Akcay, 2005; Hwang et al., 2004; Jonker-Pool et al., 2004), particularly among patients diagnosed with stage IV cancer who present with more unmet needs in comparison with patients in other stages of cancer (Au et al., 2013; Hwang et al., 2004). However, other studies did not observe any relationship between cancer stage (stages III and IV) and unmet needs (Lam et al., 2014; Liao et al., 2011). Some studies reported a positive relationship between treatments received and patient needs (Lam et al., 2014), while others reported a negative relationship (Au et al., 2013). However, other studies reported no relationship between cancer type and patient needs (Bužgová, Hajnová, Sikorová, & Jarošová, 2014; Liao et al., 2011).

7.5 Impact of unmet needs on patient Quality of life

All of the foregoing unmet needs (physical, social, spiritual, social, emotional, and psychological) affect the QOL of patients with advanced cancer; therefore, it is vital to consider QOL during cancer patient assessment. Improving QOL is a fundamental PC goal in patients with advanced cancer (Pérez-Cruz et al., 2019). It typically covers four domains: physical well-being, psychological well-being, social well-being, and spiritual well-being (van Roij, Fransen, van de Poll-Franse, Zijlstra, & Raijmakers, 2018). Although patients are satisfied with services delivered by HCPs, the problems with QOL are not ideally identified, and care needs sometimes remain unmet (Detmar, Muller, Wever, Schornagel, & Aaronson, 2001; Sanson-Fisher et al., 2000). Cancer treatment may lead to toxicities, which cause significant short-and long-term side effects, functional loss, and psychosocial distress (Weis, 2015). Thus, patient QOL and functional status may be affected and deteriorated, and patients are faced many obstacles in terms of coping and adjustment (Weis, 2015).

Several randomised-controlled trial studies have shown the beneficial effects of PC integration into oncology and how they improve the QOL of patients with advanced cancer. In a recent study conducted by Vanbutsele et al. (2018) to address the impact of early PC integration into oncological care on patient outcomes, they found that early and systematic integration of PC into oncology care enhanced the QOL of patients with advanced cancer. Another randomised-controlled trial study was conducted by Temel et al. (2010) to examine the effects of introducing a PC programme on patients after diagnosis with metastatic non–small-cell lung cancer. Findings identified that patients assigned to a PC programme have better QOL than those assigned standard care. The previous studies are reliable and robust, covering different cancer types with a significant focus on patients with advanced cancer.

7.6 Instruments used to assess patient needs

There are several instruments available in the literature utilised to assess the needs of patients with advanced cancer. Some of these instruments are comprehensive, including different domains with high psychometric properties. However, others show a minimal psychometric evaluation, and most of their psychometric properties were unclear. The choice of any of these instruments depends on several factors: the strength of its validity and reliability, the purpose for which it is to be administered, number of items included, the domain items it covers, and feasibility of the instrument (timing and responsiveness) (Carlson, Waller, & Mitchell, 2012; Wen & Gustafson, 2004).

For physical needs, authors have adopted different instruments for measuring unmet physical needs, such as the Arabic Questionnaire for Symptom Assessment (AQSA) (Al-Shahri et al., 2017), Symptom Inventory questionnaire (Matthews, Wing, Kuller, Meilahn, & Plantinga, 1994), and Edmonton Symptom Assessment System (ESAS) (Chang, Hwang, & Feuerman, 2000). It seems that ESAS and AQSA are the most commonly used in previous studies. Both instruments measure similar items with minor modifications in the Arabic Questionnaire. The AQSA is appropriate to use in the Arabic context because it is valid and highly reliable in the Arabic language (Al-Shahri et al., 2017), compared to the ESAS, which is a translation to Arabic but is not yet validated (Saudi Health Council, 2019).

Regarding spiritual needs, the most commonly available scales utilised for measuring spirituality are the Systems of Belief Inventory (Holland et al., 1998), Brief Measure of Religious Coping (Pargament, Smith, Koenig, & Perez, 1998), and FACIT-Sp scale (Brady, Peterman, Fitchett, Mo, & Cella, 1999). Some of these instruments were developed mainly for research, whereas others have been utilised, particularly in the clinical field. Each of these instruments has had a minimal psychometric evaluation. The FACIT-Sp scale became widely used in previous research to measure spirituality (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). It is valid and highly reliable in the Arabic language. It is a part of the large Functional Assessment of Chronic Illness Therapy (FACIT) measurement system that assess spiritual needs from different angles, and the scale includes different domains with high psychometric properties (Canada, Murphy, Fitchett, Peterman, & Schover, 2008; Lazenby et al., 2013; Murphy et al., 2010).

For emotional/psychological needs, it seems that the Hospital Anxiety and Depression Scale (HADS) (Herrmann, 1997; Zigmond & Snaith, 1983) and Distress Thermometer (DT) (Roth et al., 1998) were commonly adopted by scholars to comprehensively assess unmet emotional/psychological needs. HADS was explicitly designed to evaluate anxiety and depression levels, while DT is sufficient to determine distress with different types of cancer (Hoffman, Zevon, D'Arrigo, & Cecchini, 2004). Both scales are highly reliable and valid and more commonly used in Arabic studies (Alosaimi et al., 2018; Terkawi et al., 2017).

For informational, practical, and social needs, there is no specific instrument utilised by previous studies assessing the needs of patients with advanced cancer, and most of their psychometric properties were unclear. The Supportive Care Needs Survey Short Form 34 (SCNS-SF34) (Boyes, Girgis, & Lecathelinais, 2009) a highly valid and reliable instrument, was the standard instrument used by previous scholars to assess unmet needs, including informational, practical, and social needs (Au et al., 2013; Bernardes et al., 2019; Fitch, 2012; Griesser et al., 2011; Hasegawa et al., 2016; Lam et al., 2014; Lelorain et al., 2015; Nair, Hassen, Sreedharan, Qawasmeh, & Ibrahim, 2019; Nair et al., 2018; Perez-Fortis et al., 2017; Schmid-Buchi et al., 2013; Uchida et al., 2011; Waller et al., 2012). The SCNS-SF34 was translated into Arabic by Nair et al. (2018). It is valid, feasible, concise, easy to understand, and acceptable to most patients and fully covers the main domains of the unmet needs of cancer patients. Examples of relevant needs assessment instruments are presented in Table 5.

Table 5: Common instruments used to assess cancer patient needs

Name (Acronym)	**Description/purpose**	**Items and domains**	**Target population**	**Validity and reliability**	**Feasibility**
Multidimensional supportive care needs					
Cancer Patient Needs Survey (CPNS) (Gates, Lackey, & White, 1995)	Used for measuring the importance of the needs and the degree to which the requirements are met.	51 items covering five domains: coping, help, information, work, cancer shock.	General cancer patients Patients complete	Content validity: Interview with patients and caregivers, and nurses. Reliability Cronbach's alpha =0.91	Time: Average of 45 minutes Acceptability: Respondents reported no problem when used.
Patient Needs Assessment Tool (PNAT) (Coyle, Goldstein, Passik, Fishman, & Portenoy, 1996)	Used for screening patients for problems	16 items covering three domains: physical, psychological, social	General cancer patients Clinician interview	Content validity: Literature, experts Reliability Cronbach's alpha ranged from 0.85-0.94	Time: 20-30 minutes Acceptability: NA
Psychosocial Needs Inventory (PNI) (Thomas et al., 1999)	Used to assess unmet psychosocial needs of cancer patients and their caregivers	48 items covering seven domains: Disease-oriented, Items related to health professional's information need, Items related to support network, identify needs, emotional needs, Spiritual and practical needs, childcare need	General cancer patients Patients and caregivers complete	Content validity: Literature, interview, focus group Construct validity Discriminant validity detect the differences among needs at cancer trajectory Reliability Cronbach's alpha of domains > 0.7	Time: NA Acceptability: 59%, not completion rate
Cancer Patient Need Questionnaire (CPNQ) (Foot & Sanson-Fisher, 1995; Girgis, Boyes, Sanson-Fisher, & Burrows, 2000)	Used for assessing unmet needs of patients with cancer	71 items covering 5 domains: psychological needs, health information, activity daily living, patient care, interpersonal, communication	General cancer patients Patients complete	Content validity: Literature, interview, pilot test Construct validity Discriminant validity which able to distinguish patients with different stages. Reliability Cronbach's alpha range from 0.78 to 0.90	Time: 20 minutes Acceptability: 25% not completion rate

Name (Acronym)	**Description/purpose**	**Items and domains**	**Target population**	**Validity and reliability**	**Feasibility**
Supportive Care Needs Survey (SCNS) (Bonevski et al., 2000)	Used for assessing the impact of cancer on patients' lives	61 items covering five domains: Psychological needs, health information, activity daily living, patient care and support, sexuality	General cancer patients Patients complete	Content validity: It is based on CPNQ, expert review, pilot test Reliability Cronbach's alpha range from 0.87 to 0.97	Time: 20 minutes Acceptability: 35%, not completion rate
Short form of the Supportive Care Needs Survey (SCNS-SF34) (Boyes et al., 2009)	Used for assessing the impact of cancer on patients' lives	34 items covering five domains: Psychological needs, health information, activity daily living, patient care and support, sexuality	General cancer patients Patients complete	Convergent validity: Correlations (r = 0.48-0.56). Reliability Cronbach's alpha range from 0.86 to 0.96 Kappa coefficients of at least 0.83 for each domain	Time: 10 minutes Acceptability: NA
Patient Informationnel Need Questionnaire (PINQ) (Mesters, van den Borne, De Boer, & Pruyn, 2001)	Used for gaining information from cancer patients for improving clinical practice and research	17 items covering two domains: Disease-oriented, information about access to help	General cancer patients Patients complete	Content validity: Literature, interviews, Reliability Cronbach's alpha of domains range from 0.88-0.92	Time: NA Acceptability: They refuse to participate due to they did not want to remind their illness
Prostate Cancer Needs Assessment (PCNA) (Boberg et al., 2003)	Used for measuring the unmet needs of men with prostate cancer	135 items covering three domains: information, support, care delivery	Specific to prostate cancer Patients complete	Content validity: Literature, interviews, and expert review Reliability Agreement by three researchers working independently	Time: 45 minutes Acceptability: 11%, not completion rate
Supportive Care Needs Survey (SPARC) (Ahmedzai et al., 2004)	Used for assessing distress caused by advanced disease.	45 items covering seven domains: Communication & information, physical symptoms, religious and spiritual issues, independence & activity Family & social issues Treatment issues	Advanced patients Patients and professionals complete	Content validity: Patients interviews and professionals, pilot test, expert consultation Reliability inter-item correlations inter -total correlation	Time: 15-104 minutes Acceptability: NA

Name (Acronym)	**Description/purpose**	**Items and domains**	**Target population**	**Validity and reliability**	**Feasibility**
Problems and Needs in Palliative Care (PNPC) (Osse, Vernooij-Dassen, Schade, & Grol, 2007)	Used for identifying problems that patients with advanced cancer experience in PC and their needs of care	138 items covering 13 domains: Activities of daily living, physical symptoms, role activities, financial and administrative issues, social issues, psychological issues, autonomy, informational needs, consultation problems, quality of care problems, concerning the general practitioner, concerning the specialists	Advanced cancer patients Patients complete	Content validity: Literature, interview, Pilot test Content analysis Construct validity Convergent validity Make a comparison between two HRQOL instruments Reliability Alpha of problem aspect ranged from 0.67 to 0.89. Need for care aspect ranged from 0.73 to 0.92.	Time: NA Acceptability: NA
Palliative Outcome Scale (Antunes, Murtagh, Bausewein, Harding, & Higginson, 2015; Siegert, Gao, Walkey, & Higginson, 2010; Strömgren, Groenvold, Pedersen, Olsen, & Sjogren, 2002)	Used for assessing patients' PC needs. It can also be used in clinical care, audit, research and training.	Ten items cover six domains: physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns, psychosocial needs.	Patients with advanced cancer and their families Patient or healthcare professional completes	NA	Time: ≤ 10 min, mean completion time 6.9 min Acceptability: NA
Needs Assessment of Advanced Cancer Patients (NA-ACP) (Rainbird, Perkins, & Sanson-Fisher, 2005)	Used for examining the perceived needs of patients with advanced, incurable cancer	125 items covering 7 domains: Symptom analysis of psychological care Activities of daily living Social care Medical information Spiritual care Financial care	Patients with advanced-stage cancer. Patients complete	Validity Content validity Literature, expert review, focus group Construct validity was examined using principal components analysis, which revealed seven distinct domains Reliability Cronbach's alpha coefficient of domains range from 0.79-0.98 Test-retest reliability estimates were calculated using the Intraclass Correlation coefficient.	Time: NA Acceptability: Long-form to complete

Name (Acronym)	**Description/purpose**	**Items and domains**	**Target population**	**Validity and reliability**	**Feasibility**
Physical needs					
Arabic Questionnaire for Symptom Assessment (AQSA) (Al-Shahri et al., 2017)	Used for assessing the severity of symptoms and overall suffering experience among PC patients	11 symptoms. Pain, Tiredness, Nausea/vomiting, Depression, Anxiety, Drowsiness Insomnia, Dry mouth, Appetite, Confusion, Shortness of breath Overall severity	PC patients Patients complete	Reliability Variables have shown a strong correlation coefficient.	NA
Edmonton Symptom Assessment System (ESAS) (Chang et al., 2000)	Used for assessing the symptoms of patients receiving PC.	Ten items. Pain, Activity, Nausea, Depression, Anxious, Drowsy, Appetite, Well-being, Short of breath, Distress	Cancer patients Patients complete	Validity: High internal consistency High criterion and concurrent validity.	NA
Symptom Inventory questionnaire (Matthews et al., 1994)	Used for assessing the general pain symptoms	Seven pain areas: General aches or pains, low back pain, Neck pain, Headaches or migraines, Joint pain or stiffness, Belly pain or stomach discomfort, Pain or burning while urinating	Middle-aged healthy women Self-complete	A reliability index (Cronbach's α=.70) confirms the internal consistency of the composite pain index, and this pain index was used for all subsequent analyses.	NA
Spiritual needs					
Systems of Belief Inventory (SBI) (Roth et al., 1998),	Used for measuring religious and spiritual beliefs and practice from a community sharing those beliefs	15 items Beliefs subscale (10 items) Support subscale (5 items).	People with a life-threatening illness Self-complete	Reliability High internal consistency High test-retest reliability Validity High convergent, divergent, and discriminant validity.	NA

Name (Acronym)	**Description/purpose**	**Items and domains**	**Target population**	**Validity and reliability**	**Feasibility**
Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp scale) (Brady et al., 1999; Lazenby et al., 2013),	Used for assessing the spiritual well-being of patients with cancer. It is a part of FACTO-G scale which used for assessing QOL	12 items	Cancer patients and other chronic diseases Patients complete	Reliability The internal reliability (α = 0.81–0.88) 12-item was correlated with Social (r = 0.45, p = 0.01) and Functional Well-being (r = 0.48, p = 0.01).	NA
Emotional/psychological needs					
Hospital Anxiety and Depression Scale (HADS) (Herrmann, 1997; Snaith, 2003; Zigmond & Snaith, 1983)	Used for identifying and quantifying the two most common forms of psychological problems	14-items Anxiety Depression	Cancer patients and people with life-threatening illnesses	Reliability Good item-total correlations within two subscales. (alphas 0.80-0.93 for anxiety) (alphas 0.81-0.90 for depression) Validity sensitivity and specificity are good.	Time: 2-5 minutes Acceptability: Acceptable by patients
Distress Thermometer (DT) (Roth et al., 1998)	Used for evaluation of distress and depression in cancer	One-item utilises an 11-point visual scale. 36 problems- domains: Practical, Family, emotional Spiritual/religious, Physical issues	Advanced cancer patients- prostate carcinoma	NA	Acceptability: Accepted by patients
Center for Epidemiologic Studies Depression (CES-D) Scale	Used for measuring depressive symptoms among the general population	20-items covering 4 factors Depressed affect, Absence of positive affect or anhedonia, Somatic activity or inactivity, Interpersonal challenges	General population Cancer patients Self- complete	NA	NA

7.7 Gaps in the literature

Based on the preceding sections, numerous studies have been conducted to assess the unmet needs of advanced cancer patients. However, several limitations were well-documented across studies. Variations in unmet needs across countries were also reported. For example, in most Western countries, psychological needs among cancer patients were identified as frequently going unmet (Brédart et al., 2013; Knobf et al., 2012). In Asian countries, Chinese, Japanese, and Korean studies recognised that a common unmet need was attributed to health system information (So et al., 2014). In Arab countries, Nair et al. (2018), in a study conducted in the United Arab Emirates, assessed the unmet needs among cancer patients, reported that psychological needs were the most frequently unmet needs. The variations across different countries creates difficulties in generalising findings.

Moreover, the majority of studies have focused on patients with a specific type of cancer, such as lung, colorectal, lymphoma, or breast cancer. In addition, none of the studies, conducted in Arabic countries explored the unmet needs of patients with advanced cancer. Meanwhile, the variation in the findings across different countries makes it difficult to apply the findings from previous studies to the situation in Palestine. This creates a gap and encourages the researcher to assess the unmet needs of patients with advanced cancer in Palestine before the development of PC services.

This study focuses on a unique region (Palestine), where the situation in terms of religion, finances, the economy, the HCS, and access to services often differs significantly from other countries. Most of the Palestinian people are Muslims who believe in Allah (God) and the inevitability of death, which is Allah’s responsibility (Iranmanesh, Razban, Tirgari, & Zahra, 2014b). No one can stop or avoid death and illness except for Allah. The Palestinian people believe in the hereafter and eternity and agree that life is temporary and could end at any time (Puchalski & O'Donnell, 2005). After death, every person will either be rewarded or punished in the hereafter (Puchalski & O'Donnell, 2005). These beliefs and norms help patients to cope, accept illness, and die in peace (Sheikh, 1998; Wing & Handzo, 2014). Culture is another aspect that may affect patients' needs that come from their religion. Culture may influence patients' lifestyles, values, beliefs, perceptions of PC, and QOL. All of these differences may affect the services provided to advanced cancer patients, resulting in many needs going unmet, and not applicable. Regardless of the importance of the topic, no attention has been paid to identifying the unmet service needs of patients with advanced cancer in Palestine; consequently, research exploring the unmet service needs of this vulnerable group is warranted so that support can be delivered. This study was conducted to provide comprehensive information on the supportive care needs of advanced cancer patients in Palestine. The gained information will help refine the services provided and help in the future planning of the provision of PC services into their HCS.

7.8 Aim and objectives

This survey aims to identify the unmet service needs of patients with advanced cancer. The aim of this study was achieved by meeting the following specific objectives:

(1) To determine the prevalence of unmet supportive care needs in patients with advanced cancer.

(2) To determine the level of emotional/psychological distress, pain, and symptoms of patients with advanced cancer

(3) To assess QOL and spiritual well-being of patients with advanced cancer.

(4) To assess the association between patients’ characteristics and unmet needs.

(5) To examine the association between unmet needs and pain, symptoms, QOL, and the spiritual well-being of patients with advanced cancer.

7.9 Methods

7.9.1 Design

A hospital-based cross-sectional quantitative design was applied in this study. A cross-sectional study design is a type of observational study that is carried out on a population at a specific point in time or over a short period. The rationale for using this design is that the study can be conducted faster and inexpensively (Polit & Beck, 2004). It helps the researcher to study the association between dependent and independent variables in the study participants at the same time (Setia, 2016). This design also is suitable for public health planning and evaluation (Setia, 2016). As the objectives of this study are to determine the unmet service needs of patients with advanced cancer and examine the association between factors, the cross-sectional study design is an appropriate and suitable approach to meet the objectives.

7.9.2 Study setting

The study was carried out in the GS-Palestine. A narrow band of land is populated by 2,018,000 people (Palestinian Central Bureau of Statistics, 2017; Palestinian Ministry of Health, 2020). It is 45 kilometres long and 6-12 kilometres wide, with an area of 378 square kilometres (Palestinian Central Bureau of Statistics, 2017). Fifteen hospitals are providing care to the Gazan people and operated by the government; among this total, two hospitals (Al- Shifa Hospital and the EGH) provide cancer care to adult patients (Palestinian Ministry of Health, 2020). The study participants were recruited from both hospitals.

(1) Al-Shifa Hospital is the largest hospital in the west part of Gaza, with 619 beds. It has an oncology centre with 33 beds and an outpatient clinic for daily care, with 16 beds that provide cancer care for patients aged 12 or above who live in the north of Gaza, Gaza city and mid-zone of the GS.

(2) The European Gaza Hospital is located in the southern governorate of Khan-Younis with 207 beds. It has an oncology centre with 17 beds and the outpatient clinic for daily care with 16 beds that provide cancer care for adult patients who live in the south of GS.

7.9.3 Study participants

The study population consists of advanced cancer patients (diagnosed with stages III or IV) treated at one of the two cancer centres in the GS-Palestine. The total number of patients with cancer who were registered at the Palestinian Cancer Registry from 2012 to 2018 accounts for 8,326 patients (Palestinian Ministry of Health, 2020).

7.9.4 Inclusion and exclusion criteria

A convenience sample of patients with advanced cancer was invited to participate. Participants were eligible if they (i) had been diagnosed with stage III or IV cancer, as stated in their medical records; (ii) were aged 18 or above; (iii) were being treated at one of the abovementioned two cancer centres; (iv) had visited the cancer centres as outpatients for follow-up treatment, and (v) were physically able to complete the survey for the study and were willing to give written informed consent after provided with information about the study (Appendix 1 and 2). Patients were excluded if they were unable to complete the study survey due to cognitive impairment to prevent possible confounding effects on the study variables (Pendergrass, Targum, & Harrison, 2018). These included those suffering from brain tumors and those exhibiting symptoms of cognitive impairment.

Patients who met the eligibility criteria were included in the study. Prior to patients' appointments to visit the clinic, a list of patients' names who had appointments was printed from the IT department after receiving approval from the hospital director. The printed list was then forwarded to the head of the oncology department to exclude non-eligible patients. The eligible patients on the list were stratified into two groups (Stages III and IV). The patients from each group were chosen.

7.9.5 Sampling strategies

Sampling is a process that the researcher uses to select a representative group of subjects from the population to estimate the characteristics of the whole population. Estimating a sample is a crucial stage in the research design (Marshall, 1996). It has many advantages, including lower cost, time saving, and faster data collection than measuring the whole population (Sharma, 2017; Taherdoost, 2016).

There are two types of sampling: probability and non-probability sampling. Probability sampling is a sample type in which each unit in the population has a chance of being selected as a sample. There are four types of probability sampling: simple random, systematic, cluster, and stratified sampling. Probability sampling is the most frequently utilised sample adopted for a random selection of elements from the entire population (Mason, 2002, 2017). Probability/quantitative sampling draws from a representative sample from the whole population to generalise findings to larger populations (Marshall, 1996). It is the most robust approach that intends to yield a statistically representative sample of a small-scale population from which it was drawn (Marshall, 1996; Ritchie, Lewis, Nicholls, & Ormston, 2013) and is rigorous in quantitative studies when testing a hypothesis.

Non-probability sampling is commonly used in qualitative research (Holloway, 1997). There are four types of non-probability sampling, including convenience, quota, judgement, and snowball. Non-probability sampling means that some units in the population have no chance of being selected, or where the probability cannot be accurately determined. Samples are chosen to present specific characteristics of the sampled population (Mason, 2002, 2017; Ritchie et al., 2013).

Though the advantages of probability sampling in which it is the most robust approach for generalisation of results and is the most valuable way to assess the study complex phenomenon, a convenience non-probability sampling was adopted for recruiting the study sample, as it is challenging to locate the whole population everywhere and to have access to all of them from hospitals.

7.9.6 Sampling size

To determine the adequacy of the sample size, the acceptable level of significance, power of the study, expected effect size, underlying event rate in the population, and standard deviation in the population must be defined clearly (Kirby, Gebski, & Keech, 2002). However, power analysis formulas are used when the quantitative study is experimental (Lipsey, 1990). In this study, the size of the sample was calculated using the Thompson formula (Thompson, 2012, pp. 59-60). Based on the Thompson formula and a well-known study population [(8326 cancer patients (Palestinian Ministry of Health, 2020)], the result was a sample size of 368 patients. This was increased to 404 patients to compensate for non-respondents, as the average non-response rate among patients with advanced cancer was reported to be 9.4% in an Italian study (Rabitti et al., 2020) and 9.8% in a Chinese study (Jing Cui et al., 2014). The following parameters and formula used to calculate the sample are illustrated below.

$$n = \frac{\mathrm{N} \times p(1-p)}{[[\mathrm{N}-1 \times (\mathrm{d}^2 \div z^2)] + p(1-p)]}$$

Where,		
N	-	Population size (8326)
Z	-	Confidence level at 95% (1.96)
d	-	Error proportion (0.05)
$\boldsymbol{p}$	-	Probability (50%)
$\boldsymbol{n}$	-	Sample size, which was estimated (=368)

N: Number of cancer patients who are registered at the Palestinian Cancer Registry from 2014 to 2018. Z: means that 95% of findings are accurate and close to the truth. d: indicates a margin of error for a sampling proportion which is used to find the accuracy and efficiency of the sample. P: standard formula indicating the probability of including a patient in the study is equal.

7.9.7 Instruments to be used in the study

Multiple survey instruments were utilised to a comprehensive understanding of advanced cancer patients' needs (Appendixes 3-9). To better understand advanced cancer patients needs, the SCNF model was adopted (Fitch, 1994) and linked with the findings of previous reviews (Moghaddam et al., 2016; Wang et al., 2018). This model aims to assess the unmet needs of patients with advanced cancer in different areas (physical, spiritual, emotional/ psychological, informational, social, and practical needs and influencing factors), whereas other instruments mainly focus on a particular physio-psychosocial symptom in advanced cancer patients (Table 6). The findings generated from scales provide the impetus for resources allocation and a redesign of the services. This study received permission to use all of these instruments from the original authors (Appendix 10).

7.9.7.1 Dependent variable

The SCNS-SF34 was adopted to assess the unmet needs of cancer patients (Boyes et al., 2009). It is a multi-dimensional self-administered 34-item scale measuring five domains, namely psychological aspects (10 items), health system information (11 items), patient care and support (5 items), physical aspects and daily living (5 items) and sexuality (3 items) (Appendix 4). Each participant was asked to indicate their level of need for help in the last month as a result of having cancer. Each item is rated from 1 to 5, where a score of 1 indicates no need for help, 2 indicates satisfied/met needs, 3 indicates some need, 4 indicates a moderate need or 5 indicates a high need for help. Unmet need items were scored in accordance with the SCNS manual (McElduff, Boyes, Zucca, & Girgis, 2004). The total score for each domain was standardised to a score out of 100, with a higher score reflecting a higher level of need as perceived by patients. The Arabic version of SCNS-SF34 was selected because its validity and reliability have been established (Nair et al., 2018).

7.9.7.2 Independent variables

7.9.7.1.1 Physical symptoms

A self-administered AQSA was adopted to assess the presence and quantify the intensity of pain and other physical common cancer symptoms. The AQSA has been validated and translated into Arabic (Al-Shahri et al., 2017). The following 11 common symptoms are covered in the AQSA: pain, tiredness, nausea/vomiting, depression, anxiety, drowsiness, insomnia, dry mouth, loss of appetite, confusion, and shortness of breath, in addition to the item used to assess the overall severity (Appendix 5). Each symptom is rated from 0 (no symptoms) to 10 (worst symptoms). The rating is then classified into one of the following four categories: 0 for no physical symptoms, 1–3 for mild symptoms, 4–6 for moderate symptoms, and 7-10 for severe symptoms (Seow, Sussman, Martelli-Reid, Pond, & Bainbridge, 2012). Similar to SCNS-SF34, the Arabic version of AQSA has also been validated (Al-Shahri et al., 2017).

7.9.7.1.2 Emotional/psychological distress

Two instruments were used to assess emotional/psychological distress. The Arabic version of the Distress Thermometer (DT) scale (Appendix 6) was utilised to identify levels of distress among patients with advanced cancer (Alosaimi et al., 2018). It has recommended recognising and diagnosing distress in cancer patients (Holland et al., 2013). The scale is sufficient to determine the distress level in patients with different types of cancer (Hoffman et al., 2004). It is a one-item, self-reported, 11-point visual scale ranging from 0 (no distress) to 10 (high distress) (Holland et al., 2013) in which patients rated distress over the past week. Cancer patients were also asked to fill in problem lists (36 problems clustered into five domains, including practical, family, emotional, spiritual/religious and physical issues) included in the scale to identify whether they had any problem on the list. The list helps to determine the nature of the problem that increases distress. A cutoff score of 4 or more indicates significant distress (Alosaimi et al., 2018; Holland et al., 2013). The validity of the Arabic version of the DT has been established with the best sensitivity (0.70) and specificity (0.63) with a cutoff score of 4 (Alosaimi et al., 2018).

The second instrument, the Hospital Anxiety and Depression Scale (HADS), was adopted to assess the anxiety and depression levels of cancer patients (Terkawi et al., 2017; Zigmond & Snaith, 1983). It is comprised of 14 items under two validated sub-scales: anxiety (7 items) and depression (7 items) (Appendix 7). Each item is rated from 0 to 3 on a 4-point Likert scale where 3 indicate the worst symptoms, and 0 indicates the absence of symptoms. The scores in each subscale are computed and determined to fall under one of the following three categories: normal cases (score of 0-7), borderline cases (scores of 8-10) and cases (score of 11-21) (Zigmond & Snaith, 1983). The HADS Arabic version had high internal consistency with Cronbach's α coefficient of 0.83 for the anxiety subscale and 0.77 for the depression subscale. A strong correction coefficient showed in the HADS anxiety score (r= 0.67) and HADS depression score (r= 0.66).

7.9.7.1.3 Quality of life

QOL is defined as patients' perception of their position in the context of the culture, beliefs, and value systems in which they live with their expectations and concerns (Webster & Cella, 1998). QOL affects patients' physical, social, and psychological well-being (Rodrigues, 2012; Webster & Cella, 1998). The FACIT-G Arabic version (Appendix 8) was adopted to assess participant QOL (Al Barmawi, Al Hadid, Alqudah, Al Hadid, & Shamoun, 2018; Al Maqbali et al., 2020; Lazenby et al., 2013). It has been the most widely used and recommended in previous research. It is a self-administered questionnaire that covers four domains: physical well-being (7 items, ranges: 0-28), social-family well-being (7 items, ranges: 0-28), emotional well-being (6 items, ranges: 0-24), and functional well-being (7 items, ranges: 0-28). Each item rated from 0 to 4 scale; where 0=Not at all, 1=A little bit, 2=Some-what, 3=Quite a bit, 4=Very Much. The overall scores range from 0-108, with higher scores demonstrating better QOL. The FACT-G-Arabic had high internal consistency with Cronbach's α coefficient 0.92, with a subscales range of 0.73–0.91.

7.9.7.1.4 Spiritual concerns

The Arabic version of the FACIT-Sp scale (Appendix 9) was utilised to assess the spiritual well-being of advanced cancer patients (Al Barmawi et al., 2018; Lazenby et al., 2013). It is a separated subscale of the FACIT-G scale. It is comprised of 12 items distributed over the two sub-domains of peace/meaning, and faith. Each item rated from 0 to 4 scale; where 0=Not at all, 1=A little bit, 2=Some-what, 3=Quite a bit, 4=Very Much. Scores range from 0-48, with higher scores indicating better spiritual well-being. The Cronbach's α coefficient for the FACIT-Sp Arabic was 0.83.

7.9.7.3 Factors

Personal and health/illness factors have been defined as the specific background of a life and health condition (World Health Organization, 2007). Factors of unmet needs in advanced cancer patients have been divided into two main categories. The first is sociodemographic variables, including patient age, gender, marital status, level of education level, employment status, source of income, and living conditions. Health/illness variables include cancer site, stage, type, duration of time since diagnosis, and current and completed treatments (Appendix 3).

Table 6: Variables and instruments used for Study one

Variables	**Instrument (Acronym)**	**Items domains**	**Scoring and interpretation**
Unmet needs	Short form of the Supportive Care Needs Survey (SCNS-SF34)	34 items ▪ Psychological needs, Health information, ▪ The activity of daily living, Patient care support, ▪ Sexuality	5 Likert scale 1-5 point Two variables related to unmet needs: "Prevalence of unmet needs" (variable 1) was measured by categorising scale into two categories (met needs vs unmet needs). "level of unmet needs (variable 2) by utilising mean scores of the scale. Higher scores point higher level of needs
Physical symptoms	Arabic Questionnaire for Symptom Assessment (AQSA)	11 symptoms. ▪ Pain, Tiredness, Nausea/Vomiting, Anxiety, Depression, Shortness of Breath, Drowsiness, Insomnia, Dry Mouth, Loss of Appetite, Confusion. Item to assess the overall severity of the suffering	Symptom rated from 0 to 10 0 no symptoms Mild scores of 1–3 Moderate 4–6 Severe scores of 7–10; worst
Emotional/psychological well-being	Distress Thermometer (DT)	One-item utilises an 11-point visual scale. 36 problems- domains: ▪ Practical, Family, emotional ▪ Spiritual/religious, Physical issues	Item ranging from 0 to 10 10- high distress 0-no distress
	Hospital Anxiety and Depression Scale (HADS)	14 items ▪ Anxiety ▪ Depression	Item ranging from 0 to 3 Maximum scores 21. Normal case (0-7 score) Scores of 8-10 are considered borderline Over 11 indicative of clinical anxiety or depression
Quality of life	The Functional Assessment of Cancer Therapy - General (FACT-G)	27 items ▪ Physical well-being ▪ Social family well-being ▪ Emotional well-being ▪ Functional well-being	Item rated from 0 to 4 The overall score (0 – 108). A higher score indicated better QOL
Spiritual well-being	The Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp)	It consists of 12 items and three sub-domains ▪ Peace ▪ Meaning ▪ Faith	Item rated from 0 to 4 The overall score (0 – 48). A higher score indicated better spiritual well-being

7.9.8 Data collection

Self-administered questionnaires were adopted to collect data in the current study, mainly because patients with advanced cancer and their relatives were reluctant to talk about the disease. Several types of survey approaches are appropriate as methods for collecting data, such as face-to-face interview questionnaires, self-administered questionnaires, and telephone questionnaires (Fowler, 2001, 2013). Self-administered questionnaires have prominent advantages. First, the participant can independently complete the questionnaire. Second, self-administered questionnaires allow the researcher to collect data from many participants at the same time. Third, the questionnaire can be completed at the convenience of the participants. Finally, this approach saves in time and travel costs compared to face-to-face interviews (Fowler, 2001).

After adhering to the ethical considerations for conducting the study, two registered nurses whom the researcher knows were contacted to coordinate the process of data collection. The first nurse recruited eligible patients at EGH and asked them to take part in this study; he is a senior nurse with experience in the oncology department at the EGH. The recruitment is based on a printed list of names of patients who had appointments at the clinic, which was requested from the IT department. The process of recruitment is mentioned in section 7.9.4. The second nurse is responsible for the same tasks as the first nurse; he also is a senior nurse with experience in the oncology department at Al-Shifa Hospital.

In the next step, the researcher delivered the questionnaire pack to the key nurses and clarified the study participants' eligibility criteria. Both nurses distributed the questionnaire pack to eligible patients in the clinic. Each packet included a cover letter providing a detailed description of the study (Appendix 1), the consent form (Appendix 2), a questionnaire to collect the participants' sociodemographic and health/illness characteristics (Appendix 3), the SCNS-SF34 (Appendix 4), the AQSA (Appendix 5), DT (Appendix 6), Hospital Anxiety and Depression Scale (HADS) (Appendix 7), FACT-G (Appendix 8) and FACIT-Sp (Appendix, 9). The key nurses also informed participants about the box, which was placed in each department with the purpose of collecting the questionnaires. The box was locked, and only the key identified nurse could open it to gather the returned questionnaire.

To minimise a potentially low response rate, two nurses explained the study's benefits and importance as reported in the information sheet (Appendix 1) to each eligible patient and their relatives before filling in the questionnaire. They informed them of their voluntary participation in this study. The key nurse collected all returned questionnaires in the boxes in each department. Direct contact between the two key nurses and the researcher continued, so that any issues can be handled and updated with the number of returned questionnaires. Then, all questionnaires were directly sent to the researcher for data checking and entry.

7.9.9 Data analysis processes

7.9.9.1 Data analysis strategies

The Statistical Package for the Social Science (SPSS) software version 25 was used to enter and analyse data. Descriptive statistics were utilised to summarise the sociodemographic and clinical characteristics of the participants as well as all instruments (supportive care needs, physical symptoms, QOL, spirituality, etc.) and their domains. Independent t-tests, one-way analysis of variance (ANOVA) and Pearson correlation coefficient were utilised as appropriate to assess the level of unmet needs with demographic, clinical, and other independent variables. All variables with a *p*-value less than 0.10 in univariate analysis were selected for multiple linear regression to determine the relative contribution of independent variables (distress, anxiety, depression, QOL, and spiritual well-being) to the continuous dependent variable (level of unmet supportive care needs) and to identify the useful subset of possible predictors. All statistical tests were two-tailed, and *p* values of less than 0.05 were treated as significant.

7.9.9.2 Handling missing data

Missing data are a common problem in any research type (Ibrahim, Chu, & Chen, 2012). Missing data could occur due to clinical conditions that make participants unable or unwilling to respond to the questionnaire. Non-responses to items are common in several studies, particularly in PC and cancer research, due to patient characteristics such as pain, fatigue, distress, and disease progression (Preston et al., 2013).

Handling missing data with appropriate techniques is thus essential to avoid error when conducting advanced statistics. There are several crucial characteristics of missing data that must be considered before imputed missing data. First, it is essential to identify the pattern and amount of missing data, and then it is critical to assess the reasons for missing data. Finally, there is a need to describe how missing data is handled (Polit, 2010).

Missing data were replaced in this study utilising appropriate approaches to avoid the problem when using multiple linear regression, especially when comparing subgroups. The three commonly utilised approaches for handling missing are listwise deletion, single imputation, and multiple imputation (Patrician, 2002; Schlomer, Bauman, &

Card, 2010). The listwise deletion approach depends on excluding cases with missing data (Patrician, 2002). Excluding cases with missing data might affect the generalisability of the findings and might lead to bias in the results if a large amount of data is removed (Patrician, 2002; Sterne et al., 2009).

Imputation is another approach for handling missing data. The idea of imputation depends on adding value (mean) to a missing data cell based on the values of another variable. Imputing mean, however, may affect the variability between the study participants' responses (Patrician, 2002). Multiple imputation, the most popular and statistically robust technique, is used to generate missing data in this study (Rubin, 1988, 2004). It is a widely used approach in clinical research because it may reduce bias (Sterne et al., 2009). It involves creating multiple complete sets by filling in the value of missing data and generating new filled-in data sets (Little & Rubin, 2019). The results for the filled-in data sets are then merged into one result by averaging the filled-in data sets (Little & Rubin, 2019). Multiple imputation approaches can be used to handle missing data if the data are missed randomly (Patrician, 2002; Sterne et al., 2009). This approach creates five imputed datasets, which is sufficient as reported by guidelines for reported analysis (Sterne et al., 2009).

7.9.10 Ethical considerations

Research ethical approval to undertake the study was obtained from the Ethical Review Committee, The Hong Kong Polytechnic University (HSEARS20200414006) and the Palestinian Ministry of Health (SN476303) (Appendix 11 and 12). Confidentiality, anonymity, beneficence, non-maleficence, and informed verbal and written consent were obtained to adhere to the main ethical rules of respecting and protecting human participants.

7.9.10.1 The principles of confidentiality and anonymity

Discussing anonymity and confidentiality are essential before data collection for research involving human participants. Both terms may be used interchangeably in many types of research; however, there are significant differences. Anonymity means there is no way for any persons, including the researcher, to individually recognise participants in the study. This means that no personal information (e.g., name, addresses, cell phone number, identity number, photographs, and e-mail addresses) can be collected in an anonymous study. In other words, no participant identification appears on the questionnaire with no connections to the participants (Zelnio, 1980).

On the other hand, confidentiality means that while the study participants can be recognised, their information is not revealed to any person outside of the study. Only the researcher knows the identities of the study participants, and considerations are put in place to confirm that participant identities are not revealed to anyone else (Zelnio, 1980). Two methods used to ensure confidentiality are proper data management and security effectively. In terms of data management, the participants' identifying information can be linked to their data using ID codes. In terms of data security, the researcher protected all collected information in locked file cabinets and securely destroyed the data after study completion.

Confidentiality was considered in this study since only one trained nurse approached participants and collected data in each centre. In addition, data entry and analysis were carried out only by the researcher. All collected questionnaires were kept in a locked cabinet in the researcher's office, and the raw data were destroyed after study completion. Anonymity was also acknowledged by assigning a code number to each study participant during data entry and analysis. No identifying information was asked of the participants. None of the forms used in the study included participant names or any other such identifier information.

7.9.10.2 The principle of beneficence and non-maleficence

The researcher is also considered beneficence and non-maleficence as a fundamental core of ethical principles in this study, as the searching group are vulnerable to a lot of physical and emotional issues. Beneficence (do good) means that the research must imply benefit and help to study participants (Avasthi, Ghosh, Sarkar, & Grover, 2013). In this study, the researcher identified the advanced cancer patients' unmet needs that affect their health status and QOL. By recognising unmet needs, suggestions and recommendations were discussed with policymakers to overcome that and apply their needs.

On the other hand, non-maleficence (do not harm) means that the research must not imply harm to the patients or study participants (Avasthi et al., 2013). Some interventional research may imply uncomfortable and painful issues, such as surgical intervention. However, the core fundamental aims of HCPs are to work for the benefit, not harm, of patients. Therefore, the researcher must avoid causing any harm or distress to patients or study participants.

The researcher tried to avoid any physical and emotional reactions that patients may confront while completing the questionnaire in this study. The researcher explained to study participants the study purpose and importance, and how the findings reflected positively on the quality of services provided. Also, the researcher translated a message of hope and support to the patients and tried to avoid linking the study topic with death (false beliefs). In addition, the length of time for completing the questionnaire was considered while choosing the questionnaire, to minimise and avoid any emotional reactions. The chosen questionnaire is concise, robust, and short, taking about 30 minutes. The researcher also considered fatigued patients by giving them the option to complete the scales in more than one go.

7.9.10.3 The principle of autonomy and informed consent

Autonomy is one of the four basic principles of health care ethics, and has become the ‘principal principle’ of health care ethics (Milligan & Jones, 2016). It means that patients have the right to decide whether to take part in the study (Gillon, 2003; Harris, 2003). For patients to make a decision, they must first understand the study risks and benefits. Full understanding can be achieved through an informed consent process.

Informed consent means that every participant should be provided with full information about the study purpose, research process, time required when participating in the study, and the possible risks and benefits of becoming involved in the study (Gregory, 2003). Written informed consent is usually requested before interviews, and this is not usually requested for questionnaire surveys, since the completion and return of the questionnaire implies agreement consent (Watson, McKenna, Cowman, & Keady, 2008). Although, the researcher addressed the issue of informed consent via the information letter attached with the questionnaire (including the study purpose, assurance about the confidentiality of the information, the instructions on how to respond to the questionnaire) (Appendix 1), a statement indicating that participation is voluntary, and that participants could withdraw from the research process at any time (Appendix 2).

7.10 Results

7.10.1 Missing data

The patterns and amount of missing data on each scale were browsed before starting the actual data analysis. Overall, 218 (57.5%) participants completed the questionnaires. One missing item was reported in 15.3% of cases, two items missing were reported in 6.3%, and three items missing were identified in 4.5%. More than five items missing were reported in 11.9% of cases. For sociodemographic and clinical variables, missing data were only reported in income level, with a percentage of 5.3%. For the SCNS-SF 34 scale, missing data for each question ranged from 1.3% to 2.9%, while for other scales, missing data ranged between 2.9% and 8.3%. Because of the data that were missed randomly, multiple imputation was chosen as an appropriate method in this study for handling missing data.

7.10.2 Participant characteristics

Of the 404 patients who were approached, 379 patients agreed to take part in this study, with a response rate of 93.8%. The majority of participants were male (n = 193, 50.9%) and were married (n = 316, 83.4%). More than half (n = 199, 52.5%) were older than 50 years, and the mean age was 50.13 ± 14.8 years. Two-thirds of patients (n = 248, 65.4%) were living in a city. Almost (n = 243, 64.1 %) of patients reported that they had attained a secondary educational level, and only 13.5 % had primary or less education. Around half of participants were not working (n = 177, 46.7 %) and were homemakers (n = 100, 26.4%). About two-thirds of the participants (n = 249, 69.4%) had a monthly household income of less than 250 USD.

Regarding clinical characteristics, 193 of participants (50.9%) were identified as having stage IV cancer. The most common diagnosis was breast cancer (n = 83, 21.8%), followed by colon cancer (n = 58, 15.3%), and lung cancer (n = 34, 9.0%). The vast majority of participants (n = 307, 81.0%) had undergone chemotherapy. Details of the patient characteristics are presented in Table 7.

Table 7: Participant characteristics (N=379)

Sociodemographic variables	**Number (%)**		**Clinical-related variables**	**Number (%)**
Age Mean (+SD)	50.13 (14.8)		**Diagnosis/type**	
< 40 years	91 (24.0%)		Breast	83 (21.8%)
40-49 years	89 (23.5%)		Colon	58 (15.3%)
≥50 years	199 (52.5%)		Lung	34 (9.0%)
Gender			Bone	28 (7.4%)
Male	193 (50.9%)		Prostate	20 (5.3%)
Female	186 (49.1%)		Bladder	12 (3.2%)
Marital status			Thyroid	27 (7.1%)
Married	316 (83.4)		Lymphoid	26 (6.9%)
Not married[a]	63 (16.6%)		Brain and neck	25 (6.6%)
Education			Stomach	17 (4.5%)
Primary and less	51 (13.5%)		Other	49 (12.9%)
Secondary	243 (64.1%)		**Grade**	
University	85 (22.4%)		III	186 (49.1%)
Working status			IV	193 (50.9%)
None	177 (46.7%)		**Duration since diagnosis**	
Employee	102 (26.9%)		Within the last month	23 (6.1%)
Homemaker	100 (26.4%)		1-12 months ago,	136 (35.9%)
Monthly Income (USD) (N=359) [a]			Over 1 year-3 years ago	129 (34.0%)
Less than 250 USD	249 (69.4%)		Over 3 years ago	91 (24.0%)
More than 250 USD	110 (30.6%)		**Current treatment**	
Residency/Living condition			Chemotherapy	307 (81.0%)
Urban/city	248 (65.4%)		Radiation	27 (7.1%)
Rural	44 (11.6%)		Surgical	16 (4.2%)
Camp	87 (23.0%)		Bone transplantation	2 (0.5%)
			Other	27 (7.1%)

SD = Standard deviation; USD=United States Dollar

[a] Includes those who are single, widowed, or divorced.

[b] Missing data 5.3%.

7.10.3 Unmet needs of advanced cancer patients

7.10.3.1 Prevalence of unmet care needs

The Short form of the Supportive Care Needs Survey (SCNS-34) was adopted to assess participants’ unmet needs. The participants in the study reported having a variety of unmet needs. Four out of five SCNS-34 domains had a score higher than 50 (Table 8). The highest unmet needs as expressed by advanced cancer patients were in the physical/daily living (58.94 ± 20.93) and psychological domains (58.84 ± 19.49), followed by patient care and support (54.17 ± 21.64), and health systems and information (51.01 ± 18.34). Although scores in the sexuality domain were lower than 50, the margin was minimal (44.05±26.40).

Table 8: Mean scores for supportive care needs (domains)

Rank	SCNS SF-34 domain	Mean (±SD)
1	Physical and daily living (range, 0-100)	58.94 (20.93)
2	Psychological (range, 0-100)	58.84 (19.49)
3	Patient care and support (range, 0-100)	54.17 (21.64)
4	Health systems and information (range, 0-100)	51.01 (18.34)
5	Sexuality (range, 0-100)	44.05 (26.40)

SCNS-SF-34=Supportive care needs survey short form 34; SD=Standard deviation,

7.10.3.2 Prevalent unmet supportive care needs

A total of 96.8% of the patients stated that they had at least one unmet need of a 'moderate to high' level. For each of the SCNS-SF 34 items, the percentage of participants who indicated that they had unmet needs ranged from 26.9% to 58.6% (Table 9). The most frequent unsatisfied needs were in the domain of physical/daily living, followed by the psychological domain. Six of the top 10 ranked unmet needs were from the psychological domain. The top three items were: "Worry that the results of treatment are beyond your control" (58.6%), "Fears about cancer spreading" (57.5%), and "Feelings of sadness" (55.1%). In the physical/daily living domain, four out of the five items ranked among the top 10 unmet needs. The top items were: "Lack of energy/tiredness" (54.1%), followed by "Not being able to do the things you used to do" (53.6%), and "Feeling unwell a lot of the time" (48.8%).

For informational domain, the highest unmet needs were in the item "Being given written information about the important aspects of your care" (42%), followed by "Having one member of hospital staff with whom you can talk about all aspects of your condition, treatment and follow-up" (40.6%), and "Being informed about your test results as soon as feasible" (40.1%). Sexuality-related items were ranked at the lowest level.

Table 9: Sequence of 34 items in the short form of the Supportive Care Needs Survey

Rank	Item	Moderate or high Number (%)	Domain
1	Worry that the results of treatment are beyond your control	222 (58.6)	Psychological
2	Fears about the cancer spreading	218 (57.5)	Psychological
3	Feelings of sadness	209 (55.1)	Psychological
4	Uncertainty about the future	209 (55.1)	Psychological
5	Lack of energy/tiredness	205 (54.1)	Physical and daily living
6	Not being able to do the things you used to do	203 (53.6)	Physical and daily living
7	Feeling down or depressed	191 (50.4)	Psychological
8	Anxiety	186 (49.1)	Psychological
9	Feeling unwell a lot of the time	185 (48.8)	Physical and daily living
10	Pain	174 (45.9)	Physical and daily living
11	Concerns about the worries of those close to you	173 (45.6)	Psychological
12	More choice about which cancer specialists you see	169 (44.6)	Patient care and support
13	Work around the home	163 (43.0)	Physical and daily living
14	Feelings about death and dying	163 (43.0)	Psychological

Rank	Item	Moderate or high Number (%)	Domain
15	Learning to feel in control of your situation	163 (43.0)	Psychological
16	Reassurance by medical staff that the way you feel is normal	160 (42.2)	Patient care and support
17	Keeping a positive outlook	159 (42.0)	Psychological
18	Being given written information about the important aspects of your care	159 (42.0)	Health systems and information
19	Hospital staff attending promptly to your physical need	155 (40.9)	Patient care and support
20	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up	154 (40.6)	Health systems and information
21	Being informed about your test results as soon as feasible	152 (40.1)	Health systems and information
22	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	150 (39.6)	Patient care and support
23	More choice about which hospital you attend	149 (39.3)	Patient care and support
24	Being adequately informed about the benefits and side-effects of treatments before you choose to have them	148 (39.1)	Health systems and information
25	Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	148 (39.1)	Health systems and information
26	Being informed about things you can do to help yourself to get well	146 (38.5)	Health systems and information
27	Being treated in a hospital or clinic that is as physically pleasant as possible	146 (38.5)	Health systems and information
28	Being informed about cancer which is under control or diminishing (that is, remission)	141 (37.2)	Health systems and information
29	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	133 (35.1)	Health systems and information
30	Being given explanations of those tests for which you would like explanations	133 (35.1)	Health systems and information
31	Being treated like a person not just another case	129 (34.0)	Health systems and information
32	Changes in your sexual relationships	122 (32.2)	Sexuality
33	Changes in sexual feelings	121 (31.9)	Sexuality
34	Being given information about sexual relationships	102 (26.9)	Sexuality

SCNS-SF-34=Supportive care needs survey short form 34

7.10.4 Physical symptoms

The Arabic Questionnaire for Symptom Assessment (AQSA) was utilised to assess the presence and quantify the intensity of pain and other 11 common symptoms in patients with advanced cancer (Table 10). Patients who rated their symptoms as "moderate" or "severe" in intensity on the AQSA scale were considered physically ill patients and in need of an assistant. The findings revealed that the vast majority of participants (n = 346, 91%) were physically ill and had experienced physical symptoms (49.6% moderate; 41.4% severe). Each item under the domain of physical symptoms was reported to have been experienced by 69.9% - 95.0%. Fatigue was the most common symptom (n = 360, 95.0%), followed by anxiety (n = 346, 91.3%), and pain (n = 331, 87.3%). Although shortness of breath (n = 265, 69.9%) and dry mouth (n = 266, 70.7%) were reported in the lowest rank, their percentages were still high.

Table 10: Ranking of the intensity of physical symptoms as reported by participants

Rank	AQSA items	Moderate or severe Number (%)
1	Fatigue/Tiredness	360 (95.0%)
3	Anxiety	346 (91.3%)
2	Pain	331 (87.3%)
4	Depression	318 (83.9%)
5	Loss of appetite	315 (83.1%)
6	Confusion	301 (79.4%)
8	Drowsiness	299 (78.9%)
7	Insomnia	298 (78.6%)
9	Nausea/Vomiting	274 (72.3%)
10	Dry mouth	266 (70.7%)
11	Shortness of breath	265 (69.9%)

AQSA= The Arabic questionnaire for symptom assessment

7.10.5 Emotional/psychological well-being

Two instruments [The Arabic version of the Distress Thermometer (DT) scale and Hospital Anxiety and Depression Scale (HADS)] were utilised to assess emotional distress of study participants. About 86.3% of the patients had a high level of distress, with the mean DT score being 6.72 ± 2.48. A total of 67 patients (15%) reported distress at a level of 10, indicating extreme distress. The major sources of distress were related to physical (n = 373, 98.4%), emotional (n = 359, 94.7%), and practical problems (n = 324, 85.5%). For each item, fatigue and pain were the most often reported physical problems (n = 262, 69.1% and n = 248, 65.4%), respectively. Nervousness (n = 281, 74.1%) and depression (n = 276, 72.8%) were frequently reported emotional problems. Housing (n = 237, 62.5%), childcare (n = 213, 56.2%) and transportation (n = 220, 58%) were frequently reported practical problems. A list of problems is presented in Table 11.

Table 11: Distress Thermometer list of problems and their prevalence as reported by participants

List of problems	Have a problem Number (%)		List of problems	Have a problem Number (%)
Practical problems			**Physical Problems**	
Childcare	213 (56.2%)		Appearance	235 (62.0%)
Housing	237 (62.5%)		Bathing/dressing	218 (57.5%)
Insurance/financial	213 (56.2%)		Breathing	227 (59.9%)
Transportation	220 (58.0%)		Changes in urination	171 (45.1%)
Work/school	182 (48.0%)		Constipation	207 (54.6%)
Treatment decisions	194 (51.2%)		Diarrhea	174 (45.9%)
Family Problems			Eating	246 (64.9%)
Dealing with children	194 (51.2%)		Fatigue	262 (69.1%)
Dealing with partner	187 (49.3%)		Feeling swollen	201 (53.0%)
Ability to have children	178 (47.0%)		Fevers	161 (42.5%)
Family health issues	186 (49.1%)		Getting around	216 (57.0%)
Emotional Problems			Indigestion	191 (50.4%)
Depression	276 (72.8%)		Memory/concentration	194 (51.2%)
Fears	275 (72.6%)		Mouth sores	177 (46.7%)
Nervousness	281 (74.1%)		Nausea	210 (55.4%)

List of problems	Have a problem Number (%)		List of problems	Have a problem Number (%)
Sadness	265 (69.9%)		Nose dry/congested	173 (45.6%)
Worry	256 (67.5%)		Pain	248 (65.4%)
Loss of interest in activities	275 (72.6%)		Sexual	150 (39.6%)
Spiritual/religious concerns	274 (72.3%)		Skin dry/itchy	145 (38.3%)
			Substance use	113 (29.8%)
			Tingling in hands/feet	208 (54.9%)

The HADS was utilised to assess patient depression and anxiety (Table 12). About 89.5% of advanced cancer patients reported signs of depression (30.9% borderline; 58.6% definitive, mean depression HADS score of 11.17 ± 3.09), while 87.9% of patients reported signs of anxiety (26.4% borderline; 61.5% definitive, mean score of 11.34±3.38).

Table 12: Prevalence of anxiety and depression among participants

Category	Mean (±SD)/n (%)
Anxiety	**11.34±3.38**
Normal	46 (12.1%)
Borderline	100 (26.4%)
Clinical case	233 (61.5%)
Depression	**11.17±3.09**
Normal	40 (10.5%)
Borderline	117 (30.9%)
Clinical case	222 (58.6%)

N= Number; SD = Standard deviation

7.10.6 Spiritual well-being

The FACIT-Sp scale was adopted to measure patients' spirituality, consisting of 12 items and two sub-domains (peace/meaning, and faith). The mean spiritual well-being score was 31.12 ± 6.22, reflecting good spiritual well-being. The mean score of the meaning/peace subscale was 18.83 ± 14.18, and that of the faith subscale was 12.26±3.48 (Table 13).

Table 13: Frequency distribution of FACIT-Sp items

Items	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
Spiritual Well-Being					
Meaning/Peace					
I feel peaceful	8.4%	7.9%	16.9%	26.6%	40.4%
I have a reason for living	1.8%	6.3%	16.9%	44.4%	30.6%
My life has been productive	7.1%	10.0%	26.1%	35.9%	21.1%
I have trouble feeling peace of mind (r)	3.7%	12.1%	28.5%	33.8%	21.9%
I feel a sense of purpose in my life	6.3%	8.2%	26.6%	38.0%	20.8%
I am able to reach down deep into myself for comfort	9.0%	7.7%	31.7%	35.6%	16.1%
I feel a sense of harmony within myself	5.8%	13.2%	26.9%	27.4%	24.5%
My life lacks meaning and purpose (r)	12.1%	13.5%	20.3%	28.2%	25.9%
Subscale score: Mean±SD	**18.83±14.18 (range 0-32)**				
Faith					
I find comfort in my faith or spiritual beliefs	4.5%	7.1%	18.5%	18.7%	51.2%
I find strength in my faith or spiritual beliefs	3.7%	10.0%	10.0%	18.7%	57.3%
My illness has strengthened my faith or spiritual beliefs	5.8%	7.1%	19.0%	15.3%	52.8%
I know that whatever happens with my illness, things will be okay	5.5%	6.9%	7.1%	19.8%	51.2%
Subscale score: Mean±SD	**12.26±3.48 (range 0-16)**				
FACIT-Sp Total score	**31.12±6.22 (range 0-48)**				

FACT-Sp= Functional Assessment of Cancer Therapy-Spirituality
(r) Reverse item

7.10.7 Quality of life

Quality of life of patients with advanced cancer was assessed using the Functional Assessment of Cancer Therapy – General (FACT-G) scale. Findings showed that the total mean score of the FACT-G was 57.72 ± 11.81, which was slightly below the midpoint of 58. About half of patients (n = 186, 49.1%) scored less than 58, reflecting a poor QOL, while the rest scored higher than or equal to 58. The highest scoring FACT-G subscale was for social/family well-being (10.68 ± 4.12) followed by functional well-being (15.71 ± 5.43). The lowest scoring subscale was for physical well-being (10.39 ± 4.76). The data on scores for FACIT-G subscale are exhibited in Table 14.

Table 14: Frequency distribution of FACIT-G items (QOL)

FACIT-G Items	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
Physical Well-Being					
I have a lack of energy (r)	6.9%	21.9%	23.7%	29.6%	17.7%
I have nausea	5.5%	18.2%	36.1%	30.3%	9.8%
Because of my physical condition, I have trouble meeting the needs of my family(r)	6.1%	7.9%	25.9%	31.1%	29.0%
I have pain(r)	5.5%	12.1%	19.0%	32.2%	31.4%
I am bothered by side effects of treatment(r)	6.1%	9.0%	22.4%	35.6%	26.9%
I feel ill(r)	5.5%	15.6%	25.3%	27.7%	25.6%
I am forced to spend time in bed(r)	6.9%	17.7%	20.6%	29.6%	25.1%
Subscale score: Mean±SD	**10.39±4.76 (range 0-28)**				
Social/Family Well-Being					
I feel close to my friends	10.3%	4.2%	17.4%	24.0%	44.1%
I get emotional support from my family	1.8%	4.7%	15.3%	23.3%	55.1%
I get support from my friends	3.2%	5.0%	20.8%	19.8%	51.2%
My family has accepted my illness	3.4%	5.5%	19.3%	25.1%	46.7%
I am satisfied with family communication about my illness	4.0%	7.4%	17.9%	24.0%	46.7%
I feel close to my partner (or the person who is my main support)	7.1%	7.1%	13.2%	21.9%	50.7%
I am satisfied with my sex life	10.0%	9.5%	24.0%	21.6%	34.6%

Subscale score: Mean±SD	**20.92±5.28 (range 0-28)**				
Emotional Well-Being					
I feel sad[(r)]	7.1%	13.7%	23.7%	25.3%	30.1%
I am satisfied with how I am coping with my illness	2.6%	7.1%	21.9%	34.6%	33.5%
I am losing hope in the fight against my illness[(r)]	11.6%	12.1%	27.4%	28.5%	20.3%
I feel nervous[(r)]	8.2%	13.2%	19.0%	29.0%	30.6%
I worry about dying[(r)]	18.5%	15.3%	17.4%	30.6%	18.2%
I worry that my condition will get worse[(r)]	12.1%	10.0%	15.8%	34.8%	27.2%
Subscale score: Mean±SD	**10.68±4.12 (range 0-24)**				
Functional Well-Being					
I am able to work (include work at home)	20.3%	18.5%	26.6%	20.1%	14.5%
My work (include work at home) is fulfilling	14.5%	14.0%	32.7%	26.9%	11.6%
I am able to enjoy life	11.6%	20.8%	24.5%	26.6%	16.2%
I have accepted my illness	5.5%	11.1%	20.3%	30.6%	32.7%
I am sleeping well	9.5%	16.6%	30.6%	27.2%	16.1%
I am enjoying the things I usually do for fun	14.2%	13.5%	32.7%	25.9%	13.7%
I am content with the quality of my life right now	11.1%	9.5%	22.2%	30.6%	26.6%
Subscale score: Mean±SD	**15.71±5.43 (range 0-28)**				
FACT-G Total score	**57.72±11.81 (range 0-108)**				

(r) Reverse item

7.10.8 Factors associated with unmet needs supportive care needs

7.10.8.1 Sociodemographic factors

Patients younger than 50 years showed a significantly high level of unmet needs in the health information domain (F = 6.76, *P* = 0.001). Younger patients (less than 50 years) also had more unmet physical and daily living needs, psychological, and patient care and support, than older patients. Regarding gender, male patients reported a significantly higher level of unmet needs in the sexuality domain (t = 3.82, *P* = 0.000). Similarity married participants had significantly higher unmet needs for sexuality (t = -2.26, *P* = 0.036) and patient care and support (t = -2.08, *P* = 0.037) than those who were not married.

Concerning the educational attainment, patients with low levels of education stated a higher level of unmet needs in the physical domain (F = 3.71, *P* = 0.043), while highly educated patients reported higher unmet needs across other domains. Patients with a high monthly income reported a significantly higher level of unmet needs in the sexual domain (t = -4.24, P = 0.000) than those with a higher income.

7.10.8.2 Clinical factors

Concerning cancer stage, patients with stage IV reported high unmet needs in the physical and daily living and patient care support domains, and significantly higher unmet needs in the sexuality domain (t = -3.00, *P* = 0.003) than those who were identified in stage III. Regarding cancer type, participants with bone cancer indicated significantly higher unmet needs in health systems and information domains (F = 3.21, *P* = 0.001). In contrast, participants with lung cancer indicated significantly higher unmet needs in the patient care and support domain (F = 2.14, *P* = 0.020) in comparison with other cancer types. Other variables, including duration since diagnosis, and current treatment, did not seem to have any effect on the reporting of patients' unmet needs (Table 15).

Table 15: Univariate analysis of sociodemographic and clinical factors that influence patient needs

Variables	Physical & daily living			Psychological support			Patient care and support			Health systems and information			Sexuality		
	Mean (±SD)		***P***	**Mean (±SD)**		***P***	**Mean (±SD)**		***P***	**Mean (±SD)**		***P***	**Mean (±SD)**		***P***
Age			0.258			0.138			0.298			**0.001**			0.076
< 40 years	59.97	21.89		56.35	21.12		52.12	25.94		51.99	20.60		45.62	24.57	
40-49 years	61.65	17.72		62.01	17.09		56.95	16.50		56.50	15.57		48.40	26.51	
≥50 years	57.94	21.75		58.56	19.63		53.86	21.48		48.10	17.86		41.39	27.04	
Gender			0.765			0.637			0.115			0.461			**0.000**
Male	58.63	20.31		59.30	18.61		55.90	20.88		51.69	17.31		49.17	25.01	
Female	59.27	21.61		58.37	20.41		52.37	22.31		50.30	19.37		38.74	26.85	
Marital status			0.488			0.347			**0.037**			0.508			**0.036**
Married	59.33	20.11		58.38	19.03		55.23	22.40		51.31	17.91		45.43	25.69	
Not-married[a]	57.03	24.67		61.15	21.75		48.82	21.36		49.48	21.68		37.16	28.82	
Education			**0.043**			0.970			0.505			0.211			0.919
Primary and less	60.49	22.36		58.64	20.115		50.76	20.24		47.15	19.25		43.10	24.49	
Secondary	60.30	20.19		58.71	19.40		54.72	21.44		52.05	18.87		44.14	26.38	
University	54.14	21.42		59.31	19.96		54.64	23.07		50.57	16.23		44.37	27.84	
Monthly income			0.110			0.953			0.456			0.586			**0.000**
< 250 USD	59.96	20.35		59.25	19.80		54.04	21.03		51.43	18.47		41.04	26.49	
≥ 250 USD	56.22	20.41		59.13	16.59		55.88	21.52		50.38	15.77		52.84	22.92	
Stage			0.835			0.608			0.113			0.755			**0.003**
III	58.72	20.67		59.36	19.14		52.37	20.20		51.31	18.37		39.92	26.69	
IV	59.17	21.23		58.33	19.87		55.90	22.87		50.72	18.34		48.03	25.65	
Diagnosis/type			0.246			0.098			**0.020**			**0.001**			0.139
Breast	56.49	18.64		55.75	18.05		51.02	19.79		46.82	16.32		39.97	23.33	
Colon	55.63	18.24		59.81	17.53		53.27	20.74		44.25	17.44		44.62	27.12	
Lung	57.20	21.04		61.16	16.90		64.82	21.19		50.04	13.51		45.34	23.13	
Bone	61.78	22.53		66.25	19.25		50.89	26.56		63.47	23.13		50.83	32.73	
Prostate	65.00	26.50		62.22	15.38		63.10	24.29		54.77	18.47		51.25	27.91	
Bladder	64.16	17.16		60.83	18.00		60.83	15.93		58.52	13.07		60.41	23.86	

Variables	**Physical & daily living**			**Psychological support**			**Patient care and support**			**Health systems and information**			**Sexuality**		
	Mean (±SD)		***P***	**Mean (±SD)**		***P***	**Mean (±SD)**		***P***	**Mean (±SD)**		***P***	**Mean (±SD)**		***P***
Thyroid	54.59	22.27		57.24	19.81		53.34	17.48		52.34	18.55		40.00	22.70	
Lymphoma	55.38	17.48		49.57	22.04		47.30	21.69		53.37	22.90		41.66	23.15	
Brain and neck	66.00	19.31		65.02	22.53		58.20	21.20		55.18	16.05		49.66	31.50	
Stomach	59.41	20.82		58.52	22.58		46.17	19.48		52.94	21.19		47.54	24.78	
Other	63.40	25.55		57.96	21.99		54.57	23.37		51.50	16.76		38.02	28.31	
Duration since diagnosis			0.568			0.540			0.935			0.144			0.226
Within last year	58.22	20.44		59.57	20.55		54.06	21.66		52.63	17.65		42.11	26.79	
Over 1 year ago	59.47	21.31		58.31	18.73		54.25	21.67		49.83	18.76		45.46	26.07	
Current treatment			0.737			0.248			0.141			0.113			0.203
Chemotherapy	59.32	19.50		59.03	18.84		55.30	21.55		52.08	17.76		45.40	26.88	
Radiation	58.14	26.09		63.83	21.23		51.70	20.29		48.97	22.59		38.14	24.24	
Surgical	53.37	24.34		55.00	25.51		51.56	22.29		46.02	20.85		38.02	25.08	
Others	58.79	38.11		54.31	20.71		45.86	22.65		44.34	17.68		38.62	22.66	

SD= Standard deviation; USD= United States Dollar
Black colour indicates a significant level.

7.10.9 Associations between supportive care unmet needs and other variables, including pain, symptoms, quality of life, and spiritual well-being

Although significant associations were reported between unmet needs and symptoms, distress, depression, anxiety, QOL, and spirituality, the strength of correlations (r) ranged from weak to moderate (Table 16). For instance, a weak positive correlation was reported between physical symptoms and physical/daily living (r = 0.038, $p < 0.01$). Low positive correlation was stated between physical symptoms and patient care and support (r = 0.293, $p < 0.01$), health systems and information (r = 0.295, $p < 0.01$), and sexuality domains (r = 0.233, $p < 0.01$), while a moderate positive correlation was reported with the psychological domain (r = 0.456, $p < 0.01$).

Weak positive correlation was also shown between the overall psychological distress level and physical/daily living (r = 0.169, $p < 0.01$) and a low positive correlation was seen in the psychological domain (r = 0.235, $p < 0.01$). All SCNS domains positively correlated with anxiety. The SCNS domains were also correlated with depression, except for the health systems and information domain (Table 16).

Moderate negative correlation was reported in the overall QOL and physical/daily living, psychological, patient care and support, health systems and information, and sexuality domains (r = -0.336, $p < 0.01$; r = -0.442, $p < 0.01$; r = 0.307, $p < 0.01$; r = -0.226, $p < 0.01$; r = -0.164, $p < 0.01$). Weak negative correlations were reported in the overall spirituality and health systems and information, and sexuality domains, with the exception of physical/daily living and psychological domains (r = -0.192, $p < 0.01$; r = -0.215, $p < 0.01$; r = -0.278, $p < 0.01$).

Overall, a moderate positive correlation was only reported between the physical symptoms and psychological domain. In comparison, a moderate negative correlation was reported in the overall QOL and physical/daily living, psychological, patient care and support, health systems and information, and sexuality domains.

Table 16: Pearson correlations (r) between unmet care needs and other variables (Symptoms, distress, depression, anxiety, QOL, and spirituality)

Domains	AQSA	Depression	Anxiety	DL	PWB	SFWB	EWB	FWB	FACT-G	Meaning	Faith	FACIT-Sp
Physical & daily living	0.381**	0.265**	0.220**	0.169**	-0.421**	-0.018**	-0.188**	-0.200**	-0.336**	-0.003	0.039	0.020
Psychological	0.456**	0.336**	0.488**	0.235**	-0.528**	0.055	-0.562**	-0.119*	-0.442**	-0.203**	0.095	-0.083
Patient care and support	0.293**	0.129*	0.248**	0.020	-0.203**	-0.156**	-0.324**	-0.087	-0.307**	-0.167**	-0.146**	-0.192**
Health systems and information	0.295**	0.037	0.162**	-0.002	-0.131*	-0.169**	-0.292**	0.014	-0.226**	-0.174**	-0.177**	-0.215**
Sexuality	0.233**	0.113*	0.174**	0.005	-0.084	0.244**	-0.263**	0.158**	-0.164**	-0.137**	-0.334**	-0.278**

AQSA = Arabic questionnaire for symptom assessment; CI = Confidence interval; DT = Distress thermometer; EWB = Emotional well-being; FACT-G = Functional Assessment of Cancer Therapy-General; FACT-Sp = Functional Assessment of Cancer Therapy- Spiritual; FWB = Functional well-being; HDSA = Hospital anxiety depression scale; PWB = Physical well-being; SCNS-SF-34 = Supportive care needs survey short form 34; SE = Standard error; SFWB = Social/family well-being.

*P＜0.05 **P＜0.01

7.10.10 Independent predictors associated with unmet supportive care needs

Multiple linear regressions analyses were utilised to predict factors associated with at least one unmet need in each of the SCN-34 domains (Table 17). Variables with *p* values less than 0.10 in univariate analysis were considered in the regression analysis. The findings showed that level of education [primary and less education (β = 6.34; *p* value = 0.011) and secondary level (β = 6.16; *p* value = 0.027)], physical symptoms (β = 3.11; *p* value = 0.000), anxiety (β = -0.81; *p* value = 0.036), QOL (β = -0.60; *p* value = 0.000) and spirituality (β = 0.59; *p* value = 0.001) were independently associated with physical aspects of daily living in advanced cancer patients. With regard to psychological well-being, the results revealed that physical symptoms (β = 2.58; *p* value = 0.000), anxiety (β = 1.18; *p* value = 0.000), and QOL (β = -0.35; *p* value = 0.000) were independently associated with the psychological well-being of advanced cancer patients. An independent association was reported between marital status (β = -6.15; *p* value = 0.031), physical symptoms (β = 2.63; *p* value = 0.000), and QOL (β = -0.33; *p* value = 0.006) and the domain of patient care and support.

With regard to health systems and information, the findings indicated that age (β = 7.36; *p* value = 0.001), a diagnosis of bone cancer (β = 11.42; *p* value = 0.000), physical symptoms (β = 2.20; *p* value = 0.000), depression (β = -1.12; *p* value = 0.001) and spirituality (β = -0.46; *p* value = 0.003) were independently associated with the unmet informational needs of patients with advanced cancer. Concerning the sexual domain, the results showed that age (β = 6.08; *p* value = 0.049), gender (β = 8.12; *p* value = 0.002), marital status (β = -6.97; *p* value = 0.049), cancer stage (β = -5.15; *p* value = 0.043), physical symptoms (β = 2.51; *p* value = 0.002), and spirituality (β = -1.14; *p* value = 0.000) were independently associated with the unmet sexual needs of patients with advanced cancer.

In summary, multiple linear regression analyses confirmed that educational level, age, gender, marital status, cancer stage, cancer type, physical symptoms, depression, anxiety, distress, QOL, and spirituality were independently associated with unmet supportive care needs of patients with advanced cancer.

Table 17: Multivariate linear regression model for factors associated with supportive care needs

Domain	Variable	β	SE	95% CI	Wald	P
Physical and daily living	Education					
	Primary and less	6.34	3.70	-0.91-13.61	3.35	*0.011*
	Secondary	6.16	2.65	0.95-11.37	5.99	0.027
	University	Ref	-	-	-	-
	AQSA	3.11	0.63	1.87-4.35	23.69	*0.000*
	Depression	0.53	0.377	-0.21-1.27	1.96	*0.160*
	Anxiety	-0.81	0.38	-1.57- -0.05	4.49	*0.036*
	DL	0.25	0.45	-0.65-1.15	0.17	*0.582*
	FACIT-G	-0.60	0.11	-0.82- -0.37	28.72	*0.000*
	FACIT-Sp	0.59	0.17	0.24-0.94	1	*0.001*
Psychological	Diagnosis					
	Breast	2.88	2.88	-2.77-8.53	1.01	*0.318*
	Colon	6.21	3.10	0.12-12.30	3.81	*0.462*
	Lung	2.44	3.53	-4.48-9.37	0.46	*0.489*
	Bone	6.22	3.82	-1.27-13.71	2.79	*0.104*
	Prostate	2.27	4.24	-6.04-10.59	0.134	*0.591*
	Bladder	1.35	5.10	-8.65-11.37	0.07	*0.791*
	Thyroid	4.72	3.83	-2.7812.22	1.44	*0.218*
	Lymphoma	-3.56	3.88	-11.1-4.06	0.80	*0.360*
	Brain and neck	3.47	3.91	-4.20-11.15	0.77	*0.375*
	Stomach	1.81	4.46	-6.93-10.56	0.182	*0.684*
	Other	Ref	-	-	-	-
	AQSA	2.58	0.55	1.49-3.67	22.11	*0.000*
	Depression	0.15	0.33	-0.48-0.80	0.47	*0.630*
	Anxiety	1.18	0.33	0.52-1.84	12.16	*0.000*
	DL	0.09	0.40	-0.71-0.90	0.27	*0.811*
	FACIT-G	-0.35	0.09	-0.53- -0.18	15.58	*0.000*
Patient care and support	Marital status					
	Not-married[a]	-6.15	2.84	-11.74- -0.57	4.73	*0.031*
	Married	Ref	-	-	-	-
	Diagnosis					
	Breast	-0.58	3.61	-7.66-6.50	0.05	*0.872*
	Colon	-0.12	3.90	-7.77-7.52	0.007	*0.974*
	Lung	7.33	4.48	-13.73-4.83	2.46	*0.102*
	Bone	-4.45	4.73	-13.73-83	1.07	*0.347*
	Prostate	5.59	5.34	-4.88-16.06	0.89	*0.295*
	Bladder	1.63	6.43	-10.96-14.24	0.050	*0.799*
	Thyroid	1.67	4.91	-7.96-11.32	0.088	*0.733*
	Lymphoma	-5.91	4.82	-15.37-3.54	1.66	*0.221*
	Brain and neck	-0.01	4.87	-9.56-9.54	0.004	*0.999*
	Stomach	-8.63	5.54	-19.50-2.24	1.95	*0.120*
	Other	Ref	-	-	-	-
	AQSA	2.63	0.68	1.28-3.98	16.00	*0.000*
	Depression	-0.65	0.40	-1.44-0.13	2.04	*0.103*
	Anxiety	0.25	0.41	-0.56-1.07	0.17	*0.548*
	FACIT-G	-0.33	0.12	-0.57- -0.09	7.36	*0.006*
	FACIT-Sp	-0.34	0.188	-0.71-0.02	3.25	*0.065*

Domain	Variable	β	SE	95% CI	Wald	P
Health systems and information	Age					
	< 40 years	2.10	2.14	-2.08-6.30	1.15	*0.325*
	40-49 years	7.36	2.13	3.17-11.55	12.01	*0.001*
	≥50 years	Ref	-	-	-	-
	Monthly income					
	< 250 USD	3.39	1.92	-0.38-7.17	3.40	*0.078*
	≥ 250 USD	Ref	-	-	-	-
	Diagnosis					
	Breast	-3.49	2.99	-9.37-2.38	1.79	*0.244*
	Colon	-5.31	3.19	-11.57-0.95	3.13	*0.097*
	Lung	-0.94	3.63	-8.05-6.17	0.133	*0.795*
	Bone	11.42	4.01	6.55-22.28	12.47	*0.000*
	Prostate	5.63	4.26	-2.71-13.99	1.41	*0.186*
	Bladder	6.64	5.15	-3.45-16.75	1.52	*0.197*
	Thyroid	2.55	4.00	-5.30-10.40	0.40	*0.524*
	Lymphoma	8.04	4.02	0.15-15.93	3.99	*0.046*
	Brain and neck	1.09	3.95	-6.64-8.84	0.03	*0.781*
	Stomach	3.27	4.46	-5.47-12.03	0.442	*0.463*
	Other	Ref	-	-	-	-
	AQSA	2.20	0.59	1.04-3.36	14.77	*0.000*
	Depression	-1.12	0.33	-1.7- -0.47	11.73	*0.001*
	Anxiety	-0.72	0.34	-0.75-0.61	0.11	*0.836*
	FACIT-G	-0.10	-0.10	-0.31-0.09	1.34	*0.293*
	FACIT-Sp	-0.46	0.15	-0.78- -0.15	8.55	*0.003*
Sexuality	< 40 years	4.76	3.13	-1.36-10.90	2.72	*0.128*
	40-49 years	6.08	3.09	0.02-12.15	4.05	*0.049*
	≥50 years	Ref	-	-	-	-
	Gender					
	Male	8.12	2.60	3.02-13.22	9.47	*0.002*
	Female	Ref				
	Marital status					
	Not-married[a]	-6.97	3.54	-13.91- -0.03	4.68	*0.049*
	Married	Ref	-	-	-	-
	Stage					
	III	-5.15	2.55	-10.16- -0.15	3.55	*0.043*
	IV	Ref				
	AQSA	2.51	0.83	0.87-4.15	10.71	*0.003*
	Depression	-0.30	0.48	11.25-0.64	0.59	*0.523*
	Anxiety	0.73	0.50	-0.24-1.72	2.61	*0.143*
	FACIT-G	0.19	0.15	-0.10-0.49	2.05	*0.198*
	FACIT-Sp	-1.14	0.23	-1.60- -0.69	22.45	*0.000*

AQSA = Arabic questionnaire for symptom assessment; CI = Confidence interval; DT = Distress thermometer; EWB = Emotional well-being; FACT-G = Functional Assessment of Cancer Therapy-General; FACT-Sp = Functional Assessment of Cancer Therapy- Spiritual; FWB = Functional well-being; HDSA = Hospital anxiety depression scale; PWB = Physical well-being; SCNS-SF-34 = Supportive care needs survey short form 34; SE = Standard error; SFWB = Social/family well-being.

7.11 Discussion

This is the first study carried out in Palestine that provides comprehensive information on the needs of advanced cancer patients. The Supportive Care Framework for Cancer Care (SCNF) was adopted for guiding the study design (Fitch, 1994). The QOL, distress level, depression, anxiety, and spiritual well-being of the patients were also assessed in this study. A level of unmet care needs was observed among such patients. Most experienced moderate to severe physical symptoms. Two-thirds screened positive for depression and anxiety. The patients reported a low level of QOL but showed strong spiritual well-being. The multivariable model reported that education level, age, gender, marital status, cancer stage and type, symptoms, depression, anxiety, distress, QOL, and spirituality were independently associated with domains of unmet supportive care needs of patients with advanced cancer.

7.11.1 Unmet supportive care needs

Palestinian advanced cancer patients reported significantly higher unmet needs than those observed in earlier studies conducted elsewhere, ranging between 40-72% (Boyes et al., 2015; Edib et al., 2016; Hasegawa et al., 2016; Jie et al., 2020; Nair et al., 2018; Tish Knobf et al., 2012; Yu et al., 2017), compared with 96.8% in this study. The highest prevalence was reported in the physical/daily living and psychological domains. These results match those identified in earlier Arab and Islamic studies with participants who share the same religion and culture. For instance, in the United Arab Emirates, psychological needs were the most frequently unmet need (Nair et al., 2018). Among the Jordanian people, the highest unmet needs were psychological (Alananzeh, Levesque, Kwok, Salamonson, & Everett, 2019). In Indonesia, an Islamic country, physical and psychological needs were also reported as the most frequently unmet needs (Afiyanti, Milanti, & Putri, 2018). In contrast, in Asian countries, Chinese, Japanese and Korean studies reported that the most common unmet needs were due to a lack of information provided by those working in the health system (Hasegawa et al., 2016; Jie et al., 2020; Yu et al., 2017; Zhao, Wong, You, & Tao, 2019) which is inconsistent with the findings of this study. The differences in supportive care needs across countries might be attributed to cultural issues (Coreil, Wilke, & Pintado, 2004; Fielding et al., 2013; Lam et al., 2011). Fielding et al. (2013) examined the unmet variance needs among Japanese, Taiwanese, and Hong Kong cancer patients. They confirmed distinctive cultural differences in supportive care needs. Another study compared unmet supportive care needs between German Caucasian and Hong Kong patients with breast cancer; the results reported significant cultural differences (Lam et al., 2011). Thus, culture has been shown to affect patient perceptions and mechanisms related to disease management (Coreil et al., 2004; Daher, 2012).

The significantly high prevalence of unmet needs in Palestinian patients might be related to the services that are provided to cancer patients in Gaza cancer centres, which are not yet well prepared or equipped to deliver advanced cancer services, such as PC and targeted cancer therapies (Halahleh & Gale, 2018; World Health Organisation, 2020a; World Health Organization, 2019a). Furthermore, the Palestinian context might play a role in this high prevalence of unmet needs, as Palestine faces several challenges, such as scarce financial resources, high levels of poverty and unemployment, limited infrastructure, and political divisions (Maziak, 2009). As reported in this study, the majority of patients had a low monthly income, which was an obstacle to pursuing advanced and follow-up treatments outside of Gaza (World Health Organisation, 2019). These challenges are further aggravated by frequent closure of borders and ongoing sieges (Al Mezan Center for Human Rights, 2018;

Physicians for Human Rights, 2020). These explanations may help us understand why unmet care needs were more common among cancer patients in Gaza. Particular attention must be paid to the patient's needs. This requires incorporating psychological components of care within routine cancer delivery.

7.11.2 Physical symptoms

The vast majority of advanced cancer patients were physically ill and identified their symptoms as moderate to severe. Advanced cancer patients experience physical challenges resulting from their disease progression and treatment effects (Lang-Rollin & Berberich, 2018; Nayak et al., 2015; Weis, 2015). Lack of appropriate care leads to untreated symptoms that impede patients’ ability to continue their activities of daily living (Nayak et al., 2015). The findings indicate that fatigue, anxiety, and pain were the main causes of physical distress. These results matched those observed in a recent systematic review and meta-analysis (Van Den Beuken-Van et al., 2016). These findings are consistent with those observed in Western (Apolone et al., 2009; Brown et al., 2011; McKenzie et al., 2020; Spichiger et al., 2011; Uitdehaag et al., 2015), LMICs (Hasegawa et al., 2016; Molassiotis et al., 2017; Nayak et al., 2015), and Middle Eastern (Al Qadire & Al Khalaileh, 2014; Naveh, Leshem, Dror, & Musgrave, 2011) countries.

Although the findings of all previous studies corresponded to what this study has reported, the prevalence of physical symptoms is still very high in Palestinian patients. This can be attributed to a shortage of cancer healthcare experts in the GS (Halahleh & Gale, 2018), which prevents HCS from providing comprehensive care. It might be one explanation for the high prevalence of physical symptoms in this study. Insufficient knowledge and training in the delivery of comprehensive care on the part of HCPs might be another explanation for the high prevalence of physical and emotional/psychological symptoms uncovered in this study. Another explanation might be attributed to the unavailability of PC services within the Gazan HCS (Abu Hamad et al., 2016). Therefore, measuring physical symptoms would be important in enhancing cancer services (Henoch & Lövgren, 2014; Lester, Bernhard, & Ryan-Wenger, 2012). A significant emphasis should be placed on teaching and training HCPs ways of managing patients' physical and psychological symptoms. This should be done in both service areas and universities. Patients and their families should also be empowered by being instructed on how to manage their health. Therefore, educational programmes should be designed to meet the needs of patients, and PC courses should be introduced in the curriculum of schools of health.

7.11.3 Emotional/psychological well-being

Emotional/psychological distress has been recognised as a critical outcome of patient health, which can be linked with decreased treatment compliance (Greer et al., 2008), and increased risk of worsening health and death (Pinquart & Duberstein, 2010; Satin et al., 2009). Results reported a high prevalence of psychological distress among advanced cancer patients. This matches the findings in a Saudi Arabia study, which reported that 70% of cancer patients experienced significant distress (Alosaimi et al., 2018). The high prevalence of distress might be attributed to cancer treatments that may have a long-term impact on patient health and result in daily practical difficulties (O'Connor et al., 2019). The most common distress symptoms were fatigue, pain, and loss of appetite; the occurrence was over 50%. Unlike in other studies, emotional problems, including nervousness, depression, and fear, were the predictive factors of emotional/psychological distress in this study. Fatigue and pain (physical problems) also ranked among the top 10 predictive factors for distress, as cited in the previous paragraph. Despite the usage of different scales in measuring physical problems and psychological distress, both scales have highlighted the same rank of problems, and this makes the study results robust and more sensitive.

It is not surprising that more than two-thirds of patients in this study screened positive for depression and anxiety. It is not easy to diagnose anxiety and depression among advanced cancer patients; and often, anxiety and depression are not treated. Untreated depression may have a negative consequence on patients' QOL and make the palliation of physical symptoms more difficult (Giese-Davis et al., 2011; Pirl et al., 2012). Some Arab patients (Ben-Arye et al., 2012) are reluctant to disclose their feelings to healthcare professionals. This might be attributed to their beliefs, religion, and culture of the Muslim communities. Patients tolerate pain because of their religious belief that it is a test from God/Allah, and they must be patient to gain Paradise. Muslims trust Allah. Most Muslim patients grow closer to Allah during their disease progress through praying and reading the Quran, because they are confident that Allah would respond to their supplication by easing their pain. Thus, professionals assume that patients are living normally and that their psychological symptoms are normal (Maguire & Weatherby, 1995).

This study found that the prevalence of emotional/psychological distress was very high in Palestinian patients. This can be attributed to the unavailability of psychological care in the PC services offered within the Gazan HCS (World Health Organisation, 2020a). The high levels of distress indicate that the priority in developing a PC programme should be on devising treatment strategies to reduce the burden of symptoms. It is critical to identify patients who may be more likely to develop psychological symptoms, to manage these symptoms appropriately. Integrating regular screening as a part of routine cancer care is a practice that is recommended globally for standardising good care (Grassi et al., 2013) and alleviating and minimising stress, which impacts a patient's life and helps them continue good health habits (Nikbakhsh et al., 2014). It should integrate screening as a part of routine cancer care.

7.11.4 Spiritual well-being

Patient spiritual well-being is a crucial role in patient-centred care (Fitch & Bartlett, 2019). It has received growing interest and attention over the past 15 years as a dimension of PC (Cohen et al., 1995). Religion and spiritual beliefs have been found necessary for advanced cancer patients due to the confrontation with death (Conroy, Bleiberg, & Glimelius, 2003; Edwards et al., 2010; Mystakidou et al., 2008; Winkelman et al., 2011). Although no spiritual care services are available in the Palestinian HCS, the patients were observed to have robust spiritual well-being. This finding is congruent with studies that have been conducted in Jordan and Iran that reported high scores in spiritual well-being among cancer patients (Al-Natour et al., 2017; Jafari et al., 2013). The current study also highlighted a high score in the faith subscale of spiritual well-being. Arab studies support the finding that being a Muslim was linked with a high score in the faith subscale of spiritual well-being, as this subscale is mostly correlated with religion and spiritual beliefs and norms (Jafari et al., 2013).

Robust spiritual well-being might be attributed to the Islamic religion and beliefs, as all of the patients were Muslims who believe in God/Allah and in the inevitability of death, which is Allah’s responsibility (Iranmanesh et al., 2014b). Muslims believe that no one, except for Allah, can stop or avoid death and illness. They believe in life after death and eternal life, and agree that life on earth is temporary and could end at any time (Puchalski & O’Donnell, 2005). After death, every person will either be rewarded or punished in the hereafter (Puchalski & O’Donnell, 2005). These beliefs and norms help patients cope, accept their illness, and die in peace (Sheikh, 1998; Wing & Handzo, 2014). Muslims also believe that tolerating pain is a test of faith and reflects how well patients are connected with Allah (Errihani et al., 2008; Zahedi & Larijani, 2007). Patients who are able to bear the pain will end by earning a place in Paradise (Errihani et al., 2008).

7.11.5 Quality of life

Improving QOL is a fundamental goal of PC in patients with advanced cancer (Pérez-Cruz et al., 2019). QOL may be affected by unmet needs. The majority of advanced cancer patients in this study reported a low level of QOL. This is in line with studies conducted in Palestine that reported low QOL scores (ranging between 41.8% and 49.9%) among advanced cancer patients (El Noor & El Noor, 2014; Khleif & Imam, 2013; Shamallakh & Imam, 2017; Thweib, 2011). Slight variations in scores can be attributed to the use of different study instruments. However, these results are not consistent with those of studies conducted in the West (Deshields, Potter, Olsen, & Liu, 2014; Kjaer et al., 2011) and in Arab (Jordan) countries (Al-Natour et al., 2017; Al Qadire & Al Khalaileh, 2014). For example, Al-Natour et al. (2017) revealed that total QOL score among Jordanian cancer patients was 79.86%, compared with 57.7% in this study.

This considerable difference across studies may be related to the well-prepared HCSs in Jordan and Western countries, prepared to deliver PC services and staffed with well-educated and trained HCPs. It also may be related to the high level of unmet needs, distress, and severity of symptoms experienced by participants in our study, which negatively influence their QOL. To address all of these negative consequences and improve their QOL, therefore, it is recommended that a comprehensive PC programme be integrated within the current HCS. The early integration of PC into oncological care can improve patient outcomes, including their QOL (Temel et al., 2010; Vanbutsele et al., 2018).

7.11.6 Factors influencing unmet needs in advanced cancer patients

In a multivariable analysis, the findings verified that younger patients were found to have more unmet informational and sexual needs. These findings match those reported in a previous study (Jie et al., 2020). Younger patients may ask for more information about their health and the progression of their disease, as well as for information on body image and interpersonal relationships, compared with older patients. The latter may not be aware of their dangerous condition. Older people demand more care and support than younger cancer patients (Jie et al., 2020; Teunissen et al., 2006). Older people recover slowly during treatment due to their physical and health condition and are therefore in need of additional care and follow-up (Ream et al., 2008).

Married males have expressed a high level of unmet needs, significantly in the sexuality domain. Findings conflict with recent studies that showed female patients have more needs in the psychological domain (Griesser et al., 2011; Hasegawa et al., 2016; Schmid-Buchi et al., 2013). Patterns of unmet needs may differ across cultures and healthcare services that are provided (Fielding et al., 2013; Wen, Fang, & Ma, 2014). In Palestine, a low level of unmet needs among females might be attributed to the culture of Arab societies, where females are supported through the expression of empathy and solidarity when they are experiencing severe issues with their health. It might also be attributed to a husband supporting his wife during the illness trajectory. However, there is also support for males, but sexuality-related issues are still unmet. Or it might be attributed to the conservativeness of a Muslim society and the resulting unwillingness of patients to discuss sexual concerns. It is crucial to shed light onto this vital area and find appropriate ways to deliver sexual information, considering patients' emotions and feelings. Addressing routine sexual issues are a part of cancer services and may overcome cultural barriers and ensure that this sensitive aspect of patient care is met.

Patients with low educational levels expressed higher unmet physical needs. This is consistent with other previous studies that reported educational attainment had been associated with physical (Liao et al., 2011), informational (Voogt et al., 2005), and sexuality needs (Au et al., 2013). Educational level plays a significant role in patients' perceptions and understanding of their health and how to interact with HCSs, including understanding their needs, make a treatment decision and communicate with HCPs, as well as understanding health information (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011).

For health/illness-related aspects of patients with advanced cancer, the results showed that patients with stage IV cancer reported having a higher level of unmet needs. Numerous studies have stated the unmet needs of cancer patients during treatment (Gozum & Akcay, 2005; Hwang et al., 2004; Jonker-Pool et al., 2004), particularly among patients diagnosed with stage IV cancer (Au et al., 2013; Hwang et al., 2004). In contrast, other studies did not observe any relationship between cancer stage and unmet needs (Lam et al., 2014; Liao et al., 2011). Study results also revealed that patients who were diagnosed with bone and lymphatic cancer also reported a higher level of unmet needs, specifically related to informational issues. Several studies have reported a significant relationship between cancer site and unmet patient needs (Duke et al., 2001; Houts et al., 1988; Lintz et al., 2003). In these studies, higher levels of unmet needs were reported among patients who had been diagnosed with prostate and lung cancer, which was not the case in this study.

7.11.7 Relationship between unmet needs and QOL, distress, depression, anxiety, spirituality

Our results showed that unmet supportive care needs were independently associated with physical symptoms and psychological distress. This finding is consistent with those of previous studies (Hasegawa et al., 2016; Hwang et al., 2004; Lam et al., 2014; Liao et al., 2011; Uchida et al., 2011). A moderate to strong positive correlation between unmet needs and psychological distress was reported in previous evidence (Akechi et al., 2011), compared with a weak correlation in this study. An explanation of a weak correlation might be related to the high prevalence of both unmet needs and psychological distress in the study population, as nearly all patients in this study reported unmet supportive care needs. Regardless of the strength of association, HCPs should communicate and interact with advanced cancer patients to identify their unmet needs, which could help control their psychological distress.

Advanced cancer patients with a higher level of physical, psychological, and patient care and support needs were more likely to have poor QOL. This is supported by the findings of previous studies (Akechi et al., 2011; Edib et al., 2016). Understanding the impact of unmet needs on the health and well-being of patients is essential to reducing the severity of their illnesses, enhancing their QOL and increasing survival rates (Park

& Hwang, 2012). Addressing patients' unmet needs provides a rationale to enhance patients' QOL and guide development strategies in cancer settings that could reduce the burden of disease and improve QOL. The findings also revealed that patients with a high level of spiritual well-being were more likely to have a lower level of unmet supportive care needs. When the spiritual needs of patients are not addressed, they are at risk of experiencing emotional/psychological distress (Pearce, Coan, Herndon, Koenig, & Abernethy, 2012), which negatively influences their unmet needs. Spiritual care, therefore, should be integrated into and matched with patients' needs.

7.12 Implications for clinical practice, education, and research

The information provided by this study can guide and inform the future development of health services in the GS-Palestine. The study suggests the significance of the development of a PC programme within the current Palestinian HCS. A new guideline should also be developed to address the high distress levels among Palestinian patients. Frontline healthcare professionals should be alerted and trained to not only focus on managing patients' physical symptoms, but also be aware of the psychological symptoms. Regular screening of all patients with advanced cancer for psychological symptoms is recommended for standardising good care and alleviating and minimising stress, which impacts a patient's life and encourages them to continue practise good health habits (Nikbakhsh et al., 2014). It should integrate screening as a part of routine cancer care in the Gaza Strip.

For education, the findings emphasise the need to designeducational programmes to meet patient needs, then leading to the introducion of PC courses with a health school curriculum. Development of practical guidelines and a training programme to guide HCPs in managing patients' physical and psychological problems is important.

Future research is recommended to assess professionals' knowledge and their ability to help patients with symptoms and pain management. Further interventional research is also needed to evaluate the impact of psychological programmes on reducing patients' psychological symptoms and enhancing their QOL.

7.13 Study strengths and limitations

The recruitment of a relatively large and representative sample of patients from the two leading cancer centres in the GS has enhanced the generalisability of the results. The different scales that were used in this study all produced the same ranking of problems, an indication that the study results can be considered reliable and consistent. The length of the survey instruments used in this study did not affect the willingness of patients to participate in it, compared with other studies. Despite this study’s strengths, there were also several limitations. Although it was important to adopt a self-administered questionnaire that allows patients to freely answer the questions, specific types of bias might have resulted. Questions about sexuality may have led to an informational bias due to cultural sensitivities over the subject of sex, posing barriers to open discussions on this subject with patients. Furthermore, adopting the approach of convenience sampling in recruiting participants may have affected the generalisability of the study results.

7.14 Conclusion

This chapter presented the results of the first cross-sectional study. A total of 379 advanced cancer patients participated in the study to identify their unmet service needs and assess their anxiety, depression, distress, and QOL. Advanced cancer patients exhibited a significantly higher prevalence of unmet needs, particularly in physical- and psychological-related issues, compared to those in previous studies in other countries. Increasing unmet needs have contributed negatively to patients' healthy lifestyle, physical and psychological well-being, and QOL. The high prevalence supports the argument there is a need to develop a PC programme within the HCS, which would likely help enhance the care provided in the future. Patients have a greater need for different services, including physical, and emotional/psychosocial, which should be offered within the HCS, particularly within the routine delivery of cancer care. Additional studies are needed to assess professionals' knowledge of PC and the impact of a psychological intervention programme on patients' health status.

The next chapter will present in detail the second cross-sectional study that aims to assess PC educational needs and HCS-related issues, from the perspective of physicians and nurses.

CHAPTER (8): STUDY TWO-ASSESSMENT OF THE EDUCATIONAL AND HEALTHCARE SYSTEM-RELATED ISSUES OR NEEDS FROM PHYSICIANS AND NURSES: A CROSS-SECTIONAL STUDY

8.1 Introduction

The chapter presents the second cross-sectional study that aimed to assess PC knowledge, attitude, educational needs, and HCS-related issues from physicians' and nurses' perspectives before developing PC services within the HCS. This study was conducted in medical and oncology departments in Gaza hospitals. A detailed study's background, methods, results, discussion, and implication are presented in this chapter. This study is under review in an international peer-reviewed journal (Abu-Odah H, Molassiotis A, and Liu L. Assessment of the educational and healthcare system-related issues from physicians' and nurses' perspectives before developing a PC programme within the Palestinian healthcare system: a cross-sectional study, The Journal of Hospice and Palliative Nursing. 2021). Minor modifications have been applied to the paper regarding citation styles and reference lists to adhere to the structure and guidelines of this doctoral thesis.

8.2 Background

Education of HCPs is considered one of the primary constructs of the WHO public health strategy that offers the best approach for integrating a PC within a HCS at the country level (Stjernsward et al., 2007). According to the World Health Assembly, it is vital to integrate content related to PC into educational programmes (Connor & Sepulveda Bermedo, 2014). It improves HCPs' knowledge, attitudes, and skills, which act as a foundation for improving PC services (Crossetti Mda, 2009). The knowledge and skills gained through formal/academic education should adequately prepare HCPs for their responsibilities in caring for patients (Skår, 2010).

HCPs play a pivotal role in palliative and end-of-life care (EoLC) (Jamison, Rudy, Penzien, & Mosley, 1994). They are responsible for delivering PC services (Das & Haseena, 2015) and developing a care plan to support patients and their families (Karkada, Nayak, & Malathi, 2011). Physicians and nurses are the two leading valuable PC team members responsible for addressing patients’ physical, social, functional, and spiritual aspects of care (Egan & Abbott, 2002). They spend the majority of their time caring for patients (Puntillo & McAdam, 2006), developing a care plan, and actively participating in the decision-making process (Latour, Fulbrook, & Albarran, 2009). Evidence, however, has portrayed unpreparedness or the inability of physicians and nurses to provide appropriate PC, which might be related to educational-related issues such as inadequacies in education, training and negative attitudes of professionals about caring for the dying (Das & Haseena, 2015; Kassa et al., 2014).

Other evidence has demonstrated that HCS-related issues (i.e. unavailability of resources and services) may play a role in the inability of HCPs to deliver appropriate PC services (Goodridge & Duggleby, 2010). For instance, limited physical infrastructure, such as buildings, equipment, supplies, and beds were significant barriers to delivering PC (Donkor et al., 2018). Lack of a comfortable and private space can affect professionals' ability to interact and communicate efficiently with patients and their families (Eijkelenboom & Bluyssen, 2019). Lack of resources also hinders patients from reaching PC services (Ddungu, 2011). Thus, assessment of educational (i.e. knowledge and attitudes) and HCS-related issues (services, resources, barriers to

PC provision) from the perspectives of HCPs are needed to be assessed before developing a PC programme within-country HCS (Abu-Odah et al., 2020, 2021). This information can help evaluate learning needs, refine services, and develop educational intervention programmes for HCPs.

8.3 Factors influencing educational and healthcare system-related issues

The findings from the two reviews (Chapters Three and Four) support that educational (i.e. knowledge and attitudes) and HCS-related issues (services, resources, barriers to PC provision) require assessment before developing a PC programme in HCS at a country level (Abu-Odah et al., 2020, 2021). Each of these factors was highlighted:

8.3.1 Knowledge and attitudes towards palliative care

Professional knowledge and attitudes are the key factors affecting the successful provision of PC services (Abu-Odah et al., 2020; Youssef, Mansour, Al-Zahrani, Ayasreh, & Abd El-Karim, 2015). They determine the skills of professionals and their beliefs while caring for patients (Skår, 2010). Insufficient knowledge and negative attitudes about PC have been reported as significant challenges to the provision of PC services (Abu-Odah et al., 2020; Fadhil et al., 2017; Rochmawati et al., 2016). They interfere with professionals' relationships with patients and with referring patients to services (Schenker et al., 2014; Snyder, Hazelett, Allen, & Radwany, 2012). Understanding HCPs' knowledge and attitudes regarding caring for patients with life-threatening illnesses may significantly influence the quality of services provided (Braun, Gordon, & Uziely, 2010).

Several studies have been conducted to assess HCP knowledge and attitudes about PC. A recent review by Achora and Labrague (2019) analysed 26 studies extracted from five databases, reported a knowledge deficit on the part of nurses and emphasised that nurses' clinical experience influenced their knowledge of PC. Other original studies have been undertaken with the same aims. Shi et al. (2019) assessed the knowledge and attitudes of 132 community HCPs in China about EoLC, utilising the knowledge of EoL questionnaire, Bradly Attitude Questionnaire and the Death Attitude Profile-Revised (DAP-R-C). Findings showed that only 53% of HCPs knew about hospice care, and their knowledge of pain management was inadequate.They also found that years of experiences (more than 11 years) and experiences in dealing with terminally ill-patients were significant positive predictors of attitudes towards EoLC and the care of dying persons. In Vietnam, Vu et al. (2019) assessed the knowledge and attitudes of 124 nurses and 37 physicians about geriatric PC, utilising modified-PC knowledge test and Frommelt Attitudes Towards Nursing Care of the Dying (FATCOD). Results revealed that good knowledge was significantly higher among physicians, participants aged 50 years or above, holding a post-graduate degree, and having more than 10 years of experience. No difference was reported between physicans and nurses with regard to attitudes about PC. In Nigeria, Fadare et al. (2014) assessed 170 medical physicians, nurses, pharmacists, social workers, and clinical psychologists' knowledge ofPC, using a self-developed questionnaire. The results reported that HCPs had good knowledge of the definition and philosophy of PC.

Other studies have focused either on physicians' or nurses' views. For instance, Gu and Cheng (2016) administered a self-constructed questionnaire to 138 Chinese oncologists, and reported insufficient knowledge of PC among study participants. About 72.5% of participants believed that the early integration of PC could enhance patients' QOL. Zeinah et al. (2013a), who administered a self-constructed questionnaire to 42 oncologists in Qatar, identified that most participants (90%)

reported at least some interest in the PC field, while only 57.8% of them said they had self-competence in delivering good PC to dying patients. Alamri (2012) assessed the PC knowledge of 65 physicians at King Abdul-Aziz University Hospital. Findings showed that only 29.2% of physicians had previously received education on PC, and their knowledge regarding opioid use as an essential medication in PC was low. The findings also did not report differences between physicians' demographic characteristics and previous training in PC with their knowledge level. While Iranmanesh et al. (2014b) assessed 116 Iranian intensive and oncology care nurses knowledge about PC using the PC Quiz for Nurses (PCQN). Findings showed that nurses reported a high level of knowledge in the management of pain and symptoms, while the lowest level was in psychosocial and spiritual care. No correlation was reported between knowledge level and nurses' age, gender, educational level, years of experience, and years of experience caring for dying patients. Prem et al. (2012) assessed 363 Indian nurses' PC knowledge using the PC knowledge test (PCKT) and identified low levels of PC knowledge. However, excellent knowledge of psychiatric problems and the philosophy of PC was documented. Findings also revealed no association between knowledge level and gender, work setting, present work experience, and total work experience.

Some previous studies have pointed out insufficient knowledge but positive attitudes towards PC among HCPs (Shi et al., 2019; Vu et al., 2019). Years of experience in caring for dying patients was positively associated with professional knowledge and attitudes (Shi et al., 2019; Vu et al., 2019). However, other studies did not observe any relationship between professionals' characteristics and their knowledge levels (Alamri, 2012; Braun et al., 2010; Iranmanesh et al., 2014b).

While many published papers have documented professionals' knowledge and attitudes, as well as factors influencing their perceptions of PC services, the findings of these papers are inconsistent. The contradictory results may be attributed to the instruments that have been adopted to measure knowledge and attitudes and the targeted group that has been included. For instance, Shi et al. (2019) had limited inclusion criteria only to community HCPs who were less often in contact with patients at an advanced cancer stage (who were usually admitted to hospital), which makes it difficult to represent the perceptions of other HCPs. Although Fadare et al. (2014) covered different healthcare worker groups, the generalisability of these results might be limited because of a low response rate from physicians. Other studies limited their focus to either physicians (Alamri, 2012; Gu & Cheng, 2016) or nurses (Braun et al., 2010; Iranmanesh et al., 2014b). This creates a gap in assessing knowledge and attitudes among physicians and nurses using appropriate and suitable instruments.

8.3.2 Palliative care services resources

Lack of resources and basic physical infrastructure means that patients have no chance to reach and access cancer care and PC services (Ddungu, 2011). The unavailability of resources is a major obstacle to the provision of PC services within the HCS (Goodridge & Duggleby, 2010).

Only two studies have evaluated the availability of PC resources from HCPs perspectives utilising the PC Needs Assessment instrument. Silbermann et al. (2015) identified that most services offered to patients in Middle Eastern countries were pain management consultations, while providing advanced care planning and staff support in caring for the dying was less frequent. The second study conducted in the U.S. by Fink, Oman, Youngwerth, and Bryant (2013) identified that "a contractual relationship with a community hospice to provide such care and having a program to promote advance directive completion" was the main commonly available PC service. The lowest service was in professional PC educational programmes. Both studies also agreed that a lack of community awareness and staff training were the most common barriers to successful PC provision. However, inconsistent findings were reported in the availability of resources, which might be attributed to the variations in country HCS advancement and development levels.

8.4 Gaps in the literature

As presented in the previous sections, several studies have been conducted to assess educational and HCS-related issues; however, a paucity in research conducted in the Middle East was reported, as this region comprises a wide range of economically diverse countries. Some Middle Eastern countries experience financial constraints and low resources, with little or no cancer treatment capabilities (International Monetary Fund, 2016), while others are advanced countries with high-level cancer care provided to communities (Connor & Sepulveda Bermedo, 2014). These countries differ from one another regard to wealth, health insurance coverage, health expenditures, availability of treatment, quality of services, workforce, and availability of PC in the HCS. Further to that, large differences in population size (Asbu, Masri, & Kaissi, 2017), sociocultural factors, and religion play a significant role in deciding the PC approach. There are also differences regarding HCSs concerning professional education, and HCP responsibilities and roles. All of these factors should be considered and collected specifically for countries with no PC introduced into their HCSs.

To the best of our knowledge, no study has been conducted in Palestine, a country that has experienced a significant increase in cancer diagnosis, population density, economic and finance shortage, shortage of drugs, and a fragmented HCS. This study aimed to assess the educational and HCS-related issues that physicians and nurses may face in a country that has not streamlined PC services into its HCSs. This creates a clear gap and raises concerns regarding HCPs' knowledge, attitudes, and skills, as well as resources, and barriers, and how these affect the implementation of PC services. Knowing the gap is vital for developing an intervention to improve the quality of health services provided to cancer patients and provision of PC services into the HCS.

8.5 Aim and objectives

This survey aims to assess PC knowledge, attitudes, educational needs, and HCS-related issues from the perspective of physicians and nurses before the development of PC services within the HCS. The overall aim was achieved by meeting the following specific objectives:

(1) To assess the physicians' and nurses' knowledge of PC.

(2) To explore the physicians' and nurses' attitudes about EoLCand care of the dying.

(3) To assess the needs for educational programs regarding PC from the perspective of physicians and nurses.

(4) To ascertain how far PC services are available in hospitals from the perspectives of physicians and nurses.

(5) To identify the key barriers to the provision of PC into the healthcare system from the perspective of physicians and nurses'

(6) To determine the professionals' variables that influence their knowledge and attitudes towards PC and care of dying.

8.6 Methods

8.6.1 Design

A cross-sectional quantitative study design was adopted. Detailed information about this design is discussed previously in Chapter 7, section study 7.9.1.

8.6.2 Study setting

This study was carried out in the medical and oncology departments at the two leading hospitals in the GS (Al-Shifa Hospital and the EGH), where cancer patients are more likely to be treated and receive follow-up care. Detailed information about the two hospitals is presented in Chapter 7, section study 7.9.2.

8.6.3 Study participants

The study population consisted of physicians and nurses who were working in the medical and oncology departments of the two main hospitals in the GS. The total number of physicians and nurses who were working at the two hospitals, as reported in the latest Palestinian Ministry of Health (2019) report, was 273 HCPs.

8.6.4 Inclusion and exclusion criteria

A convenience sample of physicians and nurses was invited to participate in this study. Participants were eligible if they were working at one of two governmental hospitals (Al-Shifa Hospital and EGH), as these two hospitals provide care to adult cancer patients. Participants who were working at medical and oncology departments where cancer patients are more likely to be treated were included in this study, and follow-up care is provided. Participants who agreed to complete the survey and given written informed consent after provided with full information about the study (Appendix 13 and 14). Physicians and nurses were excluded if they were working at other governmental and non-governmental hospitals because these hospitals do not provide services and care to cancer patients, and were working at other selected departments because HCPs have less contact with cancer patients

8.6.5 Sampling process

The Thompson equation was used for calculating sample size where the population size is well defined (Thompson, 2012, pp. 59-60). The sample size was calculated to be 160 participants. The sample size increased to 176 participants to compensate for non-respondents, where the average non-response rate was reported as 10% in a recent Palestinian study (Samara, Toba, & Zyoud, 2018). The sampling was done proportionally according to each hospital's respective populations (nurses and physicians'). Table 18 presents the representative sample.

$$n = \frac{\mathrm{N} \times p(1-p)}{[[\mathrm{N}-1 \times (\mathrm{d}^2 \div z^2)] + p(1-p)]}$$

Where,		
N	-	Population size (273)
Z	-	Confidence level at 95% (1.96)
d	-	Error proportion (0.05)
p	-	Probability (50%)
n	-	Sample size, which was estimated (= 160)

N: Number of professionals who are working at two assigned hospitals. Z: means that 95% of findings are accurate and close to the truth. d: indicates a margin of error for a sampling proportion which is used to find the accuracy and efficiency of the sample. *P*: standard formula indicating the probability of including a professional in the study is equal.

Table 18: Distribution of physicians and nurses working at both selected hospitals

Hospital	**Al-Shifa Hospital**	**EGH**	**Total**
Total healthcare professionals	163	110	N= 273
Percentage	59.7%	40.3%	100%
Sample size calculation	**105**	**71**	**n=** 160+16=**176**
Physicians	30	21	51
Nurses	75	50	125

EGH: European Gaza Hospital

8.6.6 Instruments to be used in the study

Several survey instruments were utilised in this study and are presented in detail in the next subsection (Appendixes 15-19). The findings generated from scales provide the impetus for resources-allocation and redesign of the services. Permission to use the instruments has been obtained from the original authors (Appendix 20).

8.6.6.1 Knowledge of palliative care

Knowledge is defined as an understanding of the concept of PC, symptom management, medications and any intervention needed for PC (Ross, McDonald, & McGuinness, 1996). The Palliative Care Knowledge Test (PCKT) (Nakazawa et al., 2009) was adopted to assess nurse and physician knowledge of PC. It is a self-administered questionnaire that includes 20 items constructed into five subscales: philosophy (2 items); pain (6 items); dyspnea (4 items); psychiatric problems (4 items); and gastrointestinal problems (4 items). Each item has three answers ("correct", "incorrect", and "unsure"), and each professional should choose one answer. The correct answer was scored one point, while a zero-point score was for an incorrect or unsure answer. The total score for all correct responses is 20 (Nakazawa et al., 2009). The score out of 20 was converted to a percentage, and the higher percentage reflects good knowledge of PC.

8.6.6.2 Attitudes towards end-of-life care and care of dying

Attitudes are defined as a system of beliefs that a person has during his/her life (Massai, Amerini, Borgellini, & Bugnoli, 2007). Two instruments were adopted to comprehensively assess HCP attitudes. The Bradley attitude questionnaire (Bradley et al., 2000) was utilised to assess professionals' attitudes towards EoLC. It is a self-administered questionnaire that included 12 items; most of the items focused on PC's efficacy, with less emphasis on communication and professional responsibility. Each item is ranked into five categories, where scores ranged from 5 (strongly agree) to 1 (strongly disagree). The mean scores were calculated, with a higher mean reflecting a more positive attitude towards end-of-life-care.

The second instrument, Frommelt Attitudes Towards Care of the Dying (FATCOD Form B) Scale (Frommelt, 2003), was adopted to assess the influence of education on the development of HCPs' positive attitudes towards caring for dying patients (Loera, Molinengo, Miniotti, & Leombruni, 2018; Vu et al., 2019). FATCOD scale focused on communication, fear of death, relationships with patients and their families, and active care. It comprises of 30 items divided into two halves (15 items with content on positive attitudes, and 15 items with content on negative attitudes) using a five-point Likert scale. The mean scores were calculated and converted to a percentage, and the higher percentage reflects a more positive attitude toward the care of dying. The combination of these two instruments is expected to provide a more comprehensive view of professionals' attitudes towards PC and issues related to care of the dying.

8.6.6.3 Palliative care services/barriers

The PC Needs Assessment instrument was adopted to assess educational needs, availability of PC related-resources and barriers to the provision of PC into the HCS from physicians' and nurses' perspectives (Fink et al., 2013; Silbermann et al., 2015). It is a comprehensive instrument using both quantitative and open-ended questions, covering the following areas: PC services available, satisfaction with and barriers to PC provision and service delivery, available resources, populations requiring assistance, educational programmes attended in the past two years, and preferred learning methods. All selected instruments' characteristics are presented in Table 19.

8.6.6.4 Sociodemographic and professional characteristics

HCP sociodemographic and professional characteristics may influence their clinical decisions and interactions with patients (Boissoneault et al., 2016). Sociodemographic characteristics included age, gender, professional education (undergraduate, graduate or post-graduate). Health Professionals' variables included profession (physician or nurse), rank/status (Head, sub-head, senior, staff), work setting (medical or oncology), years of experience, previous experience in dealing with patients with advanced illness. Additional items related to PC training included the following questions: Did you receive training related to PC. If yes, what type of training did you receive? How long did you receive this training? Where did you receive the training?

8.6.7 Translation and adaptation of the study instruments

The WHO method was adopted to translate all study instruments' into Arabic (World Health Organisation, 2020c). Translation helps participants understand the items and provide clear answers. The method includes four subsequent steps: forward translation, expert panel back-translation, pre-testing, and final version.

8.6.7.1 Forward translation

The original English versions of the questionnaires were translated into Arabic by a translator who is a nurse working in a cancer department for more than 15 years, holding a master's degree in public health, and at a professional level in speaking and writing English. Detailed instructions in the translation approach were provided to the translator to focus on conceptualisation rather than literal translations, and select words that would be appropriate, simple, clear, concise, and culturally acceptable to patients.

8.6.7.2 Expert panel

A bilingual panel of experts, consisting of the Arabic version translator, two registered nurses, a physician, two nurses holding a PhD in public health, all working within the field of cancer care, as well as a health expert in instrument development and translation, were assigned by the researcher to evaluate the content of the questionnaire’s Arabic version. Each expert was responsible for evaluating each item in terms of language equivalence and content relevance. Language equivalence was evaluated utilising a 4-point rating scale (1= not clear to 4 very clear). The relevance of the content was evaluated using a 4-point rating scale (1= very irrelevant to 4 very relevant).

Based on the panel’s opinion, three questions (Q4, Q6, Q12) of PCKT were excluded because they were not practically applicable to the Palestinian context. For instance, pentazocine was not utilised in Gaza hospitals. The panel also suggested excluding Q15, “Some dying patients will require continuous sedation to alleviate suffering”, as it does not belong to a psychological subscale and does not transfer to belong to a pain subscale. The panel recommended adding more questions to the questionnaire to replace the excluded one. Three new items were added, selected based on previous literature reviews. These items were: 1) “PC is exclusively for people who are in the last six months of life” (Philosophy subscale) (Kozlov, Carpenter, & Rodebaugh, 2017), 2) “PC is specifically for people with cancer” (Philosophy subscale) (Kozlov, Carpenter, et al., 2017), and 3) “When cancer pain is mild, morphine should be used more often” (Pain subscale) (World Health Organisation, 2020d). Thus, the modified version includes 20 items constructed into five subscales: philosophy (4 items), pain (6 items), dyspnea (3 items), psychiatric problems (3 items), and gastrointestinal problems (4 items).

For the Bradley attitude questionnaire (Bradley et al., 2000), the panel suggested excluding the item “Hospice supports physician-assisted suicide” because it is not relevant to the Islamic culture. They also suggested replacing the term “hospice care” with “PC” to fit the study aims. The panel was satisfied with both versions of the FATCOD Scale (Frommelt, 1991, 2003) and the PC needs assessment instrument (Fink et al., 2013) because both were previously utilised in Middle East countries. Preliminary translated and culturally adopted Arabic versions of the questionnaires were completed in this step.

8.6.7.3 Back-translation

The preliminary translated Arabic version was backwards translated into English (original language) by an independent translator who is an expert in English with no knowledge of the original English version of the questionnaires. The translator was instructed to focus on conceptualisation rather than on a literal translation. Two versions (original English version and Arabic version) were assessed and compared by the researcher and expert panel. All were satisfied with the final version and no discrepancies have arisen.

8.6.7.4 Pre-testing

Pre-testing was conducted to test the final Arabic version and data collection procedure before actual data collection (Drennan, 2003). This step aimed to ensure the clarity of questionnaire items, determine whether the questionnaires are understandable, and identify any problem that may lead to response error. Pre-testing was conducted on 15 representative target HCPs (physicians and nurses) who were working in medical departments at EGH. The WHO recommended that the minimum number of participants should be 10 for each section (World Health Organisation, 2020c). The questionnaires were distributed to participants, and each participant was informed that the pretest was a practice run. Each participant was asked three questions related to the questionnaires' items, including 1) "What are your thoughts about what the question was asking?", 2) Could you repeat the question in your own words?", and 3) "What came to mind when you heard a particular phrase?". These three questions were repeated in each item. Participants were asked about any vague, unacceptable, or non-understandable words that they found in the items. They also were asked to give appropriate alternative words for any non-understandable words. This step was supervised by two nurses working at EGH and hold a master's degree in nursing. No comments have risen, and all participants agreed on this version, which was utilised for actual data collection.

8.6.8 Testing validity and reliability

Content validity index is the most widely utilised approach in the report of instrument development (Zamanzadeh et al., 2015). It was adopted to evaluate the content of the Arabic version of the questionnaires. As aforementioned in the previous section, each expert panel was asked to assess the instrument items in terms of clarity and relevancy. Item-level content validity index (I-CVI) and average scale-level content validity index (S-CVI) were the most commonly used indices whose values range from 0 to 1. If the I-CVI value was more than 0.79, it means that the item is relevant, the value ranging between 0.70 and 0.79 means that the item needs revision, and if the value is less than 0.70 it means that item is removed (Zamanzadeh et al., 2015). For S-CVI/Ave and S-CVI-UA, the acceptable value is 0.8 (Waltz, Strickland, & Lenz, 2010). For PC Knowledge Test, 16-items (80%) were marked as relevant. The I-CVI for items Q4, Q6, Q12, and Q15 ranged from 0.42 to 0 and subsequently were excluded. The S-CVI/Ave = 0.83 and the S-CVI-UA = 0.80. Overall, The S-CVI/Ave and S-CVI-UA showed high content validity. Concerning the Bradley Attitude Questionnaire about Care at EoL, 11-items (91.7%) were marked as relevant. Only one item (Q 8) was excluded. The S-CVI/Ave = 0.91 and the S-CVI-UA = 0.91. Overall, the questionnaire showed high content validity. The panel was satisfied with the FATCOD Scale and PC needs assessment instrument. The S-CVI/Ave = 1.00 and the S-CVI-UA = 1.00 (Table 19).

Reliability is concerned with how consistently the measurement technique measures the concept of interest; a measure is considered reliable if it provides the same findings each time the situation is measured (Polit, Beck, & Polit, 2012). Internal consistency (n = 30) was calculated using Cronbach’s alpha coefficient, and results showed acceptable reliability of all instruments (Table 19).

Table 19: Instruments used for assessing physician and nurse perspectives

Name (Acronym) **Purpose**	**Original instrument**		**Modified Arabic version**		**Scoring and interpretation**
	Items and domains	**Validity and reliability**	**Items and domains**	**Validity and reliability**	
Palliative Care Knowledge Test (PCKT) (Nakazawa et al., 2009) Used for measuring the HCPs knowledge regarding PC	20 items covering 5 domains: philosophy (2 items); pain (6 items); dyspnoea (4 items); psychiatric problems (4 items); and gastrointestinal problems (4 items).	Validity A significant difference in the score for each domain Reliability The kappa coefficient was from 0.26 to 0.74 Intraclass correlation was 0.88 The Kuder-Richardson formula was 0.81.	20 items covering 5 domains: philosophy (4 items); pain (6 items); dyspnoea (3 items); psychiatric problems (3 items); and gastrointestinal problems (4 items)	Validity S-CVI/Ave = 0.83 S-CVI-UA = 0.80. Reliability Alpha coefficient was 0.81	The correct answer was scored one point. A total score for all correct responses is 20. Total scores were converted to a percentage, and a higher percentage reflects good knowledge.
The Bradley attitude questionnaire (Bradley et al., 2000) Used for measuring HCPs attitudes toward EoLC	12 items	The overall intraclass r coefficient was 0.86 Weighted kappa coefficients greater than 0.60	11 items	Validity S-CVI/Ave = 0.91 S-CVI-UA = 0.91 Reliability Alpha coefficient was 0.63	Likert scale (1-5) Mean scores. The higher mean reflects a more positive attitude
Frommelt's Attitude Toward Care of the Dying (FATCOD) Scale (Frommelt, 1991, 2003) Used for assessing doctor and nurse attitudes toward caring for terminally ill persons and their families.	30 items 15 items with contents about positive attitudes 15 items with contents about negative attitudes	Validity An inter-rater agreement was 0.98. Reliability: Pearson's Coefficient was a 0.90	No changes	Validity S-CVI/Ave = 1.00 S-CVI-UA = 1.00 Reliability Alpha coefficient was 0.86	Likert scale (1-5) Mean scores converted to a percentage The higher percentage reflects a more positive attitude

Name (Acronym) Purpose	Original instrument		Modified Arabic version		Scoring and interpretation
	Items and domains	Validity and reliability	Items and domains	Validity and reliability	
Palliative care needs assessment instrument (Fink et al., 2013) Used for determining awareness, knowledge, education, barriers, and resources regarding PC services	<u>Seven sections:</u> current PC services; satisfaction with and barriers to PC provision and service delivery; available resources; populations requiring assistance; educational program topics attended in the past two years; and preferred learning methods.	NA	<u>No changes</u>	S-CVI/Ave = 1.00 S-CVI-UA = 1.00 <u>Reliability</u> Alpha coefficient was 0.90	Frequency and percentage of items

8.6.9 Data collection

Self-administered questionnaires were adopted to collect data in the current study. Detailed information about types of survey approaches is discussed in Chapter 7, section study 7.9.8. After obtaining ethical approval, the researcher contacted the various unit heads of departments at both hospitals to coordinate data collection. Each department head was responsible only for recruiting eligible HCPs, gently inviting them to participate in this study, and informing them that participation was voluntary. Then, the researcher delivered the questionnaire pack to the department head and clarified the study participants' eligibility criteria to participants. Heads of departments distributed the questionnaire packs to eligible nurses and physicians. Each pack included a cover letter providing a detailed description of the study (Appendix 13), a consent form (Appendix 14), a questionnaire to collect the participants' socio-demographic characteristics and professional qualifications (Appendix 15), the Palliative Care Knowledge Test (Appendix 16), the Bradley attitude questionnaire (Appendix 17), the Frommelt's Attitude Toward Care of the Dying Scale (Appendix 18), and the PC Needs Assessment Questionnaire (Appendix 19). After two weeks of distributing the questionnaires, a reminder was forwarded to the HCPs. The packs were completed and returned within three weeks in a box that was purposively placed in each department for collecting the questionnaires used for data analysis.

8.6.10 Data entry and analysis

Data were analysed using SPSS software version 25. Descriptive statistics (frequency, percentage, means and standard deviation) were calculated to summarise sociodemographic and professional characteristics as well as instruments and their subscales. Independent sample t-test and ANOVA were utilised to examine differences between professionals’ knowledge and attitudes towards PC with demographic and professionals’ characteristics. All variables with p-value ≤ 0.25 in univariate analysis were selected for a generalised linear regression. A value of 0.25 is based on previous literature (Bendel & Afifi, 1977; Mickey & Greenland, 1989). All statistical tests were two-tailed, and *p* values of less than 0.05 were treated at a significant level. For open-ended responses in the Palliative Care Needs Assessment instrument, qualitative content analysis was adopted to categorise the data based on similarity and difference.

8.6.11 Ethical considerations

Overall ethical considerations were discussed previously in Chapter 7, section study 7.9.10. For this study, as the study participants are HCPs, several criteria were considered to adhere to ethical rules of respect and protection as presented below:

8.6.11.1 The principles of confidentiality and anonymity

In addition to the aforementioned considerations of confidentiality and anonymity in Chapter 7, confidentiality and anonymity are used to protect human privacy during the collection, analysis, and reporting of data (Allen, 2017). In this study, the researcher acknowledged confidentiality and anonymity in that all retrieved data from HCPs were used only for research purposes, and the anonymity of responses was ensured by assigning a code number to each study participant during data entry and analysis.

8.6.11.2 The principles of beneficence and non-maleficence

By analysing HCPs educational issues, knowledge, attitudes, barriers, and curricula, the researcher highlighted professionals' significant needs and concerns about PC. The findings may suggest the future implementation of the educational programme and possible improvements in future. This study in any part was not likely to have the potential to induce a harm or to put the participants at risk.

8.6.11.3 The principle of autonomy and informed consent

Every professional eligible for this study was fully informed that their participation was voluntary, and their refusal to participate in or leave the study at any time would have no negative consequences. Before the decision to participate, professionals were provided with complete information about the study through an informed consent process.

Written informed consent is not usually requested for questionnaire surveys, since completing and returning the questionnaire implies agreement consent (Watson et al., 2008). However, written permission was obtained from each professional after they agreed to take part in the study via the information letter attached with the questionnaire, including the survey purpose, assurance about the confidentiality of the information (Appendix 13), a statement indicating that participation is voluntary, and they could withdraw from the research process at any time (Appendix 14).

8.7 Results

8.7.1 Participant characteristics

Of the 200 questionnaires distributed to all participants, 174 were collected from the locked box. Out of 174 collected questionnaires, five questionnaires were excluded because of significant missing data (more than 30% of questions were missed). A total of 169 participants were included in the final analysis, with a response rate of 87%. Descriptive statistics for the participants are displayed in Table 20. Most participants (n=137, 81.1%) were nurses with ages ranging between 21 and 57 years, and a mean age of 31.68±7.24 years. More than half of nurses (n = 80, 58.4%) were male, and almost all (n = 94, 68.6%) held a bachelor’s degree. The majority of nurses (n=118, 86.1%) did not have an administrative position. The total years of working experience ranged from one and 30 years, with a mean year of 7.39±5.64. While the present (at the current department) work experience ranged from one and 26 years, with a mean of 5.73±4.80 years. Only 9.5% of nurses had previous PC training. The majority (99.4%) attended general PC training; the training period ranged from two days and four months.

Of 51 questionnaires distributed to physicians, 32 physicians responded, with a response rate of 62.7%. Their ages ranged from 27 and 49 years, with a mean of 38±8 years. The majority of participating physicians were female (n = 24, 75%). Their work experience ranged between one and 16 years, with a mean of 8.37±5.02 years, while their present (at the current department) work experience ranged from one to16 years, with a mean of 7.91±5.27 years. None of the physicians had participated in any PC training course (Table 20).

Table 20: Participant characteristics (N=169)

Characteristics	**Total** **N=169**	**Physicians** **n = 32 (18.9%)**	**Nurses** **n = 137 (81.1%)**
	No. (%)	No. (%)	No. (%)
Gender			
Male	88 (52.1%)	8 (25.0%)	80 (58.4%)
Female	81 (47.9%)	24 (75.0%)	57 (41.6%)
Age[a] (mean±SD)	32.87±7.77	38.00±8.00	31.68±7.24
20-30	62 (40.3%)	6 (20.7%)	56 (44.8%)
30-39	63 (40.9%)	11 (37.9%)	52 (61.6%)
≥ 40	29 (18.8%)	12 (41.4%)	17 (13.6%)
Educational level			
Diploma or less	34 (20.1%)	2 (6.2%)	32 (23.4%)
Bachelor	105 (62.1%)	11 (34.4%)	94 (68.6%)
Postgraduate[b]	30 (17.8%)	19 (59.4%)	11 (8.0%)
Professional Status			
Head	13 (7.7%)	6 (18.8%)	7 (5.1%)
Sub-head	13 (7.7%)	6 (18.8%)	7 (5.1%)
Senior	6 (3.6%)	1 (3.0%)	5 (3.7%)
Staff	137 (81.1%)	19 (59.4%)	118 (86.1%)
Work setting/Clinical area			
Medical departments	81 (47.9%)	11 (34.4%)	70 (51.1%)
Oncology/Haematology departments	88 (52.1%)	21 (65.6%)	67 (48.9%)
Hospital			
Al-Shifa Hospital	103 (60.9%)	25 (78.1%)	78 (56.9%)
European Gaza Hospital	66 (39.1%)	7 (21.9%)	59 (43.1%)
Total years of working experience	7.57±5.53	8.37±5.02	7.39±5.64
< 5	77 (45.6%)	12 (37.5%)	65 (47.4%)
≥ 5	92 (54.4%)	20 (62.5%)	72 (52.6%)
Years of experience in the department	6.14±4.95	7.91±5.27	5.73±4.80
< 5	99 (58.6%)	15 (46.9%)	84 (61.3%)
≥ 5	70 (41.4%)	17 (53.1%)	53 (83.7%)
<u>Palliative care-related issues</u>			
History of PC training			
Yes	16 (9.5)	0 (0)	16 (11.7)
No	153 (90.5)	32 (100)	121 (88.3)

[a] Missing data 26.0%.
[b] Comprises Master or PhD or clinical Board

8.7.2 Healthcare professional knowledge of palliative care

The Palliative Care Knowledge Test (PCKT) was adopted to assess nurses' and physicians' knowledge of PC. Results showed that the overall knowledge score was 42.8±11.02, indicating that HCPs had insufficient knowledge about PC. Despite the lower overall score, the philosophy subscale reported the highest score (62.42±25.60). The lowest score of < 50 was observed in four out of five PCKT subscales. The differences between physicians and nurses are highlighted in Table 21.

Table 21: Healthcare professionals' knowledge of palliative care (n=169)

Knowledge domains (0-100)	**Total**	**Physicians**	**Nurses**
	Mean±SD	Mean±SD	Mean±SD
Philosophy	62.42±25.60	55.46±22.66	64.05±26.05
Pain	40.03±16.99	34.37±16.36	41.36±16.92
Dyspnoea	32.34±26.08	47.91±20.63	28.71±25.94
Psychological problems	41.81±27.22	40.62±26.41	42.09±27.49
Gastrointestinal problems	36.24±23.60	39.84±19.93	35.40±24.37
Total score	42.86±11.02	42.65±7.06	42.91±91

SD: Standard Deviation.

For participants' responses toward PCKT items, their correctly answered items ranged from 23.66% to 71.59%. The lowest scored correct items were observed in the pain subscale, including "Use of opioids does not influence survival time" (23.66%). Only 24.26% disagreed that long-term use of opioids can often induce addiction, and 27.81% disagreed with the statement, "When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used".

In the dyspnea subscale, the lowest knowledge item was in "Oxygen saturation levels are not correlated with dyspnea" (26.03%). In the gastrointestinal problems subscale, the lowest knowledge was reported in the item, "There is no route except central venous for patients unable to maintain a peripheral intravenous route" (26.62%), followed by the item, "At terminal stages of cancer, higher calorie intake is needed compared to early stages." (29.58%). Table 22 presents participants' responses to the PCKT items.

Table 22: Responses of professionals in The Palliative Care Knowledge Test subscales (n=169)

Subscales	Questions	Responses			% correct responses (Item-specific)
		Correct	Incorrect	Unsure	
Philosophy	Palliative care should only be provided for patients who have no curative treatments available.	52	99*	18	58.57%
	Palliative care is exclusively for people who are in the last six months of life	53	94*	22	55.62%
	Palliative care should not be provided along with anti-cancer treatments.	17	118*	34	69.82%
	Palliative care is specifically for people with cancer	22	111*	36	65.68%
Pain	One of the goals of pain management is to get a good night's sleep.	121*	29	19	71.59%
	When cancer pain is mild, morphine should be used more often.	93	53*	23	31.36%
	When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used.	51	47*	71	27.81%
	Long-term use of opioids can often induce addiction.	107	41*	21	24.26%
	Use of opioids does not influence survival time.	40*	95	34	23.66%
	Some dying patients require continuous sedation to alleviate suffering.	104*	43	22	61.53%
Dyspnoea	Morphine should be used to relieve dyspnoea in cancer patients.	73*	62	34	43.19%
	When opioids are taken on a regular basis, respiratory depression will common.	81	47*	41	27.81%
	Oxygen saturation levels are correlated with dyspnoea.	90	44*	35	26.03%
Psychiatric problems	During the last days of life, drowsiness associated with electrolyte imbalance should decrease patient discomfort.	81*	41	47	47.92%
	Benzodiazepines should be effective for controlling delirium.	82*	33	54	48.52%
	Morphine is often a cause of delirium in terminally ill cancer patients.	85	49*	35	28.99%
Gastrointestinal problems	At terminal stages of cancer, higher calorie intake is needed compared to early stages.	71	50*	48	29.58%
	There is no route except central venous for patients unable to maintain a peripheral intravenous route.	101	45*	23	26.62%
	Steroids should improve appetite among patients with advanced cancer.	75*	51	43	44.37%
	Intravenous infusion will not be effective for alleviating dry mouth in dying patients.	75*	61	33	44.37%

* Indicates the number of responses used for scoring (correct answer)

8.7.3 Healthcare professional attitudes towards end-of-life and care of dying

Two scales were adopted to assess HCPs' attitudes toward EoLC and care of dying persons. The Bradley Attitude Questionnaire was adopted to assess attitudes towards EoLC. The total score of attitudes was 3.31±0.38, reflecting that HCPs had positive attitudes toward EoLC (Table 32).

In terms of HCP responses towards EoL items, more than half of professionals (58.6%) disagree or strongly disagree that they felt like a failure when their patients received PC. About 64.5% disagree or strongly disagree that they did not have a role in PC. More than one-third of HCPs (37.8%) disagree or strongly disagree that they were uncomfortable discussing the option of PC with patients and their families. On the other hand, the majority of HCPs (69.2%) agree or strongly agree that most elderly patients did not want to be notified if they were dying. A quarter of HCPs (23.7%) agreed or strongly agreed it was important to tell patients that curative treatment was no longer successful as soon as they knew.

Table 23: Healthcare professionals' responses towards end-of-life (n=169) "Bradley Scale."

Question item	**Strongly agree /agree No. (%)**	**Neither agree nor disagree No. (%)**	**Disagree/strongly disagree No. (%)**	**Mean± SD**
Q1. Most of my physician (nurse) colleagues feel that when their patients receive PC, it reflects their own failure. *	18 (10.7)	52 (30.8)	99 (58.6)	3.68±0.92
Q2. Many of my physician (nurse) colleagues are uncomfortable discussing the option of PC with patients and their families *	55 (32.6)	50 (29.6)	64 (37.8)	3.13±1.07
Q3. Physicians do not have a role in PC. *	39 (23.1)	21 (12.4)	109 (64.5)	3.65±1.14
Q4. Most elderly patients who are dying want their doctors to determine what care is best for them.	115 (68.1)	27 (16.0)	27 (16.0)	3.52±1.02
Q5. Palliative care generally meets the needs of the family better than conventional care does.	92 (54.5)	46 (27.2)	31 (18.3)	3.41±0.98
Q6. An interdisciplinary team approach interferes with patient care. *	25 (14.8)	75 (44.4)	69 (40.8)	3.30±0.90
Q7. I feel knowledgeable enough to discuss PC with patients and families.	73 (43.2)	57 (33.7)	39 (23.0)	3.18±0.93
Q8. Most patients' symptoms, such as pain, shortness of breath, and nausea, are not controlled any better with PC than with conventional care they would otherwise receive. *	81 (47.9)	44 (26.0)	44 (26.0)	2.76±1.04
Q9. I usually order (request) as much pain medication as needed to keep terminally ill patients pain free.	100 (59.2)	36 (21.3)	33 (19.6)	3.43±0.96
Q10. I usually tell patients that curative treatment is no longer successful as soon as I know.	40 (23.7)	37 (21.9)	92 (54.4)	2.62±1.12
Q11. Most elderly patients do not want to be told they are dying.	117 (69.2)	23 (13.6)	29 (17.2)	3.72±1.16
Total score				3.31±0.38

* Indicates a reversed question (strongly disagree was coded as five).

The Frommelt Attitudes Towards Care of the Dying (FATCOD Form B) Scale was utilised to assess the attitudes of HCPs towards care of the dying. The total score of attitudes was 3.14±0.30, reflecting that HCPs had positive attitudes toward the care of the dying. Nurses had higher scores in attitude towards the care of dying than physicians (3.18±0.30; 2.96±0.19, *p-value* < 0.001 respectively).

Responses of HCPs to the self-rated attitudes items showed the majority of HCPs (82.2%) agree or strongly agree that PC was provided to dying patients. Around three-quarters of HCPs (74.0%) agree or strongly agree to involve the family in the physical care of dying patients if they wanted to. About 69.3% agree or strongly agree to provide flexible vising schedules for the caregivers of dying persons, and more than half of HCPs (53.8%) agree or strongly agree that death was not the worst thing that can happen to a person. On the other hand, more than half of HCPs (56.8%) were uncomfortable talking about impending death with the dying person, and 42.6% of HCPs did not want to care for dying persons. More than half of HCPs (53.2%) were afraid to become friends with a dying person. Detailed HCPs' responses about caring for the dying are presented in Table 24.

Table 24: Self-rated attitude responses of participants assessed on care of dying (n=169) "Frommelt scale"

Question item	Strongly agree No. (%)	Agree No. (%)	Uncertain No. (%)	Disagree No. (%)	Strongly disagree No. (%)	Mean± SD	Weighted mean (%) [a]
Q1. Giving care to the dying person is a worthwhile experience.	22 (13)	117 (69.2)	15 (8.9)	11 (6.5)	4 (2.4)	3.84±0.81	76.78
Q2. Death is not the worst thing that can happen to a person.	8 (4.7)	83 (49.1)	27 (16.0)	29 (17.2)	22 (13)	3.15±1.16	63.03
Q3. I would be uncomfortable talking about impending death with the dying person. *	12 (7.1)	84 (49.7)	28 (16.6)	37 (21.9)	8 (4.7)	2.67±1.04	53.48
Q4. Caring for the patient's family should continue throughout the period of grief and bereavement.	20 (11.8)	95 (56.2)	37 (21.9)	14(8.3)	3 (1.8)	3.68±0.85	73.58
Q5. I would not want to care for a dying person. *	20 (11.8)	52 (30.8)	22 (13.0)	51 (30.2)	24 (14.2)	3.04±1.28	60.84
Q6. The non-family caregivers should not be the one to talk about death with the dying person. *	28 (16.6)	75 (44.4)	33 (19.5)	28 (16.6)	5 (3.0)	2.44±1.0	49.06
Q7. The length of time required to give care to a dying person would frustrate me. *	16 (9.5)	57 (33.7)	33 (19.5)	52 (30.8)	11 (6.5)	2.91±1.13	58.22
Q8. I would be upset when the dying person I was caring for, gave up hope of getting better. *	20(11.8)	91 (53.8)	34 (20.1)	23 (13.6)	1(0.6)	2.37±0.88	47.42
Q9. It is difficult to form a close relationship with the dying person. *	20 (11.8)	52 (30.8)	45 (26.6)	48 (28.4)	4 (2.4)	2.78±1.05	55.76
Q10. There are times when death is welcomed by the dying person.	23 (13.6)	62 (36.7)	54 (32.0)	25 (14.8)	5 (3.0)	3.43±0.99	68.68
Q11. When a patient asks, "Am I dying?", I think it is best to change the subject to something cheerful. *	22 (13.0)	91 (53.8)	31 (18.3)	24 (14.2)	1 (0.6)	2.35±0.90	47.06
Q12. The family should be involved in the physical care of the dying person if they want to.	40 (23.7)	85 (50.3)	23(13.6)	18 (10.7)	3 (1.8)	3.83±0.96	76.74
Q13. I would hope the person I'm caring for dies when I am not present. *	43 (25.4)	46 (27.2)	33 (19.5)	39 (23.1)	8 (4.7)	2.54±1.22	50.84
Q14. I am afraid to become friends with a dying person. *	35 (20.7)	55 (32.5)	36 (21.3)	35 (20.7)	8 (4.7)	2.56±1.16	51.18
Q15. I would feel like running away when the person actually died. *	11(6.5)	51 (30.2)	33 (19.5)	49 (29.0)	25 (14.8)	3.15±1.19	63.08
Q16. Families need emotional support to accept the behaviour changes of the dying person.	26 (15.4)	91 (53.8)	37 (21.9)	13 (7.7)	2 (1.2)	3.74±0.85	74.90
Q17. As a patient nears death, the non-family caregiver should withdraw from his/her involvement with the patient. *	11 (6.5)	42 (24.9)	38 (22.5)	57 (33.7)	21 (12.4)	3.20±1.14	64.12

Question item	Strongly agree No. (%)	Agree No. (%)	Uncertain No. (%)	Disagree No. (%)	Strongly disagree No. (%)	Mean± SD	Weighted mean (%) [a]
Q18. Families should be concerned about helping their dying member make the best of his/her remaining life.	31 (18.3)	77 (45.6)	32 (18.9)	23 (13.6)	6 (3.6)	3.61±1.04	72.28
Q19. The dying person should not be allowed to make decisions about his/her physical care. *	5 (3.0)	64 (37.9)	37 (21.9)	45 (26.6)	18 (10.7)	3.04±1.09	60.88
Q20. Families should maintain as normal an environment as possible for their dying member.	47 (27.8)	74 (43.8)	28 (16.6)	15 (8.9)	5 (3.0)	3.84±1.02	76.96
Q21. It is beneficial for the dying person to verbalise his/her feelings.	28 (16.6)	93 (55.0)	23 (13.6)	14 (8.3)	11 (6.5)	3.66±1.05	73.38
Q22. Care should extend to the family of the dying person.	24 (14.2)	93 (55.0)	30 (17.8)	19 (11.2)	3 (1.8)	3.68±0.91	73.72
Q23. Caregivers should permit dying persons to have flexible visiting schedules.	30 (17.8)	87 (51.5)	37 (21.9)	13 (7.7)	2 (1.2)	3.76±0.87	75.46
Q24. The dying person and his/her family should be the in-charge decision makers.	25 (14.8)	70 (41.4)	52 (30.8)	19 (11.2)	3 (1.8)	3.56±0.93	71.24
Q25. Addiction to pain relieving medication should not be a concern when dealing with a dying person.	25 (14.8)	73 (43.2)	37 (21.9)	28 (16.6)	6 (3.6)	3.49±1.04	69.86
Q26. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying. *	25 (14.8)	67 (39.6)	37 (21.9)	33 (19.5)	7 (4.1)	2.58±1.08	51.64
Q27. Dying persons should be given honest answers about their condition.	29 (17.2)	71 (42)	46 (27.2)	20 (11.8)	3 (1.8)	3.60±0.96	72.20
Q28. Educating families about death and dying is not a non-family caregiver's responsibility. *	19 (11.2)	44 (26)	50 (29.6)	46 (27.2)	10 (5.9)	2.90±1.10	58.06
Q29. Family members who stay close to a dying person often interfere with the professionals' job with the patient. *	36 (21.3)	66 (39.1)	34 (20.1)	29 (17.2)	4 (2.4)	2.40±1.07	48.12
Q30. It is possible for non-family caregivers to help patients prepare for death. *	20 (11.8)	82 (48.5)	40 (23.7)	23 (13.6)	4 (2.4)	2.46±0.95	49.26
Total Frommelt score						3.14±0.30	62.8%

* Indicates a reversed question (strongly disagree was coded as five).

[a] Weighted mean is calculated by multiplying the percentage of responses in each category (strongly disagree – strongly agree) by its respective score (1-5), adding up these products and dividing by 5.

8.7.4 Educational needs and healthcare system-related issues

8.7.4.1 Educational needs

The Palliative Care Needs Assessment instrument was adopted to assess the needs of education, perception of availability of PC related-resources, and barriers to the provision of PC into the HCS. Results revealed that 75.1% of HCPs wished to learn more about PC. Less than half of HCPs recalled attending an educational programme related to PC. For instance, 45% of HCPs attended a symptom management programme, and about 43.8% of respondents reported that they attended pain management, communication skills (e.g., goals of care discussion, family meetings, breaking bad news), and care for the caregivers. Only 28.4% had attended the EoLC programme (Table 25).

Respondents identified various preferred methods to learn more about PC, approximately 80% of participants preferred attending professional meetings or workshops, bringing in PC consultants, taking an intensive course on PC, taking certification courses, or integrating the PC information into nursing or medical academic programmes, and about 68% of respondents favoured web-based learning.

Table 25: Educational programme attended over the last two years

Attendance in an educational programme on any of the following topics in your work setting over the past two years	**No n (%)**	**Yes n (%)**
Symptom management	93 (55)	76 (45)
Pain management	95 (56.2)	74 (43.8)
Communications skills (e.g., goals of care discussion, family meetings, breaking bad news)	95 (56.2)	74 (43.8)
Care for the caregivers – healthcare professionals	97 (57.7)	71 (42.3)
Discharge planning for patients with chronic illness	101 (60.1)	67 (39.9)
Ethics issues at the end of life	107 (63.3)	62 (36.7)
Care for the caregivers – family and friends	107 (63.3)	62 (36.7)
Community health resources	112 (66.3)	57 (33.7)
How to use online resources available (e.g., health information system used in your institution, search engines, e-library)	116 (68.6)	53 (31.4)
End of life care	121 (71.6)	48 (28.4)
The preferred methods to learn more about PC	**No n (%)**	**Yes n (%)**
Bringing in a PC consultant	34(20.1)	135(79.9)
Attending a professional meeting or workshop where this is a topic	36(21.3)	133(78.7)
Taking a physician or nurse certification course on PC with continuing education credits	38(22.5)	131(77.5)
Taking an intensive course on PC	39(23.1)	130(76.9)
Participating in web-based learning (course, self-study module) on PC	53(31.4)	116(68.6)
Partnership with local hospice or home care providers	55(32.5)	114(67.5)
Partnership with academic (teaching/university hospital), if available	68(40.2)	101(59.8)
Integrating PC information into nursing or medical academic programs	38(22.5)	131(77.5)

8.7.4.2 Healthcare system-related issues

8.7.4.2.1 Availability of palliative care services in study settings

The results displayed that the most common existing PC service offered was discharge planning for patients with chronic illness (48.5%), ethics committee (45.6%), and quality improvement for pain and symptoms management (42.6%). In contrast, programmes of bereavement (21.9%), interdisciplinary care for dying patients (25.4%), and programmes for staff support in caring for dying patients (28.9%) were the least available services in their settings. A detailed description of existing PC services is presented in Table 26.

Table 26: Palliative care services available in the setting

Existing services	n	%
Discharge planning for patients with chronic illness	82	48.5%
Ethics committee	77	45.6%
Quality improvement for pain management	72	42.6%
Quality improvement for symptom management	72	42.6%
Program to promote advance care planning (advance directives)	65	38.5%
Palliative care team or consult service	61	36.1%
Communication among healthcare team related to PC	61	36.1%
Pain management consultative team or service	58	34.3%
Physicians who are certified in hospice and palliative medicine	58	34.7%
Palliative care unit	57	33.7%
Access to PC resources outside of your hospital	57	33.7%
Nurses who are certified in hospice and palliative nursing	54	32.0%
Professional education program on PC	52	30.8%
Contractual relationship with a hospice or home care program	50	29.6%
Quality improvement for end-of-life-care	50	29.6%
Program for staff support in caring for dying patients	49	28.9%
Interdisciplinary care program for dying patients	43	25.4%
Bereavement programme	37	21.9%

8.7.4.2.2 Palliative care satisfaction and barriers

Concerning PC delivery, more than half of respondents (n = 100, 59.2%) were satisfied with the religious and spiritual care provided to patients. They were also satisfied with pain (n = 89, 52.7%) and symptoms management (n = 86, 50.9%) services. On the other hand, more than half of the HCPs reported that advance directives were not addressed in their setting. They were also dissatisfied with the discharge plan provided to patients.

Concerning barriers to the provision of PC, findings revealed that the top five barriers were patients'/families' avoidance of discussing issues around dying (n = 154, 91.1%) lack of training for staff related to PC (n = 151, 89.3%), lack of designated beds for PC services (n = 146, 86.4%), limited community awareness related to PC (n = 145, 85.8%), and lack of PC knowledge on the part of HCPs (n = 144, 85.2%).

Communication difficulties between HCPs, patients, and/or families were the least perceived barrier. An extensive list of possible barriers to providing PC is rated in Table 27.

Table 27: Barriers to the provision of palliative care

Rank	Possible barriers to providing palliative care	n (%)
1	Patients'/families' avoidance of issues around dying	154 (91.1)
2	Lack of training for staff related to PC	151(89.3)
3	Lack of designated beds for PC services	146 (86.4)
4	Lack of community awareness related to PC	145 (85.8)
5	Lack of knowledge about PC by health care professionals	144 (85.2)
6	Lack of home care availability	142 (84)
7	Lack or inadequacy of written policies and procedures about PC	140 (82.8)
8	Lack of volunteers in community	140 (82.8)
9	Lack of policy and guidance availability	140 (82.8)
10	Cultural, religious, and/or spiritual beliefs influencing end-of-life care	138 (81.7)
11	Patients'/families' fear of addiction to pain medications	138 (81.7)
12	Personnel shortages/time constraints	138 (81.7)
13	Lack of access to hospice services	137 (81.1)
14	Improper communication among interdisciplinary team	137 (81.1)
15	Professionals' fear of causing addiction by administering pain medications	135 (79.9)
16	Differences in opinion among health care professionals about PC	135 (79.9)
17	Fear of legal action by leadership or government	133 (78.7)
18	Lack of student nurse interest related to PC	133 (78.7)
19	Health care professionals' personal discomfort with death	130 (76.9)
20	The patient/family is not part of the decision-making process	129 (76.3)
21	Lack availability of medications/opioids (narcotics)	128 (75.7)
22	Communication difficulties among health care professionals, patients, and/or families	126 (74.6)

8.7.5 Factors associated with professionals' knowledge and attitudes towards palliative care

Only professionals' educational level (F = 5.02, *P* = 0.008) and previous training in PC (t = 2.39, *P* = 0.008) had a significant association with knowledge of PC (Table 28). Attitudes about EoLC were significantly higher among HCPs who had a head position (F = 2.78, *P* = 0.040), and who had previous training in PC (t = -3.21, *P* = 0.002). Moreover, significant differences in positive attitudes about care of the dying were reported in nurses (t = -4.98, *P* = < 0.001), professionals younger than 30 years (F = 6.65, *P* = 0.002), who ranked as a staff member (F = 63.00, *P* = 0.032), who worked in a medical department (t = 3.32, *P* = 0.001), and who had fewer than five years' work experience (t = 2.36, *P* = 0.001).

Table 28: Univariate analysis of professionals' characteristics that influence their knowledge and attitudes

	Knowledge about palliative care			**Attitudes About care at End-of-life**			**Attitudes toward Dying care**		
Variables	**Mean (±SD)**		***P***	**Mean (±SD)**		***P***	**Mean (±SD)**		***P***
Profession			0.870			0.24			<0.001
Physician	42.65	7.06		63.18	6.53		59.37	3.99	
Nurse	42.91	11.78		64.67	6.46		63.75	6.15	
Age			0.86			0.44			0.002*
< 30 years	43.95	10.12		64.94	5.61		65.37	5.21	
30-39 years	43.01	12.39		63.52	7.06		61.91	6.54	
≥40 years	42.93	9.21		64.76	7.62		61.74	5.59	
Gender			0.65			0.91			0.14
Male	43.23	11.37		64.44	6.74		63.57	6.92	
Female	42.46	10.69		64.33	6.22		62.22	4.86	
Education			0.008*			0.65			0.57
Diploma or less	37.79	13.66		63.47	6.24		63.39	6.00	
Bachelor	43.76	10.20		64.64	6.33		63.06	5.98	
Master/PhD	45.50	8.84		64.54	7.33		61.91	6.36	
Professionals' rank			0.66			0.040*			0.032*
Head	45.38	10.09		66.85	10.18		60.51	6.74	
Sub-head	40.76	9.31		65.87	7.82		60.76	4.58	
Senior	45.83	8.01		58.18	7.79		58.33	4.67	
Staff	42.70	11.39		64.28	5.71		63.56	6.00	
Working setting			0.86			0.37			0.001*
Medical departments	43.02	10.94		64.49	6.19		64.49	6.27	
Oncology	42.72	11.16		63.96	6.74		61.48	5.46	
Duration of the total work experience			0.28			0.56			
< 5 years	41.88	11.15		64.69	5.53		64.11	5.57	0.001*
≥ 5 years	43.69	10.91		64.13	7.19		61.93	6.13	
Duration of present work experience			0.06			0.61			0.38
< 5 years	41.56	11.05		64.50	5.78		63.26	5.91	
≥ 5 years	44.71	10.79		64.07	7.38		62.44	6.23	
Previous training in palliative care			0.001*			0.002*			0.69
Yes	49.06	11.28		69.09	8.13		63.50	5.78	
No	42.22	10.93		63.89	6.11		62.86	6.08	

[a] Statistical testing using Independent Sample t test or Analysis of Variance (ANOVA).

* Difference is significant at the 0.05 level (2-tailed).

8.7.6 Independent predictors associated with professionals’ knowledge and attitudes

The findings in generalised linear regression (Table 29) showed that educational level (β = -7.44; *p* value = 0.006) and previous training in PC (β = 6.91; *p* value = 0.013) were independently associated with professional’s knowledge of PC.

Professionals’ rank (β = -5.79; *p* value = 0.024) and previous training in PC (β = 4.14; *p* value = 0.016) were independently associated with attitudes about EoLC. Independent associations were also reported between profession/discipline (β = -6.15; *p* value = 0.031) and working setting (β = 2.57; *p* value = 0.005) with attitudes towards care of the dying.

Table 29: Generalised linear regression model for factors associated with professionals’ knowledge and attitudes towards palliative care

Domain	Variable	β	SE	95% CI	Wald	*P*
Knowledge of PC	Education					
	Diploma or less	-7.44	2.72	-12.79- -2.10	7.45	0.006*
	Bachelor	-1.55	2.21	-589-2.78	0.49	0.482
	Master/PhD	Ref	-	-	-	-
	Duration of present work experience	0.25	0.45	-0.65-1.15	0.17	0.582
	< 5 years	-1.41	1.71	-4.78-1.94	0.68	0.409
	≥ 5 years	Ref	-	-	-	-
	Previous training in PC					
	Yes	6.91	2.78	1.46-12.37	6.18	0.013*
	No	Ref	-	-	-	-
Attitudes about care at end-of-life	Profession					
	Physician	-1.50	1.30	-4.05-1.05	1.32	0.249
	Nurse	Ref	-	-	-	-
	Professionals’ rank					
	Head	2.36	1.86	-1.30-6.03	1.60	0.206
	Sub-head	1.06	1.90	-2.66-4.79	0.314	0.575
	Senior	-5.79	2.56	-10.81—0.76	5.09	0.024*
	Staff	Ref	-	-	-	-
	Previous training in					

Domain	**Variable**	**β**	**SE**	**95% CI**	**Wald**	***P***
	Yes	4.14	1.72	0.77-7.54	5.79	0.016*
	No	Ref	-	-	-	-
Attitudes towards Dying care	Profession					
	Physician	-3.38	1.25	-5.84—0.91	7.20	0.007*
	Nurse	Ref	-	-	-	-
	Age					
	< 30 years	1.13	1.90	-2.60-4.86	0.35	0.552
	30-39 years	-1.30	1.39	-4.02-1.42	0.87	0.350
	≥40 years	Ref	-	-	-	-
	Gender					
	Male	0.65	0.93	-1.17-2.48	0.49	0.481
	Female	Ref	-	-	-	-
	Professional rank					
	Head	-8.70	1.91	-4.61-2.87	0.20	0.649
	Sub-head	-1.24	1.91	-4.99-2.52	0.42	0.516
	Senior	-2.75	2.83	-8.31-2.80	0.94	0.332
	Staff	Ref	-	-	-	-
	Working setting					
	Medical	2.57	0.92	0.76-4.38	7.76	0.005*
	Oncology	Ref	-	-	-	-
	Duration of the total work experience					
	< 5 years	0.11	1.36	-2.55-2.77	0.00	0.935
	≥ 5 years					

* Difference is significant at the 0.05 level

8.7.7 Qualitative part

Existing palliative care activities, available resources, and motivation

Out of 169 professionals included in this study, 99 professionals responded to the open-ended question, "What would make it possible for you and your staff to attend a PC class or course?"; 55% reported that the main motivator was the need to learn more about PC and getting a certificate in this aspect, whereas approximately 42% were motivated by improving their skills to alleviate patients' complications.

Further, 80 professionals replied to the question "What your setting is doing well to provide PC"; approximately, 44% of them reported that his/her setting did not do any activities to provide PC, whereas, around half stated planning and workshops for patients and their families, in addition to creating a PC team. When asked about existing resources that could help to improve PC, half referred to NGO support and availability of certain logistics, and roughly 19% reported nothing (Table 30).

Table 30: Existing palliative care activities, available resources, and motivation

Question Item	Answer n(%)
What would make it possible for you or your staff to attend a PC class or course?	
Improve my skills to reduce the patients' complications	
The need for learning more about PC and to get certificate	42(42.4)
Gain money	55(55.6)
I do not have any motivation	1(1)
	1(1)
What your setting is doing well to provide PC?	
Nothing	35(43.8)
Planning	19(23.8)
Do not know	5(6.3)
Provide some financial support	1(1.3)
Workshops for patients and their family and create a PC team	18(22.5)
Only psychotherapy	2(2.5)
What resources exist in your setting and community that could be used to help improve PC?	
People and staff alone	14(17.5)
Some community resources with the staff	6(7.5)
Some NGOs support	22(27.5)
Nothing	15(18.7)
All resources are available	4(5)
Some logistics	18(22.5)
I do not know	1(1.3)

8.8 Discussion

This is the first study conducted in Palestine to assess educational and HCS-related issues from the perspective of physicians and nurses. Although nurses and physicians had reported insufficient knowledge of PC, their attitudes toward EoLC and care of dying patients were positive. The majority of professionals showed their interest to learn more about PC. Findings also revealed that discharge planning for patients with chronic illness was the common PC service available in both hospitals. The unwillingness of patients'/families' to discuss death and a lack of training for staff related to PC were the common barriers in providing PC in Gaza, as reported by professionals. Educational level and previous PC training were independently associated with HCPs' knowledge and attitudes towards PC.

Palestine is ranked by the WHO at the level of"capacity building activity-countries" with initiative designed to create a workforce, organisational and policy capacity for PC development (Connor & Sepulveda Bermedo, 2014), but no services have yet been integrated into their HCS (Abu Hamad et al., 2016). Despite these initiative activities, the majority of Palestinian nurses and physicians reported significantly lower knowledge of the principle of PC. This result is in line with previous studies conducted in Palestine (Ayed et al., 2015), Vietnam (Vu et al., 2019), and Thailand (Budkaew & Chumworathayi, 2013). However, in contradiction with observations in countries with PC integration, such as Saudi Arabia (Al-Drees et al., 2019) and China (Shi et al., 2019), their knowledge ranged between 53%-54%, compared with 42% in this study.

Nurses and physicians reported a high level of knowledge in PC philosophy. Several previous studies have demonstrated the same result (Fadare et al., 2014; Sato et al., 2014; Vu et al., 2019). A high level in philosophy attributed to fundamental items belongs to this aspect which focused on definition and targeted population, which makes it easier for professionals to remember and answer items correctly (Vu et al., 2019). On the other hand, remarkably lower scores in dyspnea, psychiatric, gastrointestinal, and pain aspects were observed in this study. The lower level might be caused by a lack of training in PC (Sato et al., 2014; Vu et al., 2019) and a short training period that can influence the quality of training materials delivered to participants.

Our results revealed that significant differences in overall PC knowledge were favoured for those who had had previous training and had completed a higher educational level. Iranmanesh et al. (2014b) reported the significant contribution of continuous training on nurses’ knowledge. Insufficient training and a short training duration among our participants might be one explanation for their poor knowledge of PC. It could also be related to the fact that in-service education was not conducted regularly in hospitals due to a workforce shortage. Good knowledge of PC is associated with positive attitudes, enhancing practices, communication skills, and pain management (Pelayo et al., 2011); thus, this lack of education will affect optimal health care provision. In-service PC education programmes are, therefore, urgently needed to enhance HCPs' knowledge and skills, particularly in the management of dyspnea, gastrointestinal, and pain.

Positive attitudes toward EoLC and care of dying were reported among the Palestinian HCPs. Attitudes make a significant contribution to the quality of services provided (Braun et al., 2010). These results match those observed in previous studies conducted in Palestine (Ayed et al., 2015), Qatar (Zeinah et al., 2013a), and Turkey (Cevik & Kav, 2013). However, they contradict those applied in China (Shi et al., 2019) and

India (Das & Haseena, 2015). This might be due to the cultural and religious differences with regard to death across nations (Glass, Chen, Hwang, Ono, & Nahapetyan, 2010). Islamic culture and religious backgrounds of our HCPs, which accept death as a normal process, play a vital roles, in developing positive attitudes. The positive attitudes of HCPs in the GS should be considered a critical point to integrate PC programmes in the Palestinian HCS.

Results also showed that nurses and those in staff positions had significantly higher levels of attitude towards care of dying than physicians in a managerial position. This might be related to the significant time spent by nurses with patients and their families compared to any other HCPs. Over long periods, strong relationships and good communication are built, and thus nurses become more emotionally involved with patients along with their families. Increasing contact (Dunn, Otten, & Stephens, 2005; Lange, Thom, & Kline, 2008) and establishing relationships made nurses more positive attitudes towards the care of dying persons, compared to those who are less often in contact with dying persons and their families. Positive attitudes might also be related to the PC training that nurses had received. Previous training is considered a positive predictor of attitudes toward EoLC and the care of dying persons, as shown in this study. Education and training positively influenced nurses' attitudes about caring for dying patients (Ablett & Jones, 2007).

A majority of HCPs would like to learn more about PC to enhance their knowledge and attitudes, which is consistent with previous work conducted in the U.S. and Middle East (Fink et al., 2013; Silbermann et al., 2015). The passion and interest of HCPs to learn more about PC is considered an opportunity to integrate education and training programmes within Gaza HCSs. Even though half of the HCPs attended pain/symptom management and communication skills educational sessions in their work settings in the past two years, their knowledge about pain and dyspnea management is still low. This might be attributed to the length of the educational sessions, ranging from two weeks and four months. Thus, comprehensive educational programmes should be designated and revised by an expert before introducing programmes to HCPs. Educational programmes, as reported by HCPs, should focus on EoL-related issues. They suggested utilising online modules and web-based instruction as the main educational strategies that positively affect delivering educational activities. Web-based learning is increasingly utilised as a tool to support a formal programme and as a means for providing online learning (McKimm, Jollie, & Cantillon, 2003). Evidence has confirmed the positive influence of online PC training on professionals' knowledge, attitude, and care satisfaction (Pelayo et al., 2011). Health academic organisations can, therefore, adopt web-based techniques as an effective HCP teaching method. These techniques have the potential to improve and accelerate the provision of PC in settings where there is a lack of workforce staff and time to attend traditional courses.

Discharge planning for patients with chronic illness was the most common existing PC service available in Gaza hospitals, as shown in this study. This result matches the findings of Silbermann et al. (2015), who assessed services in the Middle East. Discharge planning is a central component of PC consultation in hospitals (Weissman, 1997). Before discharge, HCPs provide patients and their families with supportive information about disease progression, follow-up, managing symptoms, and addressing physical and psychological concerns (Benzar, Hansen, Kneitel, & Fromme, 2011). While discharge planning is important, professionals are reluctant to discuss the patients' disease progression, fearing families' pessimism. Many families do not wish to talk about death (Vanderveken, Schoenmakers, & De Lepeleire, 2019a). Our findings support this explanation revealed the unavailability of bereavement programmes, interdisciplinary care for dying patients, and programmes for staff support in caring for dying patients. It also supported by our findings showing that HCPs were dissatisfied with discharge plans provided to patients. Thus, there is an urgent need to provide communication programmes for staff on how to care for and discuss dying-related issues with patients and their families.

Avoidance and unwillingness on the part of patients/families to discuss death was the main barrier to providing PC in the GS, as reported by our HCPs. The study result is congruent with previous research findings (Aldridge et al., 2016; LeBlanc et al., 2017). Talking openly about death is one of the main objectives for keeping patients free of suffering (Chapple, Ziebland, McPherson, & Herxheimer, 2006). Talking about death may be influenced by patients' dignity (Meier et al., 2016; van Soest-Poortvliet et al., 2011), families’ views of death (Ko, Roh, & Higgins, 2013), the ritual of death (Meier et al., 2016), religious beliefs (Generous & Keeley, 2017), and cultural background (Meier et al., 2016). In the Islamic culture, people believe in Allah/God and agree that there is a journey after death, and there will be a physical resurrection on the Day of Judgment (Sarhill et al., 2001). Despite the strong Islamic faith, patients and their families are unwilling to discuss any death-related issues. Integrating spiritual and religious care in healthcare settings is, therefore, a priority for overcoming these issues by activating the role of Sheikh. This person is respected for his piety and religious background in delivering words and meaning that support patients and their families.

A lack of PC training for HCPs is another major barrier to providing PC in the GS. Several studies have reported that an inadequately trained PC workforce was the most critical barrier to the provision of PC (Abdel-Razeq et al., 2015; Hannon et al., 2016). A shortage of nursing staff (Elcigil, 2011), especially trained female nurses (Abdel-Razeq et al., 2015), was the main barrier. The Palestinian Ministry of Health should design plans for the trained workforce by increasing national and international professional collaboration programmes, incorporating in-service training, and integrating PC into curricula and practice.

8.9 Implications for clinical practice, education, and research

The valuable information that has gained from this study can inform the future development of PC education programs and the enhancement of healthcare services in GS-Palestine. The study highlighted insufficient knowledge of, and a lack of training in, PC among nurses and physicians in this area. Once they become experienced, their learning should be self-directed, meaning that they are required to be self-starting learners, self-aware, and practitioners (Latta & MacLeod, 2018). These skills are essential attributes for providing high quality of care. Thus, adopting self-directed learning, covering formal educational endeavours, informal and unstructured activities, are all required. For example, integrating formal PC education within universities is essential and should start soon. Informal continuing education and training programmes should also be offered within health in-services settings. Other activities, such as seminars and workshops, are also required to be adopted in health settings to update professionals with new knowledge and recent research.

Despite the educational and training programme received by a few nurses, they showed a lack of knowledge about advanced issues related to PC. Designing and implementing comprehensive educational and training programmes to meet the needs of HCPs, mainly EoLCrelated matters, are required. Programmes should focus on the concept of PC generally and specifically in advanced aspects, such as psychiatric issuese, pain, and gastrointestinal management.

Although some healthcare services were available in hospital, most were not fully incorporated or activated. To provide optimal quality of care, discharge planning for patients with chronic illness should be activated and started immediately to enhance patients' lives and decrease hospital readmission rates. With increased numbers of advanced cancer cases in Gaza, the hospital may have to discharge admitted patients before they fully recover from their acute symptoms. Thus, they often need continuous care post-discharge and recurrent visits to an outpatient clinic for follow-up. Optimal discharge planning while hospitalised is vital for enhancing hospital resources utilisation and patient health improvement.

Incorporating spiritual care services in healthcare settings is also required to support patients and their families. These services can help patients talk openly about PC-related issues, such as death, as talking about death is one of the significant barriers to the provision of PC in Gaza. In addition, training of HCPs communication skills around sensitive issues such as death, and considering patients’ physical, mental, and psychological status is essential. This study emphasises HCPs learning skills on how to care and discuss disease progression and dying related issues with patients and their families, particularly in discharge planning. Learning skills help professionals in discussing such sensitive matters.

Future comprehensive studies are needed to assess the educational needs for PC. These studies should focus on pain assessment and symptom management, counselling, PC-related material resources, and ethical approaches to protect patients. Large-scale studies utilising random samples are also warranted to generalised the study findings.

A study to explore training needs is required to determine what professionals need in terms of PC training and skills. Future research is also recommended to assess the influence of communication on patients’ and their families' perceptions of death, and how it can influence the quality of the relationship between professional-patients-families. Further interventional research is also warranted to evaluate the effectiveness of communication and dialogue on patients’ and their families’ perceptions of PC.

8.10 Study strengths and limitations

This study has some limitations. A scarcity of research in Arab countries leads to difficulties in enriching the discussion and synthesising the findings. Adopting a cross-sectional design makes it difficult to conclude the causal relationship. Moreover, adopting a small convenience sampling size makes it difficult to generalise the study findings. Although four instruments that cover several components (i.e. philosophy, pain, dyspnea, gastroenteritis) were utilised, other components, such as interprofessional collaboration and communication, preparation for and care at the time of death, care plan, ethical issues in EoLC, were not measured. Despite these limitations, the lack of previous similar studies conducted in Palestine is the strength and uniqueness of this study. The findings of this study are considered a base informational resource for the Ministry of Health in developing PC in Gaza. The results also provided valuable insights into how HCPs perceived PC.

8.11 Conclusion

This chapter presented the results of the second cross-sectional study that targeted HCPs. Assessing HCPs knowledge, attitudes, educational and healthcare-related issues are important before developing PC services within the HCS. One hundred sixty-nine professionals participated in the study. Findings have shown that Palestinian

HCPs had insufficient knowledge of PC, particularly knowledge of pain, dyspnea, and gastrointestinal problems. This study also revealed that a significant factor influencing professionals' PC knowledge and attitudes was educational level and previous PC training. Integration of formal and informal PC education within care services and health curricula is, therefore, a priority. Educational and training programmes should be comprehensive, covering the basic and advanced principles of PC, including gastrointestinal and psychiatric problems and pain management. This study also highlights that HCPs exhibit positive attitudes regarding EoLC and care of dying persons. Positive attitudes should be considered a positive point for integrating the PC programme in the HCS and health education programmes.

The next chapter will present the third qualitative study exploring the decision and policymakers' perspectives on PC.

CHAPTER (9): STUDY THREE-EXPLORING THE PERSPECTIVES OF DECISION AND POLICYMAKERS ON THE PROVISION OF PALLIATIVE CARE SERVICES INTO THE PALESTINIAN HEALTHCARE SYSTEM: A QUALITATIVE STUDY

9.1 Introduction

The chapter presents the third qualitative study that explores policy-related issues from decision and policymakers' perspectives before developing PC programmes with the Gaza HCS. The study's background, objectives, methodological underpinnings of the study methods, results, discussion, and implications are presented in detail in this chapter. This study is under review in an international peer-reviewed journal (Abu-Odah H, Molassiotis A, and Liu J. Gathering policymakers' perspectives as an essential step in planning and implementing palliative care services at a national level: an example from a limited resourced country, BMC Palliat Care. 2021). The paper has been slightly modified regarding the citation styles and the reference lists to adhere to the structure and guidelines of this doctoral thesis.

9.2 Background

Finally, as illustrated in Chapter Three (the study's conceptual framework), discussing PC policy-related issues with decisions and policymakers is one of the key pillars required before the development of a PC programme with a country's HCS (Abu-Odah et al., 2020, 2021). Other main pillars, unmet needs, and educational and HCS-related issues have been researched and presented in Chapters Seven and Eight, respectively. Discussing the three pillars above with decision and policymakers are necessary for the future direction of PC services development, which will help set priorities for the provision of PC and improve the quality of care provided to patients with advanced illnesses, which is a primary focus of governments (Kurella Tamura & Meier, 2013).

Palliative care has been highlighted as one of the top national priorities by governments worldwide (Sleeman, Leniz, Higginson, & Bristowe, 2018). It has been mentioned as one of the U.S.'s six national priorities (National Priorities Partnership, 2008). It is ranked as the top policy priority in LMICs (Stjernswärd, Foley, & Ferris, 2007). It also has received greater attention from international and national healthcare institutions that have recommended providing PC during the illness trajectory (Hui et al., 2012; World Health Organization, 2017). Many countries worldwide have been working towards developing PC through setting PC policies based on their resources and the goals of their HCS, while other countries are updating their policies to ensure the accessibility of PC services to all patients. However, other countries still struggle with introducing PC services in their HCS (Connor & Sepulveda Bermedo, 2014).

There are still many challenges hindering the introduction of PC services, particularly in LMICs. One-third of PC provision challenges fall within the policy aspect (Centeno et al., 2017). The main PC provision challenges are a lack of decision and policymaker support, and lack of a comprehensive national plan for implementing PC (Ddungu, 2011). Each country needs to build its policy development capacity and establish guidance utilising national and international policy frameworks to combat these challenges. It is also essential to develop policies that align with national laws and engage policymakers in practical/effective policy dialogues.

The engagement of decision-and policymakers in PC development is critical, as they have a pivotal role in developing a PC programme at the national level. They are responsible for making important decisions related to financial, governorate and services delivery arrangements. Several actions that policymakers can undertake to facilitate PC programme provision include developing policies, guidelines, and strategies for implementing decision-making processes that support PC services provision (Connor & Sepulveda Bermedo, 2014). Introducing PC within a country's HCS requires not only prioritisation by policymakers, but also policies plans/strategies and guidelines for measuring and supporting the progress and effectiveness provision of PC across settings (National consensus project for quality palliative care, 2018; Sleeman et al., 2018).

Despite the increasing recognition of PC's role, policymakers' priorities to support PC are still unclear and have sometimes engendered controversy (Sleeman et al., 2018). Thus exploring the policymakers' perspectives and views in the context of the existing HCS is a key step for a successful provision of a PC program (Rassouli, Farahani, & Khanali, 2017). Involving and exploring decision and policymakers’ perspectives in the early stage of PC planning and development is a significant strength, as it can help identify issues/policies that need more focus. Thus, the findings of this study, in conjunction with the other two studies (Chapters 6 and 7), will provide evidence acquisition around areas that need to be considered before PC is introduced and before making recommendations to the government.

9.3 Policies to address palliative care

Developing policies is not an easy task and requires planning and revising before implementation. The policy is defined as the decisions, plans, and actions that governments undertake to fulfil their particular healthcare goals within a community (Buse, Mays, & Walt, 2012; Tomson & Biermann, 2015). A PC policy is defined as “an intention and broad guideline which elaborates government’s goals and actions when it comes to implementation of PC services across all levels of the health system" (Luyirika et al., 2016). It can present in many forms; it can be a standalone policy, part of a national healthcare plan, or an element of a national non-communicable diseases strategy (Maetens et al., 2019).

The findings from the two systematic reviews presented in Chapter Four (Abu-Odah et al., 2020, 2021) supported by the WHO model (Stjernsward et al., 2007) confirmed that policy-related issues are essential components to be examined before developing a PC programme within-country HCS. Policy-related issues are categorised into three types: 1) Policies supporting the integration of PC into the structure of national HCSs (i.e. guidelines, standards, resources, etc.), 2) policies for strengthening human resources (i.e. training of HCPs, educating professionals through including PC into the curricula or all new health professionals, as well as educating volunteers and the public), and 3) policies that ensure the availability of essential medicines for pain and symptom management. Each of these policies is highlighted below:

9.3.1 Policies that support PC integration into the structure of healthcare systems

9.3.1.1 Strategies and guidelines

Developing PC guidelines and supportive legislation have been recognised as a critical component of the policy (Department of Health and Children, 2001; Hospis Malaysia, 2016). Developing these policies based on a country's resources is critical for successful PC provision. Guidelines are considered central to the successful development of PC. Guidelines are statements developed by governments to assist HCPs and patients in making decisions about proper care for a specific patient population (African Palliative Care Association, 2010). They are frequently utilised as a path to minimise treatments' differences within institutions, to develop customised protocols for hospitals, and to educate staff (Grant, Elk, Ferrell, Morrison, & von Gunten, 2009; Mast, Salama, Silverman, & Arnold, 2004). Guidelines also allow policymakers to monitor the progress of PC development (World Health Organisation, 2016).

Despite the importance of guidelines for integrating PC, most guidelines have focused on clinically-related issues (Van Beek et al., 2016). For instance, a study conducted by Van Beek et al. (2016) assessed the extent to which PC has been integrated into guidelines for cancer patients in Europe. Of 60 guidelines identified, most focused on specific cancer, including breast and lung cancer, and only four guidelines deal with general oncology. Most of the guidelines emphasise a holistic patient assessment approach, including the patients' biopsychosocial-spiritual circumstances. All of these guidelines also strongly recommended the involvement of multidisciplinary PC teams in caring for patients. Siouta et al. (2016) assessed the guidelines for PC interaction in advanced heart failure and chronic obstructive pulmonary disease in Europe. Most of the included guidelines shed light on patients' holistic assessment, identified their needs and goals, and outlined advanced care planning. Most of the guidelines addressed suffering, reducing intervention, and illness prognosis.

9.3.1.2 Resources and funding

Funding and resource-allocation models are required to effectively integrate PC into the HCS (Ddungu, 2011; Fraser et al., 2017; The Economist Intelligence Unit, 2015) and the sustainable provision of high-quality care (Groeneveld et al., 2017). Availability of resources influences policymakers’ decision to choose how to provide PC in HCSs (Connor & Sepulveda Bermedo, 2014). For example, India developed a community-based PC programme that ultimately depended on locally trained volunteers who are linked and supported by a network of trained professionals (Connor & Sepulveda Bermedo, 2014). Romania connected and made a partnership with a British hospice based in Dartford to introduce and support PC development for life-limiting diseases. The U.S. moved beyond general PC to specific programmes that have achieved the high penetration level in the population requiring PC.

The above successful examples depended on the context of a country's HCS, such as availability of resources, financial budgets, and policymakers' support. Most of these countries are supported by policymakers who have subsidised the PC services' social component by funding from the Ministry of Labour and the local authority. The previous evidence supported by the two systematic reviews (Chapter Four) confirmed that discussing budget allocation and funding support with policymakers is essential before providing PC within country’s HCS (Abu-Odah et al., 2020, 2021).

9.3.2 Policies for strengthening and expanding human resources

The WHO’s approach is also concerned with education and training as a critical strategy for the provision of PC (Maetens et al., 2019). Integration of PC training into all health curricula as an educational strategy is mentioned across recent governmental reports of Australia (NSW Ministry of Health, 2019), the UK (National Palliative and End of Life Care Partnership, 2015), New Zealand (Ministry of Health, 2001), Malaysia (Hospis Malaysia, 2016), Uganda (Palliative Care Association of Uganda, 2017) and Lebanon (Soueidan et al., 2018). For instance, Australia focused on ensuring that HCPs have EoL conversational skills with people to assist them in the care planning process (NSW Ministry of Health, 2019). Belgium seemed to be more focused on training curricula on symptom management and communication skills (Keirse et al., 2009). In Iran, Ansari et al. (2018) 22 stakeholders’ (cancer patients, caregivers, HCPs, experts, and policymakers) views of the factors influencing the design of a PC system and its policy analysis, utilised a "policy analysis triangle" framework. Iranian stakeholders reported that education managment played a major role in PC policies analysis.

Strategies should focus on awareness and knowledge of PC's principles across the health workforce, not only among specialised PC professionals (NSW Ministry of Health, 2019). While specialised PC training is important, basic PC covering principles and good pain management should also be provided to all HCPs by incorporating them into training, as most professionals may not have received adequate training. Policies should, therefore, focus on PC training at all levels of HCPs’ training.

Training HCPs (physicians, nurses, non-physician clinicians, and community health workers) effectively and efficiently provide PC tasks (World Health Organisation, 2008). The WHO recommended that the training programme concentrates on four main components: pain and symptom management, psychosocial support and EoLC, and supervision (World Health Organisation, 2008). Pain management training should cover how to conduct pain assessment, teach patients and families how to give pain medication and oral morphine, and treat mild, moderate, and severe pain utilising chronic pain management guidelines. For symptoms management, training should concentrate on common symptoms, such as nausea, fever, anxiety, depression, and insomnia. Counselling, psychological and spiritual care are the main issues that psychological support training should focus on (World Health Organisation, 2008).

9.3.3 Policies ensuring the availability of essential medicine

Enhancing access to medicine for PC and pain relief is an essential component of a comprehensive WHO public health strategy (Maetens et al., 2019). The concept of essential medicines should be adopted during national medicine policy development. This helps set the HCS’s priorities, sustainability in the pharmaceutical branch, and provide a suitable framework for setting national goals. Essential medicines, as identified by the World Health Organisation (2021) model list, include medicines for pain relief and most symptoms associated with advanced illnesses. This model can help countries determine which essential medicines are in line with their own needs and resources. Accessibility of medicine for those in need is the next step that should be considered. PC leaders revealed that the problem is not only related to the availability of medication, but also related to prescription difficulties (Centeno et al., 2017). Many patients with life-threatening diseases did not have access to essential medicine. Therefore, countries should set policies and plans based on their own needs and resources to ensure access to and availability of medications.

The Saudi Council, for example, has issued the National Clinical Guidelines for Palliative Medicine in Oncology that brings together evidence-based best practices in treating adult patients suffering from life-threatening diseases. This national achievement serves the various health sectors that provide palliative medicine services to cancer patients and their families. The clinical guidelines facilitate HCPs in identifying types of cancer pain, and methods of assessing and treating pain in an effective and fast manner for patients of different ages. It also covers the treatment of shortness of breath, gastrointestinal disorders, itching, anorexia, general lethargy, high blood calcium, depression, acute bleeding, dehydration, epilepsy, snoring death, and psychological and social care (Saudi Health Council, 2018). In Lebanon, the Ministry of Public Health has established a PC national committee to lay the foundations for PC and pain treatment for cancer patients and patients with a number of chronic diseases. The committee included experts from all concerned medical and nursing specialties, consultants, and civil society associations to provide PC services. The committee has also seen many achievements at the national level since its inception, including but not limited to: the inclusion of a new specialty on the list of medical specialties in Lebanon, which is the specialty of palliative medicine, and the development of a national PC plan that included all axes (Ministry of Public Health-Lebanon, 2020). According to the experiences of the aforegoing countries, developing essential medicine policies should begin with assessing the current availability of PC medicines, the patient group (adult- paediatrics), the availability of other opioids for pain relief, who prescribe medication, and what restrictions are in place (Maetens et al., 2019).

9.4 Gaps in the literature

As presented in the preceding sections, most of the previous evidence was policy documents. Few peer-reviewed studies have been conducted; most of them shed light on PC and policy analysis obstacles. Furthermore, most of the evidence was focused on the micro-level (daily patient management) with less attention paid to the macro-level (role and responsibilities of decision and policymakers). Despite the critical findings of previous studies that helped and guided countries on developing a PC plan, each country has a unique position and has different views of PC as a part of the HCS (Higginson et al., 2007).

To provide a suitable platform for the provision of PC as part of Palestinian HCSs, there is a need to comprehensively assess the current system based on the WHO model, including education, patients' needs/services, and policy components. These components must be assessed before developing a PC programme into a country's HCS. The first two components (education and implementation) were assessed.

Policy-related issues, the third component, should be assessed to understand all components comprehensively, as these components interact with and dynamically influence each other. Thus, this study is an essential complementary study that was conducted to understand the decision and policymakers' perspectives towards providing a PC programme in Palestine, a country that has not streamlined PC services into its HCSs (Halahleh & Gale, 2018). Discussing policy-related issues is critical for the future direction of PC services development and will help set priorities for PC provision. Although decision and policymakers' role is important, no study has been done to explore policymakers’ perspectives towards the provision of PC at the national level in Palestine.

9.5 Aim and objectives

This study aims to comprehensively explore policy-related issues from decision-and policymakers’ perspectives before developing PC programmes with the Gaza HCS. The main research objectives for this study are:

1. To understand the extent to which palliative care has been identified as a priority from policymakers' perspectives.
2. To discuss with policymakers’ the existing and new policies (strategies, plans, resources, directives) that support the integration of palliative care into the structure of national healthcare systems.
3. To explore policymakers’ perspectives on policies/work that has been done regarding strengthening human resources, such as training and education.

4. To identify which essential medicines for pain and symptom management are available in the healthcare system, their cost, and prescribing-related issues from policymakers' point of view.
5. To identify the challenges and facilitators to the provision of palliative care from policymakers' perspectives.

9.6 Study methodological underpinnings

This section provides an in-depth description of qualitative research and justifications for adopting qualitative methodology as a research design strategy and following its philosophical approach adopted in this study.

9.6.1 Theoretical rationale of qualitative research

Qualitative research is a research approach aimed at studying scientific phenomena or problems by describing phenomena scientifically to develop specific frameworks, theories, or understanding of a phenomenon (Hammarberg, Kirkman, & de Lacey, 2016; Pathak, Jena, & Kalra, 2013). Qualitative research is a specific activity that locates the observer in the world. It is an inductive and naturalistic (interpretive) approach to the world (Denzin & Lincoln, 2011). Qualitative research focuses on the qualities of entities and meaning that cannot be experimentally measured (Denzin & Lincoln, 2011).

Qualitative research provides researchers with a rich description of social reality (Denzin & Lincoln, 2003). Qualitative researchers study phenomena in their context-specific environments-settings, and attempt to understand or interpret them in terms of the meanings that participants bring to them (Denzin & Lincoln, 2011). It is appropriate when researchers attempt to understand and share personal stories, understand the phenomena, or set issues, generate theories, and when quantitative analysis does not resolve the problem at hand (Creswell, 2003).

Adopting qualitative methodologies has increased among health researchers due to the complexity of social phenomena, which requires using an interpretive approach to achieve a thoughtful exploration of the phenomena (Creswell, 2003). Qualitative research may include different data collection methods, including interviews, cases, visual texts, photovoice, and observational methods (Creswell, 2003). Using one or more methods helps researchers to understand and make sense of phenomena(Creswell, 2003; Denzin & Lincoln, 2011).

In comparison with quantitative approaches, although they may use similar data collection methods, researchers are keen on measuring the relationships between variables and concerned about statistical factors associated with the studied area. They are not concerned about the (interpretive) meaning attached by participants (Finnerty, 2003; Ritchie & Lewis, 2003; Ritchie et al., 2013). Qualitative researchers move beyond statistical facts to in-depth understanding and interpretive exploration of the complex phenomenon (Pope & Mays, 1995).

In this study, the researcher explores the perspectives of policymakers on the potential provision of PC services in the GS, which involve complex strategies, involving the agency of individuals accessing environmental supports (i.e., strategies, guidelines), and resources (i.e., workforce, funding, medications, etc.). According to the previous explanations and comparisons between qualitative and quantitative research, a qualitative stance is the best approach for exploring policymakers’ experiences and presenting facts in a real context. The following sections describe the different paradigms and approaches that may be utilised in this study.

9.6.2 Philosophical orientation

Any research process is guided by philosophical assumptions/paradigms that researchers adopt when planning to conduct a study (Creswell & Tashakkori, 2007). The researchers bring their own beliefs, views, and assumptions to the research project, guiding them to conduct and write the study in a robust manner. Before discussing this study's qualitative paradigmatic assumptions, it is valuable to start with a clear definition of paradigm, types, and various perspectives.

Paradigm is a "*world view*" (Rocco, Bliss, Gallagher, Pérez, & Prado, 2003, p. 19). It is defined as a set of researchers' beliefs or assumptions regarding ontology, epistemology, ethics, and methodological questions on reality's nature (Lincoln et al., 2011). Ontology means the nature of the world/reality (theory or set of ideas), and epistemology refers to what is known about reality (set of questions). Methodology refers to how knowledge about the world is gained (methods of data collection and analysis) (Lincoln et al., 2011).

The two commonly adopted paradigms are *positivist and constructivist*; each one has different beliefs. Quantitative research is based on *positivist* beliefs, which means there is singular reality, and researchers can discover it by utilising appropriate methods in a detached manner. On the other hand, qualitative research is generally based on *constructivist* beliefs, which confirm there is no singular reality, because many factors, such as contextual circumstances and individual culture, may influence the nature of reality, and thus studying the phenomenon from participants' view of reality is central to qualitative research (Bergman et al., 2012). *Constructivist* paradigm is alternatively identified as an interpretive (Guba & Lincoln, 1989; Merriam & Tisdell, 2016) and naturalistic paradigm (Guba & Lincoln, 1989).

In the *constructivist* paradigm, researchers develop their study from their own beliefs and assumptions utilising different approaches, which are different than those utilised in a *positivist* paradigm. For example, in *positivist* (quantitative) research, the approach ranges from randomised controlled trials, experimental studies etc., while in *constructivist* (qualitative) research, it ranges from a phenomenology, grounded theory, case study, qualitative description, etc. (Cresswell, 1998). Considering the study aim and basic assumptions of each paradigm, *constructivist* appears to be the most appropriate to guide this research framework. The next sections provide an overview of the common qualitative approaches that may be utilised to address the study aim and rationale for adopting the qualitative description.

9.6.3 Types of qualitative research methodologies

There are several qualitative research approaches; the commonly adopted approaches are phenomenology, ethnography, cases study, and grounded theory (Cresswell, 1998). Phenomenology is utilised to put emphasis on individuals' perceptions in which they live and essential meanings of what phenomena "are" (descriptive phenomenology), or how phenomena come to be known (interpretive phenomenology) (Reiners, 2012). Thus, phenomenology focuses on people's *lived* experience (Langdridge, 2007). Phenomenology has been designated as a philosophy as well as a methodology (Kafle, 2011). Phenomenology has been frequently used in qualitative research when the study attempts to theoretically abstract phenomenon following the philosophy that interprets participants' meanings for rich and deep understanding (Van Manen, 2016). This is the most suitable approach, which seeks to capture the "essence" of a phenomenon through in-depth interviews to get at the existential (lived) experience of a phenomenon (Giorgi, 1997; Van Manen, 2016).

Ethnography is used to gather data through interviews, observations, and documentary to produce a comprehensive account of social phenomena (Reeves, Peller, Goldman, & Kitto, 2013). It explores social interaction and culture in groups experiencing a phenomenon, whether these groups are identified as teams, communities, organisations, or societies. It also tends to put emphasis on understanding things from the "insiders'" (emic) point of view, rather than only from that of the observer or researcher's (etic) viewpoint (Denzin & Lincoln, 2003).

Grounded theory aims to generate or develop a theory (Glase & Strauss, 1967). It is defined as "the discovery of theory from data systematically obtained from social research" (Glase & Strauss, 1967, p. 2). It is integral to exploring social relationships and group behaviour where little theorisation exists of how social and environmental factors are connected to an individual's experiences (Crooks, 2001). Unlike phenomenology, grounded theory attempts to explain how the phenomenon is theoretically constructed from social knowledge of the world (Astalin, 2013).

Case study research is used to examine and analyse a phenomenon defined as a "single unit" such as person, organisation, or institution (Yin, 2011). The phenomenon is clearly bounded in the type of questions that is being asked, whether by the individual, data sources used, settings, and/or study population involved (Yin, 2011). Similar to other qualitative study designs described, many data sources can be adopted in collecting data, such as observation, interviews, and documents (Holloway, 1997).

Although there are many traditional qualitative approaches, researchers may encounter a topic that belongs to the qualitative paradigm but does not precisely align with well-documented and clearly defined approaches. Various terms have emerged to describe research that does not conveniently fit within a traditional approach, such as the “noncategorical” qualitative research approach (Vaismoradi, Turunen, & Bondas, 2013, p. 169), “basic or generic qualitative research” (Merriam, 1998, p. 20), and “basic or fundamental qualitative description” (Sandelowski, 2010, p. 335). These alternative terms create ambiguity among researchers in relation to qualitative description research as a methodology. In 2017, Bradshaw et al., clearly described qualitative description studies as those representing the characteristics of qualitative studies, but do not aim to generate a theory as with grounded theory, explore culture as in ethnography or lived experiences of people as in phenomenology (Bradshaw, Atkinson, & Doody, 2017). The next section elucidates in detail what is a qualitative description approach and the rationale of adopting it in this study.

9.6.4 Qualitative description as a research design and rationale for adopting it

Qualitative description approach has received health researchers' interest in recent years, in which more than half of qualitative studies have adopted a qualitative description to address their aims (Ryan-Nicholls & Will, 2009). Qualitative description is identified as an alternative research inquiry and it is described as one that provides a “comprehensive summary of the event” (Sandelowski, 2000, p. 334), with less interpretation than other approaches (Sandelowski, 2010). The interpretation in qualitative description leads to thematic detailing and clustering rather than transformation and developing theory (Sandelowski, 2010). Qualitative description aims to explore phenomena, problems, or issues relating to individual knowledge, perceptions, experiences, and views (Cronin, Coughlan, & Smith, 2014). The philosophical assumptions of a qualitative description approach lie within naturalistic inquiry, meaning that phenomena can be understood through accessing the meanings that participants attribute to them (Parse, 2001).

Qualitative description seems to be the most appropriate approach in this study for several reasons. First, little is known about policymakers' perspectives on PC provision in the Palestinian HCS, and how PC services are prioritised by policymakers compared to other services. Despite little information being available in some countries, each country has a unique surrounding circumstance that should be considered before PC provision. In Palestine, no study has been conducted exploring the decisions and policymakers' views regarding PC, the country that experiences limited resources, poor physical infrastructure, an underdeveloped HCS, and insufficient services.

Second, qualitative description provides a more flexible way to get at subjective knowledge of a phenomenon, which is less interpretive than ethnography and grounded theory; the latter also are guided by specific philosophical or theoretical orientations (Cronin et al., 2014). In this approach, the researcher does not require moving as far from, or into the data, and does not need a conceptual or highly abstract rendering of the data, as compared to phenomenology, grounded theory, and ethnography (Sandelowski, 2000, 2010). In addition, analysis in qualitative description stays "close" to data to discover patterns or clusters in its interpretation, rather than transforming data into more abstract higher-order understanding, for example, a theory (Sandelowski, 2010).

Third, the researcher aims to remain at the fundamental understanding of policymakers' perspectives and views, for which qualitative description is well-suited. In addition, qualitative description facilitates a rich and robust description of the data. More specifically, a qualitative descriptive inquiry is appropriate to receive undefined responses to specific questions such as, "What are the concerns of people about an event? What are people’s responses towards an event? What factors facilitate and preclude recovery from an event?” (Sandelowski, 2000, p. 337). Utilising a qualitative description approach facilitates the understanding of decisions and policymakers' perspectives towards the provision of a PC programme, exploring the work being done by ministries to support PC provision, and identifying the challenges and facilitators to the provision of PC. All of the reasons mentioned above provide a strong justification for adopting qualitative descriptive inquiry.

9.7 Methods

9.7.1 Design

According to the previous sections, a descriptive, exploratory qualitative design was the best approach to capture key decision and policymakers' perspectives regarding PC provision. The qualitative description refers to a study design that tries to reveal the fundamental descriptive understanding of a topic about which little is known (Sandelowski, 2000).

9.7.2 Participant selection

9.7.2.1 Sampling

In qualitative research, non-probability sampling principles are used to demonstrate purposive ones to get at appropriate participants and have data “rich” in knowledge of the phenomenon. Appropriateness means identifying participants who can best inform the research, and adequacy refers to having “enough” data to produce a detailed description of the phenomenon (Morse & Field, 1995). In this qualitative study, purposive sampling refers to inviting those who can provide a rich description of the phenomenon, problem or issue (Grove et al., 2012). The way to do this is by selecting participants who are typical of the population (Haber, 1998). So, a purposeful approach to sampling was utilised in this study for recruiting participants.

Participants identified as having a policy-making role in the HCS who are responsible for making executive and legislative decisions about matters related to services (including PC). These decision and policymakers have diverse positions from different ministries, ranging from deputy Minister of Health who represents the top level of MOH, to individuals involved in decision-making and writing health policies and guidelines, to healthcare experts who are working with cancer patients, to a representative of health-related disciplines, such as the Palestinian Medical and Nursing Council. These policymakers had prior experience, either clinical and/or managerial positions in health services developments. The demographic description of study participants is presented in section 9.8.1. The list of potential participants was prepared based on the researcher's knowledge of the literature and experience of the local (Palestine) HCS, having worked more than 10 years in three healthcare sectors in Palestine: the clinical field, General Directorate of Nursing, and higher education (universities). Table 31 shows the key decision and policymakers included in this study.

Table 31: Key decision-and policymakers included in this study

Org. abbreviation	Full name (participants affiliation)	No. of Participants in the interview
MOH	Director of Doctors Affairs in Hospital Administration	**1**
	Nursing Consultant of Minister of Health	**1**
	Deputy GD of Nursing	**1**
	Head of Nursing Policy and Quality Department	**1**
	Deputy Head of the Pharmaceuticals and Medical Supplies	**1**
	Head of the oncology department at Al-Shifa Hospital	**3**
	Head of the oncology department at European Hospital	**2**
	Member of National Committee of Palliative Care	**1**
PMC	A representative of the Palestinian Medical Council	**1**
	Total participants	**12**

GD: General Director; MOH: Ministry of Health; PMC: Palestine Medical Council

9.7.2.2 Sample size

Qualitative description utilises a small sample size, usually ranging between four and 50 participants, which cannot be determined explicitly in advance (Holloway & Wheeler, 2002). In this study, to gain adequate and sufficient data to produce a detailed description of the phenomenon and explore the topic in-depth, the researcher anticipates an estimated number of 12 participants (Table 31). This study's sampling approach is not typical of qualitative research, which depends on data saturation (Morse, Barrett, Mayan, Olson, & Spiers, 2002), as the study participants' are a well-defined small group on leading political or management positions. Data saturation is less applicable or appropriate in this study (Vasileiou, Barnett, Thorpe, & Young, 2018). This number represents different specialties that play roles in developing health services. The number may be increased by asking interview participants to nominate other participants. Each policymaker was a representative of the institution directly linked to the phenomenon under study. The goal is not to achieve data saturation, but to obtain data from all available key policymakers.

9.7.2.3 Recruitment of participants

Following ethical approval from the Ethical Review Committee - The Hong Kong Polytechnic University, the researcher initially contacted the secretary in the office of all potential participants via telephone and e-mail, asking to arrange a meeting with participants to identify the meeting purpose. Then the researcher prepared an envelope, including a letter describing the study purpose (information sheet) (Appendix, 21), a copy of the consent form (Appendix 22), and the study interview guide, and delivered it to the secretary to pass it on to the participant. The researcher contacted the office about the participants' decision. For participants who respond positively, the researcher asked the secretary to arrange an interview at a convenient time and place. A reminder for those who did not respond to the first invitation was sent within two weeks.

9.7.3 Data collection

Semi-structured interview is a common technique utilised in qualitative description designs (Al-Busaidi, 2008; Stanley, 2014). Other methods, such as observation, focus groups, videotapes, or document review can also be adopted in qualitative description design (Colorafi & Evans, 2016).

In this study, face-to-face, semi-structured interviews were employed to collect data. Semi-structured method is appropriate when the interviewer possesses knowledge about the study phenomenon without being able to predict the answers (Morse & Field, 1995). This method also enables the interviewer to explore phenomena with participants by encouraging in-depth discussions facilitating emerging new concepts that contribute to the richness of data required in the qualitative description. The semi-structured interview guide is presented in the next section.

All interviews were conducted according to an interview guide (Table 32). A pilot interview was performed with the head nurse to evaluate the interview guide and modify it if necessary. In addition, the pilot interview was performed with two PhD nurses who are experts in qualitative research for help on how to run the interviews. The pilot data were not added to the final dataset. Interviews were conducted face-to-face in a quiet place, preferably of participants' choice according to prior arrangements.

9.7.4 Interview guide/schedule

Based on the previous reviews (Chapter Four) and expertise of the researcher, who has worked in the clinical field for over 10 years, the researcher created the interview guide. The interview guide is a data collection tool in which study participants responded to open-ended questions and features the flexibility to "probe" or "prompt" participants for further explanation (Parahoo, 2014). Prior to using the guide in the actual interview, the researcher forwarded the guide by e-mail to two national and three international members who are experts in the field of PC policy, to provide comments about the final version. The first expert is from Sheffield University-Health Science school, an expert in PC policy for more than eight years, and a BMC-PC journal reviewer. The second international expert is from Leeds University-School of Medicine, working at the university as a PC researcher for more than 10 years. He was invited to review this guide because he is familiar with the Palestinian context, and he supervised a student who did a qualitative study on the cancer situation in Gaza. The third expert is from Toronto University. She is an expert in qualitative PC research and is familiar with my PhD progress and project. The other two national experts are PhD researchers in health policy working at the Palestinian MOH to develop plans and strategies. The experts were asked to give their opinions on the guide and their suggestions to develop the interview questions. They were also asked to suggest any questions related to the study objectives and to check the flow of the questions. Interview guides were refined based on the experts' feedback. The final set of interview prompts is illustrated in Table 32.

Table 32: Final set of an audio-recorded interview guide

Study Objectives	**Questions**	**Probe**	**Type of participants will be offered the question**
Warm-up enquiries	1. *Could you briefly describe your position/role? Especially your role in developing health services and policies.*		All participants
	2. When we talk about patients with advanced diseases, *how are they currently managed?*	• Probe about services supports them. • Probe about services available to families. • Probe about existing policies for managing patients with advanced diseases.	All participants
	3. So, we will now be talking specifically about PC; *what does PC mean in the Gaza context?*	• Probe further to which group of patients PC should be provided? Why do you consider this patient group?	All participants
1. To understand the extent to which PC has been identified as a priority from policymakers' perspectives.	1. *How does the government consider PC as a priority in the current healthcare system?*	• If yes, probe further to what extent/level PC is considered a priority for the Ministry? • Probe further about reasons for PC to be a priority at this level. --- • If say no, ask why it is not a priority?	All participants
	2. *How is the government or hospital planning to introduce PC into the healthcare system of Gaza?*	• If yes, probe about the approach/approaches adopted. Why you chose this approach? • What are the strategies for achieving this? • Probing question about possible timelines for it] --- • [if they say no, ask why do they have no plan? • Ask about future plans? Probing question about possible timelines for it]	All participants

Study Objectives	**Questions**	**Probe**	**Type of participants will be offered the question**
2. To explore the policymakers' perception about policies (guidelines, strategies/plans, standards, resources) that support the integration of PC into the structure of national HCSs.	1. *Tell me about the work/policy that is being done by the Ministry to support PC provision.*	• Ask if there *is a national policy for PC provision?* • What type of policy is developed (guidelines, strategies/plans, standards)? • If say yes, how this policy was developed? • Who participates in developing this policy? • How often is this policy reviewed? -- • If say no, why do they have no plan? • Ask about plans for developing national policy? Probing question about timelines for it]	All participants
	2. *From your experience and your position, what types of guidelines/ policies are existing to support PC provision?*	• If yes, what these guidelines are talking about? • Probe further if the guidelines are developed based on patients' holistic needs- biopsychosocial-spiritual circumstances? • Probe further about a group of patients that guidelines focus on • Probe about the type of guidelines (general or specific). • Probe also about the content of guidelines **Prompt**: how about addressing suffering reducing intervention and illness prognosis. • Probe if the content of guidelines quantifies each healthcare provider's role and their interaction and timing of patients' assessment. • Probe about findings of the study (1) almost all cancer patients in Gaza experienced unmet needs, why? -- • If no, ask why it is not developed? • Probe about strategies, future plans or recommendations to develop PC guidelines in the near future]	All participants
	3. Based on your pervious clinical experiences, how are PC patients managed in hospitals?	• Probe about plans to improve the care pathways of such patients?	GD of Hospitals GD of Nursing Head of oncology department

Study Objectives	**Questions**	**Probe**	**Type of participants will be offered the question**
	4. From your experience, what *is the government allocated budget/resource/manpower for PC services?*	• If say yes, probe about the budget estimation for PC services development (e.g., beds, infrastructure, healthcare professional education and training, essential medications, etc.)? **Prompt**: how the budget is utilised? Probe about the role of donor support to support PC. • Probe about plan/strategy of the government for seeking external funds from international organisations? -- • If no, why do they have no budget, etc. • Ask if there are future strategies or recommendations to allocate budget for PC services improvement?	Director of doctors affairs in hospital administration
3. To explore the policymakers' perspective about policies/work been done regarding strengthening human resources, such as training and education.	*1. What have been done or will do to prepare frontline workers/clinicians/nurses in PC services, particularly education and training?*	• If say yes, ask how the content of the training was developed? Is it based on the assessment of professionals' educational and training-related aspects? • Probe further is the training developed based on WHO four main components, including pain and symptoms management, psychosocial support and end-of-life care, and supervision. • Is the content also shed light on communication and conversation skills? • Probe about the place where training had been conducted—in-services, for example. • Probe further about the group of professionals who received training. Why this group? • Probe about the findings of the study (2) that reported less than 50% of professionals knew about PC. Why do you think so? How this situation could be changed. • Probe about the challenges with changing this situation. -- • If say no, why do they have no plan to do so? • Probe further if the Ministry is planning for integrating PC into healthcare training curricula.	Head of Palestine Medical Council GD of Nursing Member of National committee of Palliative Care

Study Objectives	**Questions**	**Probe**	**Type of participants will be offered the question**
	3- From your view, how 'ready' is the system or government in Gaza to develop PC.	• If ready. Probe about the level of PC provision? • If not ready. Probe about the reasons of that. (go to challenges questions). • Probe about the future plan for providing PC.	All participants
4. To explore the policymakers' perspective concerning the availability of essential medicine for pain and symptom management.	1. *To what extent has the Ministry adopted the WHO essential medicines in PC?*	• Probe about the essential medicine availability into healthcare system? • Probe further about medicines for pain relief and for most symptoms associated with advanced illnesses? • Ask about who prescribe medications? Probe further if there is clinical guideline adopted for prescription of medications? • Probe further about challenges or restrictions that are in place to access essential medications? If there are challenges. Probe further about strategies to ensure the access to medications.	GD of Pharmaceuticals and Medical Supplies
5. To identify the challenges and facilitators to the provision of PC from policymakers' perspectives.	1. From your perspective, what are the challenges and facilitators regarding the development of PC into the healthcare system?	• If say yes, probe about challenges based on three policies (structure, human resources, and medications). • Probe about the main challenges to the provision of PC. • *For Structure*, probe about challenges in developing policies, guideline, • *For human resources*, probe about the shortage of staff, training, knowledge of the staff • *For medication*, probe about availability of medication, access to medications. • Probe about facilitators based on three policies (structure, human resources, and medications).	All participants
Ending of interview	Is there anything else they would like to add or suggest as the next important step in the process to implement PC.	key aspects of PC that should be prioritised (i.e. education, training, access to opioids)	All participants

GD: General Director; MOH: Ministry of Health; PC; Palliative Care

9.7.5 Process of data translation

Translation of data is vital in qualitative research. It often threatens the data's validity and integrity (Esposito, 2001) unless it is conducted in a systematic and robust manner (Temple, 2002). The translation is central in all research phases, ranging from data collection, analysis, and representation of the findings (Al-Amer, Ramjan, Glew, Darwish, & Salamonson, 2015). Rigorous translation is necessary to produce valid data in cross-language studies (Al-Amer et al., 2015). Translation is required in this study, as all analysed Arabic interview data were translated into English for reporting and dissemination of the findings. Translating data from Arabic into English requires the researcher to consider the data's meaning and linguistic context. Despite the importance of translation, there are no standardised methods for translating Arabic data to English (Al-Amer et al., 2015). However, other methods were available for translation data in research involving non-English speaking participants. The Ho, Holloway, and Stenhouse (2019) analytic method for translating Mandarin data to English was adopted. Adopting such a method in this study is critical to maintain validity and avoid losing the meaning of the data, and minimising language differences. The translation method involves several steps:

First, analysing data and developing codes, subcategories, and categories in Arabic. In this study, the interviews were audio-recorded in their native language of Arabic, transcribed and analysed in Arabic, as the interviewer and study participants speak the same language (Arabic). Analysing data in Arabic minimises language differences that may arise in data collection, transcription, and during the first phase of analyses, as the coding phase is usually staying close to the data. Analysis data were applied line-by-line coding or segment-by-segment coding, depending on the content provided by participants. This enables the researcher to understand the essence of what was being said. Each set of data (chunk) was examined closely to generate a code that may contain more than one code. Analysing data in the original language helps in ensuring the validity of the data and keeping the distance between the meaning of the data as experienced by participants as close as possible to the meaning of interpreted findings (Polkinghorne, 2007; van Nes, Abma, Jonsson, & Deeg, 2010). Although the data were analysed in Arabic, the researcher translated three Arabic transcripts into English to involve both supervisors with the process of analysis and coding, as both speak English. This is also an important step in ensuring the validity of the coding process.

The next step was to translate the coded data from Arabic to English. Once subcategories and categories were developed in Arabic, the researcher could have encountered difficulties translating these developed categories into English, which may be due to the lack of equivalent concepts. Thus, the researcher addressed this issue by sending the Arabic subcategories and categories to an expert (who holds a PhD in health policies, who is bilingual and has experience in qualitative research) for translation categories to English. The versions, Arabic and English, were then precisely revised, checked, and cleaned for accuracy of interpretation by the researcher. If there were any discrepancies in the three versions, the researcher arranged a meeting with the expert for discussion. Involving one translator with high qualifications and experiences increased the data's reliability and trustworthiness (Kwok & White, 2011; Twinn, 1997). This step minimised language differences that might have occurred during the translation phase.

Third, the researcher went back to check the Arabic coded data, translated these coded into English, and coded the translated data in English. The researcher was then responsible for developing subcategories and categories in English and comparing the translated codes and categories with the Arabic version to develop meaning-based translated findings. The translated results were compared with the original Arabic data to ensure meaning-based interpretation and confirm that the findings were as close to participants' responses as possible. The researcher also involved the expert in this process, to ensure the validity of the coding process and compare the two versions.

After completing the translation process, the English version was forwarded to supervisors for further discussion and interpretation of the findings. Language differences may occur during this interpretation phase when the data are being discussed with supervisors. Therefore, the researcher explained the interpretations to the supervisors in English and provided a very good understanding of subtle meaning differences, to come to the best English wordings.

9.7.6 Data analysis

The two common approaches for data analysis in qualitative research are thematic and content analysis, which are often inaccurately utilised interchangeably (Miles, Huberman, & Saldana, 2014). Both approaches share several similarities, including searching for themes (Vaismoradi et al., 2013) and utilising qualitative description designs (Bradshaw et al., 2017). However, the content approach focuses more on quantifying data (Vaismoradi et al., 2013) and straight description of the data (Sandelowski, 2000), which aligns with qualitative description design.

Therefore, the qualitative content analysis approach was adopted for the analysis and interview data. There are three qualitative content analysis approaches: *summative, directed, or conventional*, in which any approach can be utilised in qualitative description studies (Hsieh & Shannon, 2005). *Summative content analysis* is utilised in studies when the researchers need to quantify and interpret words in their context and explore their usage (Hsieh & Shannon, 2005). *Directed analysis* is utilised in research with existing theories or studies that need a further description of an incomplete phenomenon. In contrast, *conventional analysis* is utilised in studies aimed at description phenomenon, where existing theory is limited (Hsieh & Shannon, 2005).

In this study, a *directed approach* was utilised to provide inductive organisation and interpretation of the narrative responses through generating new patterns and developing themes from the data (Hsieh & Shannon, 2005). The purpose of using the inductive approach is to condense raw textual data into a simple, brief format and link the research objectives and the summary findings derived from raw data to produce reliable and valid results. The inductive content analysis creates transferability by presenting examples of the raw data generated by study participants to determine its fit within their local settings (Patton, 2002). The content analysis was carried out utilising Graneheim and Lundman (2004) five steps, including immersion in the data, meaning units, coding process, creating subcategories, and identifying categories.

Immersion in the data is the first most difficult, complex, and creative step in data analysis. The researcher followed several techniques to become immersed in the data. First, all interviews were audio-recorded in participants' native language of Arabic and transcribed verbatim within the same day of conducting an interview, which helps ensure familiarity with the data. This also helps to recognise gaps in data and unanswered questions and overcome them in the next interviews. The researcher listened to audiotapes several times to ensure the accuracy of the verbal transcription. During the actual analysis, the researcher spent enough time organising the collected data. MAXQDA, a software program designed for qualitative research, was utilised to organise and manage the transcript analysis. MAXQDA aids the researcher in creating a visual image of the data. During this step, the researcher cleaned up the data that seemed irrelevant and unmanageable. The researcher also logged the interview dates, the place where the interview was conducted, and the person with whom the interview was conducted (Table 33). In this step, the researcher also confronted the voluminous amount of data after conducting all interviews. The researcher encountered this issue by arranging at least four-day intervals between each interview to help read and re-read the transcripts and become more familiar with them.

Meaning units is the second step referring to the constellation of the words, sentences, or paragraphs that refer to the same meaning or are related to each other through their content or context. For instance, different aspects of policymakers’ perspectives on PC were selected in an inductive approach (e.g. barriers to the provision of PC from the policymakers' perspective were constellated as a unit and labelled as 'challenges to PC'.

Table 33: Log of data gathering activities

Date	Place	Participant's identity in result quote	Who
09.03.2021	GD of Nursing	(P1, Female, Head Policy Department)	Head of Nursing Policy and Quality Department
14.03.2021	GD of Nursing	(P2, Male, Deputy GD)	Deputy GD of Nursing
18.03.2021	Al-Shifa Hospital	(P3, Male, clinical nurse supervisor)	Clinical supervisor at Al-Shifa Hospital
22.03.2021	Islamic University	(P4, Male, Representative Palestinian Medical Council)	A representative of the Palestinian Medical Council
26.03.2021	Rantisi Hospital	(P5, Male, PC National Committee Member)	Member of National committee of Palliative Care
28.03.2021	EGH	(P6, Female, Head Clinical Nursing Department)	Head of the oncology department at EGH
01.04.2021	Al-Shifa Hospital	(P7, Female, Head Clinical Medical Department)	Head of the oncology department at Al-Shifa Hospital
05.04.2021	Al-Shifa Hospital	(P8, Male, Head Clinical Nursing Department)	Head of the oncology department at Al-Shifa Hospital
09.04.2021	Rantisi Hospital	(P9, Female, Deputy Head Pharmaceutical Department)	Deputy Head of the Pharmaceuticals and Medical Supplies
11.04.2021	EGH	(P10, Male, Head Clinical Medical Department)	Head of the oncology department at EGH
15.04.2021	GD of Nursing	(P11, Male, Nursing Consultant)	Nursing Consultant of Minister of Health
28.04.2021	MOH-Main building	(P12, Male, Medical Director)	Director of Doctors Affairs in Hospital Administration

GD= General Directorate; MOH= Ministry of Health; EGH= European Gaza Hospital

Coding of data is the challenging third step: the tangible action taken during analytic thinking to generate categories and subcategories. Continuous meetings with the expert and supervisors for more in-depth discussion and emerging codes and categories were conducted. Creating subcategories and categories is the main feature of qualitative content analysis. A category is a group of content that shares similar features or attributes (Krippendorff, 2018). Under the auspicious mentorship of supervisors, the researcher inductively coded the first three interviews to confirm agreement on a set of codes and categories. After developing categories and themes, interpretations of data were begun to bring meaning and coherence to the categories and themes. Finally, the final data analysis report was written, coherently and comprehensively. All data analyses were performed under the auspices of the supervisors.

9.7.7 Quality in research/rigour

Rigour is defined as the strength of the research design and the appropriateness of the method to answer the questions (Morse et al., 2002). In qualitative research, the word trustworthiness is used to describe rigour, which can be a challenge because of the approach's contextual and subjective nature (Cronin et al., 2014). To achieve trustworthiness of this research, the Guba and Lincoln (1981) four criteria (credibility, transferability, confirmability and dependability) were adopted, which are the most common approach used by qualitative description scholars.

9.7.7.1 Credibility

Credibility refers to the trust given to accurately describe participants’ perspectives, in that it “rings” true for them (Lincoln & Guba, 1985). It is similar to internal validity in quantitative research, assuming that facts are viewed as valid (Morse & Field, 1995). However, qualitative research acknowledges that there are various facts, and the researcher’s task is to communicate participants’ accounts as accurately as possible (Morse & Field, 1995). In this study, credibility was ensured by accurately identifying and describing participants' characteristics in research and selecting the most appropriate sample size. Probes and prompts were also used through the interviews to gain more in-depth data. Sending the interview guide in advance to participants also helped achieve credibility. Repeat or follow-up interviews were conducted to explore unclear issues from the participants. It was also confirmed by participants’ validation of their statement through summarising participants' interviews. Finally, credibility was ensured by assigning the researcher responsibility for evaluating the data to determine the accuracy of the conclusion.

9.7.7.2 Dependability

Dependability refers to data stability over time and conditions (Cronin et al., 2014). It means that if another researcher repeats the interview with the same participants, the findings should be similar/consistent. This can be checked by external audits (Lincoln & Guba, 1985). In this study, a detailed audit trail of how the data were coded and changes formed to the codes was created in MAXQDA. Revision of the data, audit trail, and participant observations were also reviewed and discussed continuously with both supervisors to confirm that the category/code being identified was accurate.

9.7.7.3 Confirmability

Confirmability focuses on the data's accuracy and meaning in its interpretation (Cronin et al., 2014). This means that the study results should be shaped based on participant responses and not the researcher's point view (no bias). In this study, confirmability was assured by reviewing the data and the audit trail with both supervisors to offer transparency of the entire study process. It was also be confirmed by ensuring reflexivity - the researcher's contextual relationship and position (Berger, 2013). A reflexive diary was maintained throughout the study.

9.7.7.4 Transferability

Transferability refers to “a judgment about whether findings from one context are applicable to another” (White & Marsh, 2006, p. 36). Transferability is the extent to which the qualitative results can be used in other populations or settings like those in the study (Parahoo, 2014). This study's transferability was accomplished via rich description of the setting, participants, and raw data that exemplify the researcher’s interpretations to allow the readers to judge its transferability.

9.7.8 Reflexivity

Reflexivity is a concept that has been embedded in qualitative research to describe the intersecting contextual relationships between the researcher and the study participants (Dodgson, 2019). It is defined as the researcher's ability to recognise that his/her background, experience, and relationship with participants may influence the research findings (Malterud, 2001). Thus, it is essential to clearly explain the positionality of researchers to what is being studied. “Researchers need to increasingly focus on self-knowledge and sensitivity; better understand the role of the self in the creation of knowledge; carefully self-monitor the impact of their biases, beliefs, and personal experiences on their research; and maintain the balance between the personal and the universal” (Berger, 2013, p. 220).

The importance of describing the contextual relationship and position of the researcher is critical for enhancing the research's accuracy and increasing credibility and confirmability of the results by accounting for the researcher’s knowledge, values, and biases (Berger, 2013; Cutcliffe, 2003). Reflexivity helps the researcher to be more objective and aware of their role rather than be biased. Bias can affect the process of data collection and quality of the interpretation of the findings, which may arise from research knowledge, beliefs, and personality.

Reflexivity is also a way to ensure the rigour and quality of the work and determine trustworthiness (Buckner, 2005; Teh & Lek, 2018) in all research process phases (Bradbury-Jones, 2007). For example, during interviews, self-reflection aids the researcher to identify questions and content that he/she tends to focus on or turn away from and be aware of his/her reactions to the participants' thoughts, emotions, and triggers. In content analysis, it helps the researcher to become immersed in the data and comprehensively analyse it.

In the context of the current study, being a researcher and a nurse who had a managerial and clinical position for more than 10 years is one of the main issues to consider in reflexivity. This may create a potential bias while interviewing and analysing the data, since the researcher contacted a number of policymakers who were already known to the researcher by working together in different settings. Discussing my own experiences with my supervisors helped maintain critical self-reflection during data analysis to minimise bias.

9.7.9 Ethical considerations

The general principles of ethical conversations were discussed in previous chapters. As the study participants are known and easily identified, several criteria were considered to adhere to ethical rules of respect and protection. To adhere to confidentiality and anonymity rules, the acknowledgement to de-identify participants’ information (e.g., name, address, cellphone number, identity number, photographs, and e-mail addresses) from any publications. Only the participants' titles were used and not names. The identity of participants in verbum quate in the analysis was identified as (P1, Male, clinical nurse supervisor). For confidentiality, only the researcher knows the identities of the study participants. For data management, the participants' identifying information can be linked to their data using ID codes or pseudonyms. In terms of data security, the researcher protected all audio recorded collected data and the transcripts files by encrypting data files, saved in locked cabinets, and securely destroyed the data after study completion.

Confidentiality was considered in this study, since only the researcher approached participants and collected data by interviewing them. In addition, data analysis was applied by the researcher only. Permission to audio record all interviews was sought and granted. All collected data (recorded and transcripts) were kept in a locked cabinet in the researcher's office, and the raw data was destroyed after study completion. Anonymity was also acknowledged by assigning a code number to each study participant during data entry and analysis, for example, (P2, Female, Head Policy Department). None of the forms used in the study contained the names of the participants or any other such identifying information. Each participant was referred to by assigning a code number during data entry and analysis.

The researcher also considered beneficence and non-maleficence as the fundamental core of ethical principles in this study. The study's findings may recommend the development of the PC programme and improvement in cancer care services. This study does not have the potential to put the participants at risk. The researcher also explained to study policymakers the purpose and the importance of the study, and how the findings reflected positively on PC services provision. The interview time, ranging between 30 and 55-min duration, was taken into account while developing the interview guide, to avoid any reactions.

To protect autonomy, before participants decide, they must understand the risks and benefits of the study. Full understanding can be achieved through an informed consent process. The researcher addressed the issue of written informed consent via the information letter attached with the purpose of the study, assurance about the confidentiality of the information, a statement indicating that participation is voluntary, and they could withdraw from the research process at any time.

9.8 Results

9.8.1 Participant characteristics

A total of 12 decision and policymakers participated in the study. Interviews were conducted from 9th March to 28th April 2021 and were of 30–55-min in duration. Most participants were male and held postgraduate degrees (M.A or PhD). Eight participants had more than 20 years of experience at the Ministry of Health (Table 34).

Table 34: Characteristics of study participants

Characteristics	**Number**
Age	
35-45	5
46-55	3
>55	4
Gender	
Male	8
Female	4
Educational level	
B.A	2
M.A	6
PhD	4
Years of experience	
10-20 years	4
>20 years	8

B.A: Bachelor's degree; MA: Master degree; PhD: Doctoral degree

9.8.2 Qualitative results: categories and subcategories

In-depth semi-structured interviews were applied to gain a broad overview of decision- and policymakers' perspectives on PC. The interviews generated four primary categories and 11 subcategories, as shown in Table 35. Each category and subcategories are presented in detail in the following sections.

Table 35: Categories and subcategories

Category	Subcategory
Nature of current PC healthcare services	• Lack of recognition of holistic PC services • The subordinate status of PC to acute care • Healthcare policies and practice that ignore family needs for PC
Potential benefits of PC	• Healthcare system benefits • Patient benefits
Challenges to PC provision	• Lack of political and social infrastructure for PC • Limited human resources in PC • Unavailability of essential medication
Considerations for PC integration into the healthcare system	• Beginning PC in a centralised location • Development of PC policies • Healthcare professional capacity building

PC: Palliative care

9.8.2.1 Category 1: Nature of current PC healthcare services

This category describes the current health services provided in the GS as highlighted by participants. It comprises three subcategories: available curative health services, PC status, and lack of family support.

9.8.2.1.1 Lack of recognition for holistic PC services

Healthcare services provided to patients with chronic diseases, including cancer, do not provide PC in a comprehensive manner, as reported by the participants. Most of the participants highlighted that despite the varying needs of oncology patients in terms of the nature of the disease and pain, the services they receive are no different from those provided to patients with other chronic diseases. Whether oncology or chronically ill patients, health services are often limited to providing symptomatic management and follow-up potentially highlighting a significant focus on curative services. Despite this finding, participants (5/12) stated that other psychological and spiritual services are available, but that these are not well integrated into the Gaza HCS.

"Patients with chronic disease are treated like any patient. There are no special departments or services to treat or provide to them. Most of the care provided to patients is medical treatment and follow-up in outpatient clinics. About cancer patients, they are not different from the rest of the chronic patients, although they have a special peculiarity, as they are the patients who need psychological, social and other supports the most" (P7, Female, Head Clinical Department)

"...In the Ministry of Health, we have appointed psychologists in every hospital to meet the psychological needs of patients. I mean, we are now starting to take care of this aspect, wherewe felt there was a shortage of service from the ministry". (P11, Male, Nursing Consultant)

"...the psychological aspect has not received the required focus. If we want to say it is ignored, some people may be upset, as they are not completely ignored, but they are not within a specific template or protocol. They are semi-autonomous activities, but we hope, through the work of the mental health committees, that there will be clear protocols and programmes for oncology patients". (P2, Male, Deputy GD)

Participants further noted that the current curative focus of the Gaza HCS did not appear to be commensurate with the needs of patients with cancer. Generally, the services were insufficient, and where they were available, they were often fragmented, and delivery was a significant area of concern:

"...some of the services provided to oncology patients have insufficiency, as most of the services focus on fulfilling the physical needs of the patients. Although some psychological, social, and nutritional support services are provided to cancer patients, they are not provided in a systematic manner". (P11, Male, Nursing Consultant)

9.8.2.1.2 The subordinate status of PC to acute care

Participants pointed out that PC is at the top level of the Ministry's priorities, and it is clearly stated in the Strategic Plan 2021-2025. It is atthe top level of the Ministry's hierarchy due to its importance to GS:

"To be honest, in the Ministry of Health strategic plan 2021-2025, PC is mentioned as one of the priorities. There is a timetable for providing PC within the health system, and it is over the next five years. The Ministry of Health plans to have PC in every hospital in Gaza. Uh, all this is in the plan, but nothing is happening yet". (P12, Male, Medical Director)

"This is a difficult and embarrassing question, specifically for the Ministry of Health, because sometimes the priorities fluctuate. If we talk about the past year, PC was among the main plans of the Ministry. Still, the coronavirus pandemic changes the priorities and focuses on coronavirus… Perhaps in the period beforeCOVID-19, the Ministry's concerns were focused on emergencies due to the return marches and the large number of traumatic injuries resulting from these events. In short, PC is part of the programmes in the strategic plan of the Ministry of Health. Sometimes some priorities could advance, while others might be delayed based on the unstable conditions in the GS". (P2, Male, Deputy GD)

In contrast to the above finding, policymakers working in the hospital who participated in the study noted that PC is not considered a priority by the Palestinian Ministry of Health, considering the ministry's significant focus on other services, such as cardiac surgery, maternal and child health, and emergency services where the chance of recovery is high. Persons with incurable chronic diseases, such as cancer, are often considered out of this scope, due to the long-standing nature of their ailments. Participants felt the attention given to these persons was inadequate, in comparison to the attention given to persons with acute ailments. Participants highlighted that even if PC services were a part of the ministry's strategic plan, there is often a gap between the plan and what happens in practice and reality, as the focus is still on acute care:

".... Of course, PC is not among the MOH priorities. All cancer patients are not among the priorities of the Ministry. You are talking about patients who suffer from chronic diseases throughout their lives, and the Ministry does not care about them. The Ministry of Health focuses on saving cases with hope for recovery, such as a case under operation. I mean, the disease is treated, but the MOH deals with cancer patients as if they are dead". (P9, Female, Deputy Head Pharmaceutical Department)

"I cannot answer accurately whether PC is among the Ministry's priority or not, but I mean they have formed a PC committee, and I am a member of it. I believe that the Ministry has placed PC within the Ministry's strategic plan, but I do not know to what extent. Putting PC into the plan is one thing, and having the capabilities to implement the plan is another thing". (P4, Male, Representative Palestinian Medical Council)

Despite the unclear focus on PC services in the study area, most participants reiterated that PC was needed due to the high incidence of incurable diseases, such as end-stage-renal failure, and cancer:

"...There is a steady increase in the number of chronic patients, and subsequently, their needs also increase. Moreover, the economic situation in Gaza, the blockade, and patients waiting for periods that may extend for months to leave Gaza for hospitals abroad to receive treatment- require care during this period that qualifies them psychologically and physically". (P3, Male, clinical nurse supervisor)

9.8.2.1.3 Healthcare policies and practice that ignore family needs for PC

All participants agreed that no services would support the family due to a general lack of PC policy interest in this regard. Further, healthcare staff seem to have a significant focus on the patient, with little attention to spare for families.

"Of course, there are no services provided to the patient's family. The reason may be due to the lack of interest from the Ministry, and the political situation may also play a role, as most patients are referred to receive service outside the GS. In addition to the pressure on a health system that may play a role in the incompleteness of health services". (P1, Female, Head Policy Department)

Participants noted that most of what is presented to families is information about the nature of the patient's illness. Some participants mentioned a lack of suitable locations (specialized private rooms) to provide information or psychological support. The families are provided with information either between corridors or near a nursing station.

"....I tell you that we want the Ministry to provide a comprehensive services to patients. …We, as a health staff, strive to provide the families with the information they request, as most of them ask about disease progress and the length of time for the patient to live, and we try as much as possible to give them information and support them psychologically.... There is no special place where we provide information. We can only talk to the family in the corridor or at the counter". (P8, Male, Head Clinical Nursing Department)

9.8.2.2 Category 2: Potential benefits of holistic PC

This category discusses the potential benefits of PC provision to the Gaza context. The two subcategories include HCS benefits, and patients with their families, benefits.

9.8.2.2.1 Healthcare system benefits

All study participants noted that PC is an important concept and an essential service for patients in the GS. They attributed the importance of PC because the Strip has a specialty that differs from all other parts of the world, since it has a significant burden of patients with chronic disease. Participants underscored that it might be cost-effective if PC was fully integrated into the Gaza HCS. Additionally, participants mentioned that integrating PC could reduce patient admissions and pressure on the health system, which suffers from an apparent increase in the number of admissions and may positively affect patient recovery.

"PC is critical to the GS...Introducing PC into Gaza hospitals will enhance the quality of services provided as well as will decrease hospital readmission." (P4, Male, Representative Palestinian Medical Council)

9.8.2.2.2 Patient benefits

Participants mentioned that all patients in the GS will benefit from PC. As an order of priority, participants noted that persons with cancer are the most in need of this service, followed by persons with renal conditions. Participants reiterated that patients in these two categories suffer from the symptoms of the disease, including psychological pressure and physical exhaustion. Further, patients with advanced stage disease have a lower curative rate and often end up with severe complications, which require supportive care from well with PC services:

"...by God, in general, the entire GS needs PC (hahaha). Chronic diseases are common. Patients with cancer and patients with chronic diseases are the most people in need of comprehensive and complete PC, because we are talking about a lifelong concern that is not a passing issue, like an acute appendicitis patient". (P2, Male, Deputy GD)

"Oncology and dialysis patients, in my opinion, are the patients who require this service the most. Cancer is common in Gaza, its numbers are very high, and it is increasing. The second thing is that the progress in treatment protocols has allowed patients to live longer. As the disease period increases, the patient will surely suffer from symptoms and therefore urgently needs care and rehabilitation in terms of psychological and other aspects, all of which fall under PC. Dialysis patients spend years undergoing dialysis, and some are young, between 40-50 years old - and the problem in Gaza is that patients of this age is considered old. What about the children in dialysis, of course, they need special care, such as PC, for them and their families". (P3, Male, clinical nurse supervisor)

9.8.2.3 Category 3: Challenges to palliative care provision

This category illustrates several challenges in the provision of PC into the Palestinian HCS, as highlighted by participants. The identified challenges were structured based on the WHO public health model categories, which are summarised in Table 36.

Table 36: Challenges and recommendations for the provision of palliative care in the Palestinian healthcare system

	Challenges	**Recommendations/suggestions to overcome challenges**
Main Subcategory: lack of political and social infrastructure		
	• Lack of PC policies (guidelines, protocols, strategies)	• Adopted neighbour country policies that share Palestinian culture, norms, and system
	• Lack of PC fund/budget allocation - No independent budget for the MOH - All budget-related issues of the MOH are managed centrally with the Ministry of Finance	• External donation - Presence of donors from abroad to fund the PC program
Main Subcategory: limited human resources in PC		
	• Shortage of HCPs	• Hire new staff to overcome the shortage.
	• Lack of specialised experts in PC	• Scholarship/fellowship for professionals abroad
	• Insufficient knowledge and professional training of professionals	• Involve staff in-service training and encouragement for reading PC articles.
	• Misunderstanding and lack of awareness of decision-makers of the concept of PC - Most policymakers linked PC only with pain management.	Prepare workshop for policymakers informing them about the importance of PC for the HCS
	• Cultural barriers, including language - Majority experts who gave training in Gaza speak English.	• Invite Arabic experts in PC for training professionals in Gaza
Main Subcategory: unavailability of essential medications		
	• Lack of continuity in the availability of drugs	• Funding sources from donors to purchase medicines
	• The exploitation from private pharmacy owners	• Establishing strict laws to curb extortion of pharmacy owners
	• The political conflict between the ministries of health in Gaza and the West Bank	• Cooperating with international institutions to supply medicines to Gaza without the interference of the Gaza government

HCS: Healthcare system; MOH: Ministry of health; PC: Palliative care

9.8.2.3.1 Lack of political and social infrastructure for PC

This subcategory presents the policies, guidelines, supportive legislation, funding, and resource allocation that obstruct the provision of PC in the GS. It is found that a lack of PC policies and strategic direction, and a lack of funds/budget allocation is the main political and social infrastructures challenge, as shown in verbal quotes:

A lack of PC policies is one of the challenges in the provision of PC into the Palestinian HCS, as reported by all participants. They attributed the unavailability of policies due to the novelty of this topic in the GS, where the concept of PC has only emerged in the last 10 years. Participants reported that the Ministry could adopt PC policies from neighbouring countries that share our culture and modify them according to the Palestinian health system.

"...of course, the lack of policies is one of the major challenges in introducing PC into the Gaza healthcare system. We do not have national policies for PC. Perhaps because this is a new issue in the country. I think that in the coming years, we will think about developing PC policies". (P12, Male, Medical Director)

"Although there are no PC policies in the GS, which is one of the obstacles, there is no problem in developing policies and adopting the policies of neighbouring countries that are similar to us in system and culture". (Male, Nursing supervisor- Shifa Hosp.)

A lack of fund/budget allocation is another significant challenge to PC provision in Gaza, as reported by study participants. There is no independent budget for the Ministry, and the development problem of the Ministry of Health is related to budgets and funding. The Ministry of Finance manages and distributes budgets to all ministries, including the Ministry of Health. The funding problem could be solved by the presence of donors from abroad to fund the PC programme, as noted in the verbatim quote below:

"…We don't have a specific budget. All budget-related issues of the Ministry of Health are managed centrally with the Ministry of Finance… the Ministry of Health does not have its own independent budget for development; its budget is at the Ministry of Finance…There is no problem with the Ministry in the presence of donors from abroad to fund the PC programme. According to the Ministry's capabilities, the Ministry is ready for logistical support and to provide a place and others". (P12, Male, Medical Director)

As reported by study participants, there is no Ministry of Health representative at the Ministry of Finance. When the Ministry of Health needs a budget to develop or repair equipment, the Ministry of Health officially addresses the Ministry of Finance and waits for their budget approval. Of course, this needs time. The Ministry of Health suffers and struggles until any budget request is approved by the Ministry of Finance. The Ministry of Health often purchases any equipment or tools from its own budget, which is too little to fund and support programmes such as PC.

"...No, no, no one represents us in the Ministry of Finance. There is no special budget for the Ministry of Health, will they develop PC. There was only a budget for the Norwegian project "Pain Management" because it was from external funding, so it had a budget. I mean, if the donor did not support the project, it would not have been accomplished". (P12, Male, Medical Director)

Allocating a separate budget for MOH is required to enhance healthcare services and integrate a PC programme within the Gaza HCS. Seeking funds from external donors is also a strategy for PC provision. In addition, one participant stated that the Ministry requires logistical support to provide funding to enhance the Ministry's capabilities.

"By God, I will lie to you if I promise you. As I told you, we do not have a special budget to develop the basic services of the Ministry of Health, such as purchasing equipment and others, not to talk about PC...To allocate a budget for PC, we need to have a special budget, and this is difficult in the GS because this is an old system, which is that all ministries' revenues are directed to the Ministry of Finance, and the latter is the one that pays salaries, development, and others." (P12, Male, Medical Director)

9.8.2.3.2 Limited human resources (Education and Training) in PC

This subcategory presents the human resources-related challenges (education and training) that preclude the provision of PC in the Gaza HCS. The study participants reported that a shortage of specialised/expert PC professionals, insufficient knowledge and professional training, misunderstanding and a lack of awareness on the part of decision-makers of the concept of PC, and cultural barriers, including language, are the main human resources challenges.

Participants acknowledged the noticeable increase in the number of cancer patients, however the number of health staff working in oncology departments did not increase. There is little employment, compared to the increasing number of patients. Providing sufficient numbers of staff trained in PC is a necessary proactive step before introducing PC.

"A major problem is that we have an increase in the number of cases, but unfortunately, there is no increase in the number of medical staff, including specialised doctors and nurses". (P1, Female, Head Policy Department)

"The number of medical staff is inadequate, creating a burden on the health staff. For example, a nurse works in the department, and we assign him to play an additional role, that of a PC nurse, and this is not acceptable". (P4, Male, Representative Palestinian Medical Council)

"We need to provide sufficient numbers of trained staff to understand what palliative treatment is. These are proactive measures before the introduction of the PC programme in Gaza. All our problems lie in the shortage of health staff with sufficient knowledge to provide PC services." (P2, Male, Deputy GD)

Lack of knowledge and training of HCPs is also one of the significant challenges in the provision of PC in the GS. YouTube and reading articles are the two methods utilised by professionals to gain knowledge about PC, as policymakers highlighted.

"...The most important issue is that we are trained by ourselves, and from my point of view, this training is still insufficient. We do not have staff in Gaza who have trained abroad or have a fellowship". (P7, Female, Head Clinical Medical Department)

"Unpreparedness of HCPs in terms of knowledge and training is one of our problems. The training we are currently carrying out is based on the personal diligence of the committees and YouTube follow-up. No experts are preparing teaching and training material, which is also one of the obstacles". P3, Male, clinical nurse supervisor)

Misunderstanding on the part of decision-makers, of the comprehensive meaning of PC and its importance in enhancing services and reducing hospital admission, is another challenge in the provision of PC. Many policymakers have linked PC with pain management only. Some of the participants suggested convincing policymakers about the benefits of PC through talking to them, as noted in the verbatim quotes below:

"We don't fully understand the concept of PC. PC may mean that the patient lives the remaining days of his life without pain. Most of our focus is on pain medication, such as morphine". (P2, Male, Deputy GD)

"...During the first international PC conference held in the GS in 2018, the Deputy Minister of Health said that we have now two PC teams in the GS. The first at Rantisi Hospital and the second at Shiffa Hospital. I told him no, at Shiff Hospital there is a pain management unit, which is different from PC" (P4, Male, Representative Palestinian Medical Council)

".....policymakers are not aware of the importance and benefits of PC. I think it is important for people who have experience in this field to knock on doors and talk with decision-makers about the importance of PC". (P1, Female, Head Policy Department)

Some participants underscored there are many workshops conducted in the GS on PC. Most of these workshops were presented by English speaking experts. This is an obstacle for most attendees, who do not understand what the lecturers say, so their comprehension is minimal. She suggested inviting Arabic native experts who are knowledgeable about the Arab culture and norms.

"…I prefer to attract experts who speak Arabic, because a number of health teams find it difficult to understand English. We know medical terms, but there are words we don't know. For example, my English is weak, and this honestly did not make me benefit a lot from the course, because I could not understand the whole course". (P7, Female, Head Clinical Medical Department)

9.8.2.3.3 Unavailability of essential medicines for pain and symptom management

This subcategory presents the challenges to the availability of essential medicines from participants' perspectives. All participants reported that the unavailability of drugs is one of the main challenges to PC provision in Gaza, including a lack of continuity in the availability of drugs and the exploitation of private pharmacy owners.

Although the Ministry of Health has adopted the WHO essential drug list, many essential medications are unavailable or intermittent (not constantly available). Unavailability of medications is reported as a significant challenge for providing PC in Gaza, as reported by study participants. The lack of these medicines forces the patients' families to buy them, which is a burden, considering the siege and the increase in unemployment and poverty in the GS. Policymakers attribute the unavailability or interruption of medicines to political quarrels between the Ministry of Health in the GS and the Ministry of Health in Ramallah, and a lack of funds to purchase medicines, as the Ministry relies on foreign donations. The political situation in the country has affected the development of health services and limited it to acute care services only, not PC, which may arguably form a part of essential services.

"Of course, we, as the Palestinian Ministry of Health, adopt the WHO essential drug list. Unfortunately, many medicines are not available for several months, and this is a problem that affects the lives of patients…Continuous interruption of narcotic drugs is among the problems. The interruption and lack of medicines can last for a month or two, and patients suffer a lot from that…. this requires families to buy them". (P9, Female, Deputy Head Pharmaceutical Department)

"…The stores of the Ministry of Health in Gaza do not contain medicines. I mean, those here in Gaza don't want to buy medicines from their budget and wait for the Ministry of Health in Ramallah to send them medicine. Here, the patient is in a big problem between the two ministries and the conflicts between them". (P10, Male, Head Clinical Medical Department)

"…For instance, the medicine of Bicalutamide, that the patient takes at home - of course not available in the Ministry… There are medicines that you find available this month and the next month they will not be available.... The interruption and lack of medicines can last for a month or two, and patients suffer a lot from that." (P9, Female, Deputy Head Pharmaceutical Department)

The unavailability of chemotherapy drugs forces physicians to refer patients to hospitals in the West Bank for treatment and return to hospital in the GS to complete their follow-up, which constitutes a psychological, physical, and material burden on patients. In terms of PC medications, many medications are also not available, affecting the lives of patients who suffer from psychological, physical, and other problems.

"…we are forced to refer a patient to Ramallah for treatment due to the unavailability of medicine in Gaza. I mean, if treatment were available, we would spare the patient the suffering of travel. Some patients travel only to receive a dose of medicine, although we have the capabilities in Gaza to give doses, but the medicine is not available". (P12, Male, Medical Director)

"Currently, Tramadol is available at hospitals– which has been cut off for a while. I mean, before a few months ago, Tramadol was not available. Oxycodone and morphine are

> *constantly available, they have been available for more than two years…. Doctors say we don't want to start with oxycodone, I want to start with the lightest, Tramadol. But unfortunately, its lack of availability forces the doctor to start with strong narcotic drugs. Another example is that some patients with tumours become constipated, as they need Avila, which is cut and unavailable. And this is what most colon cancer patients need.... Enanstrone medicine for vomiting is also cut. Psychological medications are very neglected. I mean. Medications for depression do not reach our hospital, although many patients and their families need it. I do not know the reason, maybe because there is no psychiatrist in the hospital, which might be one of the causes of neglect." (P9, Female, Deputy Head Pharmaceutical Department)*

A problem that patients face when seeking narcotic treatments from private pharmacies is extortion by some pharmacy owners. They either raise their prices or inform patients that they are unavailable and sell them to other customers, who are addicted to the medication and are willing to pay a high and exorbitant price. To overcome this problem, the Ministry of Health, in coordination with some pharmaceutical companies, provides narcotic drugs, such as Tramadol, in hospital, to avoid such extortion.

> *"Some doctors write a prescription for the patient so they can buy it from external pharmacies, but unfortunately, some pharmacies say they do not have it, they hide it and they sell it to addicted people at a higher price. It means the patient has lost. Or if the outside pharmacist wants to sell Tramadol, he sells it at a high price for the patient. I mean the addicts in Gaza have ruined things for patients. I mean, some pharmacies blackmail patients and sell them treatment at a high price. Hence, the Ministry has directed the provision of Tramadol at the hospital, and an agreement took place with the Dar Al-Shifa Company for Medicine to supply medicines inside hospital pharmacies." (P9, Female, Deputy Head Pharmaceutical Department)*

When addressing strategies to solve the unavailability or interruption of medicines, participants indicated that separating health services from political conflict is very important for the sustainability of medication delivery. Seeking donors is also essential to purchase costly medications that are stressed on the MOH budget. Hospitals have also purchased medications to prevent intermittent medication availability.

"...we just want money to solve the problem of the medicine. I mean, if the dispute between Gaza and Ramallah is resolved, the whole problem will be resolved. I mean, most of the medicines that are cut off in Gaza are available in Ramallah. Because of the conflict and division, we have two ministries, one in Gaza and the other in Ramallah, and the people and patients are lost between them. I mean, hospitals in the West Bank, the health service situation is excellent, and all medicines are available, but Ramallah punishes Gaza, so some medicines are prevented from reaching them, but if there is reconciliation, I think things will improve and medicines will be available". (P12, Male, Medical Director)

9.8.2.4 Category 4: Consideration for PC integration into the healthcare system

This category describes the actions needed to integrate PC into the current HCS. It compromises three subcategories: establishing PC in a centralised location, the development of PC policies, and healthcare professionals’ capacity building (education and training).

9.8.2.4.1 Beginning PC in a centralised location

The hospital-based approach is suggested by participants as the “best to begin PC”, within the context of the Gaza situation, as policymakers have mentioned. Most patients are diagnosed in advanced stages and need treatment in hospital - and our potential (shortage of staff) in Gaza does not allow the Ministry to adopt any of the other approaches (such as home-based and community-based approaches), as noted in the verbatim quotes below:

"The GS being small, I believe that we need a PC programme in the major hospitals. For example, the PC unit in major hospitals and three community teams cooperate with these hospitals. We need a hospital approach for acute cases for patients hospitalised for one or two days. Then when the patient is discharged home, they will be followed by telephone or visited at home". (Male, A representative of the Palestinian Medical Council)

"From my point of view, it is best to apply PC at the hospital, because we know the patient’s condition. All people need PC, even those at home. But as I know their situation and needs, I think the hospital is better for them. It is better at the hospital, as we are a

small setting and patients visit us easily to receive the services they need...Within our plan, we have home visits for patients. Unfortunately, we haven't been able to apply it because we need transportation and more staff for this work. There is no car available for the doctor and nurse to visit patients in their homes". (P7, Female, Head Clinical Medical Department)

9.8.2.4.2 Development of PC Policies

Developing policies in the upcoming five years is the main task of the Ministry of Health, as reported by participants. There are protocols for treating each type of cancer, but policies and protocols for PC are not yet available or developed. A special national committee for PC was formed, and its tasks included developing policies and protocols for PC treatment.

".... During the next five years, policies for cancer and PC will be developed, reviewed by experts, and we will train our staff on them". (P1, Female, Head Policy Department)

"There are treatment protocols for cancer, and these are drug protocols according to the type of disease and the degree of its progression. Also, chronic diseases have their own protocols. There is no problem in the availability of treatment protocols and policies, despite the siege". (P2, Male, Deputy GD)

9.8.2.4.3 Healthcare Professional Capacity Building (Education and Training)

As reported by participants, investing in HCP education and training should be considered while developing PC in the GS. They emphasise integrating PC within the curricula and encouraging training in a clinical context. Participants underscored that several activities have been applied since 2011 for disseminating the PC concept among professionals, particularly physicians and nurses. For instance, in 2011 and 2015, many training courses have been conducted in partnership with experts from Britain and Scotland, held at the Islamic University.

While in nursing, what is being trained is courses related to oncology, and these courses included a two-hour PC lecture. These nursing courses were based on personal diligence from supervisors and heads of oncology departments in hospitals. These courses touched on essential aspects related to the WHO model. They focused on QOL - communication - psychosocial issues and how to break bad news.

"...In 2011, I began another initiative to spread the culture of PC among physicians, because the idea did not exist at all. This is the reason I did not know anything about PC... From 2011 until 2015, five workshops were carried out for medical staff... In 2015, I started expanding this work by including an expert PC team from Britain and Scotland ... We formed a steering committee for PC, and the committee's goal was to spread the culture of PC and integrate it into the medical, nursing and physiotherapy student curricula, and present it within the services provided by the Palestinian Ministry of Health and the UNRWA". (P4, Male, Representative, Palestinian Medical Council)

"We do not have a training plan in the current period. We only train the nursing staff who work in the oncology departments on topics related to oncology... The programme (training material) was prepared by experienced nursing supervisors working in oncology departments. The material was not built based on the needs of the nursing staff, but rather based on the experience of the Oncology Committee". (P1, Female, Head Policy Department)

The focus on education and training emerged after establishing a PC Steering Committee in 2015, including a representative from the World Health Organization, Ministry of Health, Azhar University, Islamic University, private hospitals, UNRWA, NGOs, and Palestine Children's Relief Fund. This committee aimed to spread the concept of PC more widely in the GS and integrate it into the curricula of doctors, nursing, and physiotherapy and provide it within the services provided by the Palestinian Ministry of Health.

In 2016, a new subject was incorporated into the curriculum of the Faculty of Medicine at the Islamic University, called PC and Pain Management. In the same way, lectures related to PC were integrated into the College of Nursing and the College of Physiotherapy curriculum at the Islamic University. The work effort was expanded to include the Department of Dawah and Fundamentals of Religion, who were persuaded of the importance of their role in PC.

The study participants acknowledged that nurses have an interest in the knowledge of PC. At the same time, some indicated that the general situation of a lack of salaries (incentive) affects staff encouragement and interest in developing themselves and keeping pace with science.

"…there are many reasons, as we recently started training the staff and we only focus on nursing. I think nurses are more familiar with the concept of PC than doctors. Doctors do not read about this aspect compared to nurses in the GS, who are interested in PC… Also, in the curriculum, the concept of PC is not comprehensively and adequately addressed". (P1, Female, Head Policy Department)

"…We have focused on PC in recent years in hospital, so the healthcare staff will certainly have limited knowledge. The number of courses that dealt with PC is few, and their duration is very, very short, and they were limited to nursing only and medical students at the Islamic University. Physicians working in hospitals need training that is not targeted in PC courses. Also, we did not focus in our courses on Advanced PC, it was the concept in general". (P3, Male, clinical nurse supervisor)

9.9 Discussion

This is the first qualitative study to explore the decision and policymakers' perspectives on providing PC services into the HCS of a country with limited resources. The current PC healthcare services provided to Palestinian patients with life-threatening illnesses and their families are fragmented. There is a Palestinian national strategic plan for developing PC; however, the development goals are not clearly defined in the plan, and the capacity to implement the plan is inadequate. Several challenges to the provision of PC in Palestine were related to education and training-related issues, funding allocation and medications availability.

Providing optimal care to the patients at the end of life influences health outcomes (Afshar et al., 2019). Most healthcare services provided to Gazan patients are often fragmented and limited to treating the symptoms of a disease and side effects caused by the treatment of a disease. Fragmented healthcare services may negatively affect patients' treatment regimens and daily living activities (World Health Organization, 2017). Several studies underscored a high prevalence of distress and poor QOL among Palestinian patients with life-threatening diseases, including cancer (Salah, Reyala, & Al Jerjawy, 2018; Shamallakh & Imam, 2017), which might be attributed to the limited healthcare services tailor-made to meet the needs of this specific patient group. Limited and underdeveloped healthcare services are ascribed to limited resources and the ongoing siege of GS since 2007 (Halahleh & Gale, 2018). Enhancing end-of-life patient health outcomes is the most cost-effective method for countries with limited resources (Smith, Brick, O’Hara, & Normand, 2013) which can be achieved through integrating PC with the HCS. The WHO has recommended integrating PC within HCS as one of the cost-effective mechanisms to provide optimal care for patients and their families (World Health Organization, 2002, 2017) and alleviate their distress (World Health Organization, 2017).

Families play a substantial role in providing support to end-of-life cancer patients (Lapid et al., 2016). They are highly influenced by the disease’s challenges and changing roles related to the patient's illness (Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010). They have experienced fatigue, anxiety, depression, sleep disturbances, and burnout (Golics, Basra, Finlay, & Salek, 2013). There are no services to support families in the GS, either during active treatment or in the bereavement period. Lack of family support services has a subsequent negative impact on the QOL (Cui, Song, Zhou, Meng, & Zhao, 2014) and daily living of both family caregivers and patients (Drabe et al., 2008). As stated by the National Institute of Health on End of Life Care, addressing the needs of families is essential, especially when preparing a loved one for death (Dahlin, 2005). Families are required to handle their psychological and emotional distress, patient care, and concerns about the future. Introducing PC services within the Gaza HCS is therefore essential to address families' needs before and after a patient's death. Follow-up care for bereaved families should be considered to address any consequences of losing the beloved person.

Designing a comprehensive national strategic plan is essential for the successful development of PC (Koh et al., 2017). There is a Palestinian national strategic plan for developing PC; however, the development goals are not clearly defined, and capabilities to implement the plan are limited. The results of this study are similar to those reported in most low resource countries (Lau & Pickersgill, 2019; Silbermann et al., 2015). There is a need to have sufficient HCPs and PC specialists deployment to achieve strategic plans (Connor & Sepulveda Bermedo, 2014). Malaysia and South Africa, for example, have adequate PC specialists; however, the shortage of staff (physicians and nurses) who support specialists is still a major problem for PC implementation (Lau & Pickersgill, 2019; Stockley & Forbes, 2019). In Palestine-GS, the problem of staff shortages and lack of PC experts is complex. Investing in PC training is a necessary proactive step before introducing PC in the Palestinian HCS.

Several challenges to PC provision in the GS were identified in this study. The identified challenges are similar to what has been documented in both high-income countries and LMICs. Insufficient PC knowledge among HCPs (LeBlanc et al., 2017) and lack of a trained PC workforce (Abu-Odah et al., 2020; LeBlanc et al., 2017) were the main challenges identified in the literature. In Palestine, the low level of knowledge of HCPs is attributed to the emerging PC concept in GS. There is no PC diploma or Master's degree to train specialist professionals in PC in the GS; and PC training has not yet been integrated into university curricula. In 2015, PC was only incorporated into the curriculum of the Faculty of Medicine at the Islamic University as an intensive short subject for five days, including hospital training (Coghlan, Leng, Shamieh, Elessi, & Grant, 2019). Accreditation bodies, such as the Ministry of Higher Education Accreditation Commission, should integrate PC into the Palestinian university educational curricula. Making PC compulsory in courses leading to basic professional qualifications is one of the main strategies called by the WHO (WHO Expert Committee on Cancer Pain Relief and Active Supportive Care & World Health Organization, 1990). Several countries with a success story in PC development indicated the importance of transferring and incorporating education in PC within the existing HCS (WHO Expert Committee on Cancer Pain Relief and Active Supportive Care & World Health Organization, 1990).

Insufficient knowledge of HCPs might also be attributed to cultural barriers-language. Because of globalisation, it becomes easy for organisations to host international experts for workshops, and attendants/participants interact in a foreign language in the workshops (Shadiev, Chien, & Huang, 2020). Most workshops given to professionals in GS were presented by English speaking experts. Not every professional completely comprehends the lecturer's communication content in a foreign language. The responsible bodies in the GS should consider and overcome this critical issue by inviting Arab experts for training in PC.

A workforce shortage and specialised experts in PC were commonly identified challenges. There is a significant shortage of specialised PC experts globally (Abu-Odah et al., 2020). Shortages of professionals may affect the quality of services provided to patients (Lupu & American Academy of Hospice and Palliative Medicine Workforce Task Force, 2010). Due to financial constraints in the GS, which may prevent the hiring of new staff, the government can adopt volunteers as substitutes to overcome the workforce shortage (Centeno et al., 2015). Utilising volunteers in caring for and providing health and education support is considered an efficient mechanism in LMICs for lowering the economic burden of delivering PC services (Scott & Kelly, 2014).

Other unique challenges affecting the provision of PC in the GS are misunderstanding on the part of policymakers about the PC concept, a lack of policies and legislation for PC, limited resources, and unavailability of narcotic drugs. These challenges are congruent with those reported in LMICs (Abu-Odah et al., 2020). Palestinian policy makers' restricted their recognition of PC to the scope of mental health, which is not aligned withthe WHO definition (World Health Organization, 2017). To date in the GS, there have been no PC policies developed. The provision of PC in a country's HCS requires policies supporting and measuring provision progress (Sleeman et al., 2018). PC policies have been suggested as a significant driver for introducing optimal care (Sleeman et al., 2018). According to the Atlas for PC in the Eastern Mediterranean region, Jordan, Lebanon, and Qatar have developed national policies for providing PC services (Osman et al., 2017). Sudan has established a national cancer control programme that sheds light on early detection, prevention, enhanced treatment and PC (Hamad, 2006). Although Palestine has also designed comprehensive national cancer control programmes, gaps in the cancer control strategy were reported (Abo Ammer, 2012). These gaps are mainly related to financial constraints, poor administrative coordination, shortages in human healthcare resources and an inadequate workforce, which affects the development of PC services (Abu Hamad et al., 2016). The Gaza context plays a role in determining the priorities of the MOH in terms of the services they provide.

The unavailability of narcotic drugs is one of the challenges in the provision of PC in LMICs (Abu-Odah et al., 2020). In the GS, it has been a significant problem since 2007 (Humaid, 2018), where about 60% of cancer drugs are unavailable (Middle East Monitor, 2021). The unavailability of drugs is attributed to the Palestinian political division/tensions and siege of Gaza for the past 14 years. The MOH in GS strives to overcome the shortage of drugs by searching for substitutes, including cooperation with national and international organisations to provide narcotic drugs. Because of the exposure of some families to exploitation from private pharmacy owners, who raise the price of drugs, establishing strict laws that punish extortionists who are proven guilty, such as closing pharmacies, fines for the pharmacist and imprisonment, are needed to control such unethical activities.

For the future provision of PC into the Palestinian HCS, the study participants acknowledged a hospital-based PC approach as the best approach to be introduced into HCS. No evidence has been reported about which approach best fits the setting (Brazil, 2018). Decisions about what types of approaches are suited are based on country context, resource availability, and the goals of their HCS (Shaw, Rosen, & Rumbold, 2011). However, the WHO strongly recommends integrating PC within hospitals, particularly in countries with a high number of incurable chronically-ill patients (Soueidan et al., 2018). In Palestine, there is a significant number of patients with advanced-stage disease (Abdalla, Mansour, Ghanim, Aia, & Yassin, 2019). The effectiveness of adopting such an approach has been underscored in recent studies, including decreasing length of stay (Kyeremanteng, Gagnon, Thavorn, Heyland, & D'Egidio, 2018) and reducing hospital costs (Kyeremanteng et al., 2018). Therefore, a hospital-based approach seems the best fit for the Palestinian situation to overcome scarce financial resources, a shortage of staff, and limited infrastructure.

9.10 Implications for clinical practice, education, policy, and research

This study sheds light on the main areas that need to be considered to develop PC from decision-and policymakers’ perspectives. For clinical practice, investing in staff training is a necessary proactive step before introducing PC in Palestinian HCS to overcome the staff shortage, through cooperation with international PC organisations for training staff, sending staff abroad to gain postgraduate education in PC, and attracting international

Arabic speaking experts to Gaza for in-service staff training. Providing ongoing support to families is required to handle their psychological and emotional distress, patient care, and future concerns. Introducing PC services within the Gaza HCS is essential to address families' needs before and after a patient’s death.

For policy, there is a dire and urgent need for the Palestinian government to develop policies that align with national laws and engage decision and policymakers in national dialogues to set country priorities. Once these policies are formulated, several challenges to PC delivery would be resolved. The presence of policies will ensure the standardisation of care, sustainability in the availability of narcotic drugs, adequate funding, and standardisation of PC education. Because of the exposure of some families to exploitation from private pharmacy owners who raise the price of drugs, establishing strict laws that punish extortionists who are proven guilty, such as closing pharmacies, fines for the pharmacist and imprisonment, are needed to control such unethical activities.

For education, accreditation bodies such as the Ministry of Higher Education Accreditation Commission should ask for PC to be integrated into the Palestinian universities’ educational curricula as an obligatory course. There is also a need to establish high degree programmes in PC to overcome the shortage of PC specialists. Most training programmes did not effectively contribute to professional knowledge and skills, as they are not built on professional needs; thus, healthcare professionals need an assessment.

Our study raises several opportunities for future research. First, even though policymakers were interested in the provision of PC into the Palestinian HCS, the problem lies in the unavailability of practical guidance or steps to integrate PC. There is little guidance available on how integrated PC could be into the HCS, considering the country's context (Payne, Hughes, Wilkinson, Hasselaar, & Preston, 2019). Thus, research is recommended to develop operational guidance on integrating PC into countries’ HCSs, based on their constrained healthcare budgets, and what should be prioritised for implementation. Second, a study is also warranted to comprehensively understand the non-governmental organisations' policymakers' perspectives on PC and how to cooperate in providing these services into the HCS. Findings also showed that professionals possessed insufficient PC knowledge due to language barriers. Third, further interventional research is also warranted to evaluate the effectiveness of Arabic PC educational programmes on healthcare professionals’ knowledge of PC. Finally, studies are required to determine the needs, problems, and distress of families of cancer patients in the Gaza Strip. Psychological intervention programmes, such as Family Focused Grief Therapy (Kissane et al., 2006) and psychoeducational programmes (Hudson et al., 2008) positively reduced distress among PC families, are recommended for alleviating distress. Follow-up care of families is also needed to mitigate any negative consequences.

9.11 Study strengths and limitations

Utilising semi-structured interviews may prevent participants from expanding their perspectives regarding the topic compared with unstructured interviews. However, our participants reflected a variety of specialties and leadership roles. Interviewing well-known decision- and policymakers may prevent them from talking freely about PC-related issues, such as funding.

9.12 Conclusion

This study reveals that Palestinian decision and policymakers view PC as an important service that should be implemented into HCS. PC services are still limited because of the significant challenges that obstruct the development of PC into HCS. Integration of PC into Palestinian university educational curricula as a compulsory course and establishing higher degree programmes in PC to overcome the shortage of PC specialists is required. Developing policies aligned with national laws could help enhance healthcare services to patients and their families and resolve several challenges. Cooperation with national and international institutions for funding allocation could help in PC development and medication availability.

The next chapter will bring the main results of the three separate studies to draw a conclusion that will contribute to implementing a PC programme into Palestine's HCS.

CHAPTER (10): SUMMARY AND CONCLUSION OF THE ENTIRE RESEARCH THESIS

10.1 Introduction

This is the last chapter of this doctoral research thesis, which presents the main findings and recommendations of the three studies to draw a map guiding the development of a PC programme into the Palestinian HCS. The findings serve as a point for a discussion on how to move forward in providing a PC programme into the Palestinian HCS. The methodological issue of the doctoral research thesis is also discussed in this chapter. The chapter ends by outlining activities that will guide the government in integrating PC into existing HCS, future research that should be done to have a complete picture of PC development, and the conclusion of the entire research thesis.

10.2 Research thesis key findings and recommendations

This doctoral research study aimed to contribute to the development of PC programme into the Palestinian HCS through exploring the factors and needs associated with PC from different key stakeholders' perspectives. The research thesis was guided by the WHO Public Health PC Model (Stjernsward et al., 2007; World Health Organization, 1990) and the SEM (McLeroy et al., 1988). Both models provided a solid-based framework covering all factors and needs that may affect the development of PC programmes: 1) implementation of service needs, 2) education and HCS, and 3) policy-related issues. Ideally, assessing these three components is the first step before developing a PC (Maetens et al., 2019; Stjernswärd et al., 2007). To address the aim and objectives of the three studies, a multimethod research design was adopted. The main findings of the three studies presented in the following sections have provided the researcher with valuable information that helps write an outline of activities that will guide the government in developing PC into HCS (Figure 9).

10.2.1 Implementation of service needs

- The advanced cancer patients exhibited a wide range of unmet service needs, particularly in physical- and psychological-related issues, followed by health informational needs.

- Most patients showed a high level of physical distress related to fatigue and pain, which were the leading causes of physical distress. Psychological distress was also common among advanced cancer patients, and the main common distress symptoms were fatigue and pain (physical problems).

- Unmet care needs were independently associated with physical symptoms and psychological distress. Advanced cancer patients with a high level of physical, psychological, and patient care and support care needs were more likely to have poor QOL.

- The findings drawn from the first study indicated the direction of developing a PC programme within the Palestinian HCS. Patients have a greater need for different types of services, including physical and emotional/psychosocial, which should be offered within the HCS, particularly within the routine delivery of care.

10.2.2 Education and HCS

- The Palestinian nurses and physicians reported limited training and insufficient knowledge about PC, particularly in terms of pain, dyspnoea, and gastrointestinal problems.

- Professionals had positive attitudes toward EoLC and the care of dying patients.

- Educational level and previous training in PC were independently associated with HCPs’ knowledge and attitudes towards PC. The short duration of the training period influenced the quality of training materials delivered to participants.

- The majority of HCPs would like to learn more about PC to enhance their knowledge and attitudes.

- Discharge planning for patients with chronic illness was the common PC service available at Gaza hospitals.

- The unwillingness of patients/families to talk about death and lack of training for staff related to PC were common barriers in providing PC in Gaza.

- This study recommended the integration of formal and informal education about PC within care services and the health studies curricula. Educational and training programmes should be comprehensive, covering PC's basic and advanced principles, including gastrointestinal and psychiatric problems and pain management. These programs should be designated and revised by an expert before introducing programmes to HCPs.

10.2.3 Policy

- The current PC healthcare services provided are not comprehensive and are limited to symptomatic management.
- Misunderstanding of decision- and policymakers of PC, which they connected to the scope of mental health.
- The goals of developing PC in the Palestinian national strategic plan are not clearly defined, and capabilities to implement the plan are inadequate.
- Education and training-related challenges were the frequent challenges in the GS, followed by funding allocation and medication availability.
- A hospital-based approach seems the best for implementation into the HCS that fits the Palestinian content.
- This study recommended developing policies aligned with national laws and engaging policymakers in a national dialogue to set country-wide priorities. It is also recommended for integration of PC into Palestinian universities' educational curricula as a compulsory subject.

Application of the WHO Public Health PC Model and the SEM in practice based on findings grasped from the three studies are recommended, as they contribute to a comprehensive understanding of the unmet service needs of advanced cancer patients, how professionals' knowledge and education affects patient needs, and the role of decision and policymakers in developing PC policies towards enhancement services and improving professionals' knowledge and training. The next section will discuss the methodological issues, outlining activities that will guide the government in developing PC into existing HCS, and future research.

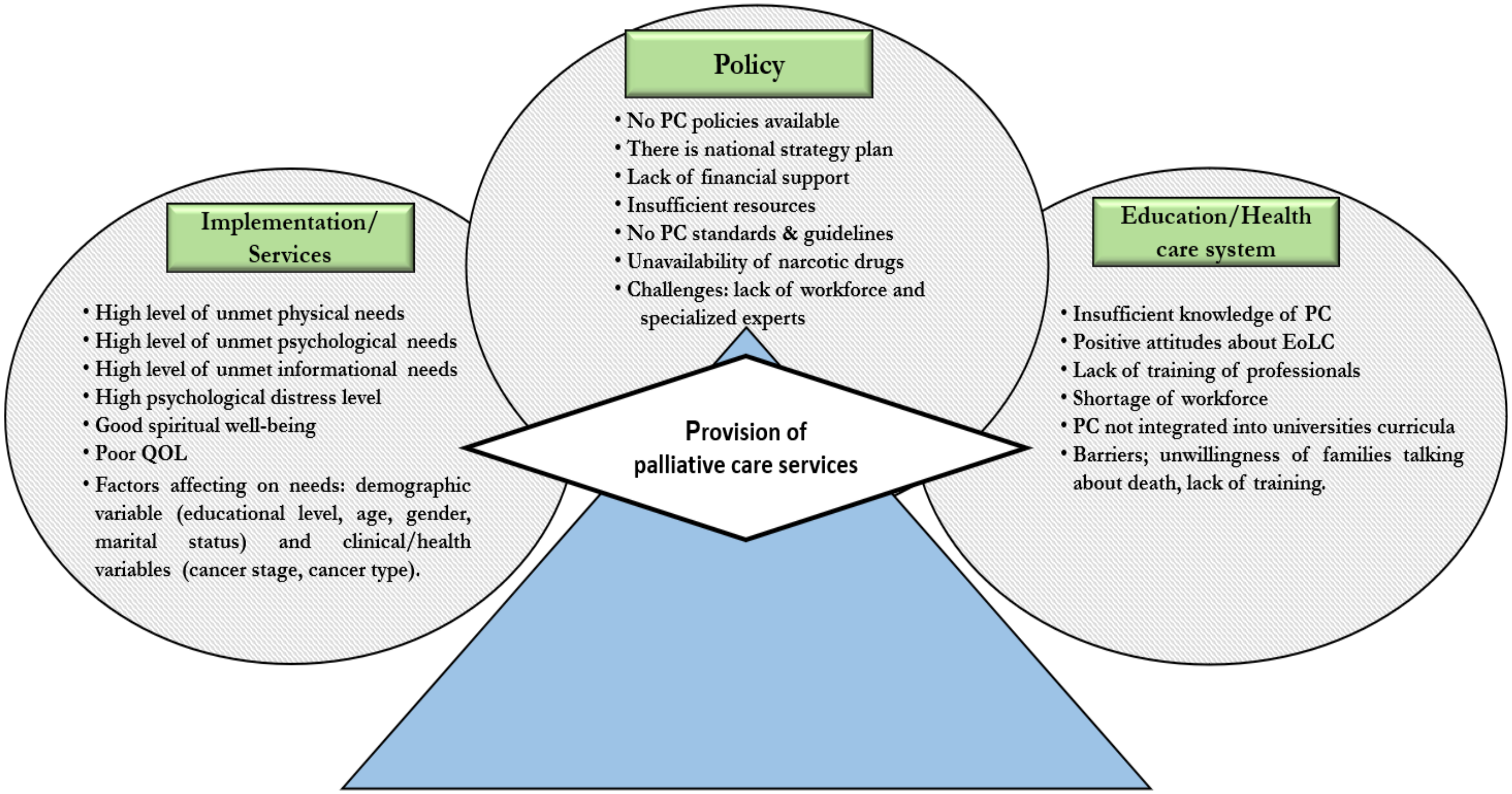


Figure 9: Main study findings based on the proposed conceptual framework for the current doctoral study

10.3 Discussion of the methodological issues of the entire research thesis

As aforementioned, a multi-method research design was employed in this research thesis, which enhanced the robustness of our understanding of the research (Mingers, 2001). The multi-method research design used different approaches/methods to form essential, comprehensive and workable solutions/components of one research programme (Creswell & Clark, 2011; Morse, 2003). This design provided an opportunity to study a multitude of variables associated with PC from different key stakeholders' perspectives (Mertens, 2014). Looking at the research from different angles/variables provided the doctoral researcher with an opportunity to look for corroboration in the results from different methods (Brewer & Hunter, 1989; Greene et al., 1989) and provide a comprehensive depth and breadth understanding of this doctoral research thesis. Adopting the multi-method research design reinforced the doctoral researcher to overcome the time limitations of the data collection period. This strategy helped the researcher collect both types of data simultaneously, as they are not dependent on each other. Thus, this strategy was efficient and feasible for the circumstances of this doctoral research thesis.

Adopting a quantitative design in the first two studies (Chapters 7 and 8) as our aim to analyse data from the population in time, looks at several characteristics at once, and provides information about the current population status. It is applicable to conduct qualitative research in the first two studies for a comprehensive understanding of patient needs and professional educational and HCS-related issues. However, our aim is to quantify the unmet needs of patients and the gaps in education and HCS to support the provision of PC. Sequential mixed methods exploratory design can be applied in the first study for an in-depth understanding of the high level of physical and psychological unmet needs among advanced cancer patients in the GS. It will help us to look at why sexual needs were ranked the lowest; whether they are related to cultural issues and the Islamic religion. In the third study, we adopted a qualitative description approach to construct and understand the views of policymakers on PC, not to interpret with the data.

10.4 Outline of activities that will guide the government in developing palliative care in the existing healthcare system, based on the findings of the doctoral thesis.

Palliative care is recognised as a human right by the International Covenant for Economic, Social and Cultural Rights (Brennan, 2007; Gwyther, Brennan, & Harding, 2009) and the WHO (World Health Organisation, 2020b). However, PC services are still unavailable in Palestine, despite the growing number of patients diagnosed with advanced cancer and other life-limiting illnesses, the high burden of non-communicable diseases and the rapidly ageing population. Particular challenges to the provision of PC in Palestine were knowledge deficits and misunderstandings on the part of HCPs and policymakers about PC and an inadequate number of trained workers. In addition, the unavailability of narcotic drugs has been considered a key problem since 2007 (Humaid, 2018; World Health Assembly, 2019), as more than 60% of cancer drugs are not available in the GS (Middle East Monitor, 2021).

Several countries have successfully developed PC into their HCS, adopting strategies to overcome challenges and successfully implement PC into their HCS. Education and appropriate policies were the most frequent strategies covered by all pioneering countries (Abu-Odah et al., 2021). These adopted strategies are aligned with the WHO Public Health PC components (Stjernsward et al., 2007; World Health Organization, 1990).

Most of the pioneer countries focused on cancer when they developed their PC programmes before introducing them to other groups of patients with EOL and PC needs (Connor & Sepulveda Bermedo, 2014). This is a reason why this research thesis focused on cancer patients. Other reasons are that most cancer patients in LMICs, including Palestine, are diagnosed at an advanced stage (Bray et al., 2018; World Health Organization, 2018a), making them more inclined to experience severe pain and distress (Abu Hamad et al., 2016). In Palestine, cancer is the second leading cause of death, with an expected increase in the number of cancer deaths in the upcoming years (Palestinian Ministry of Health, 2019). Considering the ethical imperative to provide PC for all patients with life-limiting illnesses, many of the questions asked in Studies Two and Three (Chapters Eight and Nine, respectively) are not specific to cancer PC. The questions were focused on PC educational and training needs, the availability of PC services, barriers to the provision of PC, existing and new policies (strategies, plans, resources, directives), and essential medicine for pain and symptom management. Cancer was used as a working example to explore people's suffering in a country with no PC services, but the results are applicable to other life-limiting illnesses.

Based on the aforementioned thesis’ main findings and pioneering countries recommendations, this thesis provides a comprehensive outline of activities that will guide the government on how to implement PC in their HCS to achieve the vision of a comprehensive care service delivery in Palestine, as follows:

Setting appropriate PC policies

Developing appropriate national PC policies is the first and most frequent strategy to implement PC into their HCs (Abu-Odah et al., 2021). In Palestine, there are no policies to support the provision of PC into the HCS. A national policy makes it possible to set goals and ensure universal access. The Palestinian MOH should develop comprehensive national policies, including the following elements:

- The process of PC provision into HCS,
- Ensuring the continuum of care (primary, community, home, to hospital-based care services),
- Ensuring equitable access to PC care to all patients in need,
- Financing and insurance mechanisms,
- Identification of resources to support the provision of PC.

The Palestinian government should involve national and international partners when planning its policies. Partners will be instrumental in supporting the development of national PC policies (Luyirika et al., 2016). The partners should include the following:

- Ministry of Health and Ministry of Higher Education.
- The Palestinian national PC committee
- Palestinian Medical and Nursing Council.
- Health and social workers
- Universities.
- Fundings agencies,
- NGOs,
- Ethical committees.
- International partners, such as the United States Agency for International Development (USAID), WHO country office, UNRWA, international NGOs, such as EAPC and IAHPC, and regional technical experts should also be involved.

As there is a national PC committee, the MOH should activate and give power to the committee to cooperate with national and international partners to develop policies aligned with the Palestinian context. The committee is responsible for contacting neighbouring Arab countries with a sound PC system, such as Jordan and Lebanon, to learn from their experiences in developing their PC policies. For example, in 2011 the Lebanon government established the first National committee for pain control and PC, responsible for setting policies and strategies for PC development in Lebanon. Since then, the committee has launched several activities, including workshops with policy advocacy leaders and NGOs to develop policies. In 2018, the first PC brief policy was developed to integrate PC into HCS (Soueidan et al., 2018). In 2019, the government issued a Decree 1/447 to integrate PC into the Lebanese HCS (Osman, 2019). In Jordan, the government also developed a steering PC committee responsible for advocacy for PC integration and setting policies. PC is provided at the hospitals in Jordan, the King Hussein Cancer Centre and Al Basheer Hospital (Bingley & Clark, 2008). In cooperation with USAID and the Jordan Competitiveness Program, the committee recommended establishing the National Home Healthcare Project in 2015. The Palestinian committee may discuss adopting the Jordanian policies with national and international partners and making modifications to them for application in Palestine.

In the long term, the MOH, in consultation with national and international partners, can develop their own policies to align with national laws and strategies by engaging decision-makers in a national dialogue to set country-wide priorities. These policies would aim to guide the implementation process, ensure the standardisation of care, sustainability in the availability of narcotic drugs, adequate funding, and standardisation of education on PC.

Enhancing professional knowledge and training

After developing PC policies, the government should strengthen human resources for PC, which is one of the main components of PC policies. The government requires establishing an educational steering committee for PC, including representatives from MOH, Ministry of Education, Palestinian Medical and Nursing Council, and universities. The committee's responsibility is to develop strategy with a timeline table on how to enhance professionals’ knowledge and training in the upcoming years. In the first stage, the committee should focus on healthcare professionals working at cancer centres. Then education should translate to other professionals working in medical departments.

In-service training is an effective strategy to enhance professionals’ skills and readiness to provide PC, considering the shortage of staff in Gaza. Training should concentrate on basic PC principles training, as almost no professionals in Gaza have received training in PC. PC training in tertiary care is also essential, given the increasing number of patients diagnosed with advanced stage disease, so a great deal of care will be provided in hospital and include specialised professionals. The committee should also consider the increasing population growth in the coming years; thus, there is a need for training generalised professionals in primary and community care to identify people who require PC services.

Dissemination of PC educational and guideline materials in Arabic to professionals will also improve their knowledge and clinical practice, which will improve the process of care and patient outcomes (Wisyonge, 2008). Skilled and expert professionals should develop practical guidelines to guide staff in managing patients' physical and psychological problems. The committee should also be responsible for nominating and sending staff to other countries to gain knowledge and skills in PC. These staff will disseminate their new knowledge to their colleagues when they return to the country.

The committee should endorse incorporating PC courses into all universities' educational curricula as an obligatory subject, which can be achieved by cooperation between the MOH, Ministry of Higher Education Accreditation Commission, and universities. Incorporation of PC within university curricula is a recommended strategy by the WHO to enhance professionals' knowledge of PC (World Health Organization, 2014). This will help to overcome the shortage of PC specialists in the future.

Access to pain relief and palliative care medications

Ensuring the sustainability and availability of narcotic medications in PC centres is crucial before setting up PC services that the Palestinian MOH should consider. The Lancet Commission on Global Access to PC and Pain Relief sets a policy pathway for access to PC medicines (Knaul et al., 2018). It designed an essential package of essential PC medicines, human resources, basic equipment and psychological intervention that helps alleviate suffering in LMICs (Knaul et al., 2018).

The essential package must be a part of universal health coverage to achieve the United Nations Sustainable Development Goals by 2030 (Nations, 2015). The package, as recommended by the WHO, essential medicines list should include the following drugs: Amitriptyline, Bisacodyl, Dexamethasone, Diazepam, Diphenhydramine, Fluconazole, Fluoxetine or other selective serotonin-reuptake inhibitors, Furosemide, Hyoscine butylbromide, Haloperido, Ibuprofen (naproxen, diclofenac, or meloxicam), Lactulose (sorbitol or polyethylene glycol), Loperamide, Metoclopramide, Metronidazole, Morphine (oral immediate-release and injectable), Naloxone parenteral, Omeprazole, Ondansetron, Paracetamol, and petroleum jelly.

At the first step, the MOH should determine the minimal essential medicines required for PC, based on the WHO essential medicines list. After the list is finalised, MOH should clearly state the intended use and authority of the list to all. The next step is ensuring the access of the list to all in need. The MOH then should implement a strategic plan to ensure access to medicines.

Setting up palliative care services

Palliative care services are required for all patients with life-threatening illnesses and their families to address their needs and alleviate suffering, which can be achieved by symptom prevention and management, good communication, discussion of goals of care, and providing an extra layer of support of practical needs at the patient's home (Hawley, 2017; World Health Organization, 2017). After developing policies and preparing well-educated professionals, the MOH can integrate PC services. There is no single best starting point approach (Brazil, 2018). Decisions about what types of approaches are suited are based on the country context, resources availability, and the goals of their HCS (Shaw et al., 2011). It seems that a hospital-based approach is currently more suitable to be implemented into the HCS, as it fits with the Palestinian content. In the long term, PC should be implemented into primary and secondary level care, given the increasing number of non-communicable diseases in the GS, to achieve maximum care coverage (Mathew, Cowley, Bliss, & Thistlewood, 2003).

In future, the Palestinian government should also consider home-based care in the national plan for patients at EoL. The QOL of dying patients should be taken into account, as well as the QOL of family and loved ones (Nabudere, Obuku, & Lamorde, 2014). The shortage of healthcare professionals in Palestine may be an obstacle to implementing home-based care, but the government can depend on volunteers to meet the needs of patients and families at home. Home-based care will increase patient satisfaction (Nabudere et al., 2014), minimise the pressure on the HCS, and decrease hospital admissions. Vocational education for volunteers and family caregivers could be a strategy to prepare them to provide care at home (Legg et al., 2011). Volunteers can provide education and psychological support to patients and families, which is considered an efficient mechanism to decrease the economic burden of delivering PC services (Sales et al., 2013; Scott & Kelly, 2014).

Equitable access to care

To achieve the United Nations Sustainable Development Goals by 2030 (Nations, 2015), the Palestinian national health system is responsible for integrating PC in the continuum of care of patients with life-threatening illnesses, linking it with early diagnosis and treatment programmes. This can be done by following the WHO public health model, which includes policies that integrate PC into the structure of the national HCS at all levels of care, policies for strengthening human resources, including training of professionals, embedding PC into the university curricula of all health professionals, and policies that ensure the availability of essential medicine.

Palliative care should be provided in accordance with universal health coverage principles. Regardless of income, age, and illness type, all patients should receive essential health services, including PC. The social protection system should consider the human right to PC for marginalised and poor population groups (World Health Organisation, 2020b). Comprehensive integration of PC into different levels of HCS utilising PC teams is recommended by the WHO (Nabudere et al., 2014) to ensure equitable access to all those in need of PC.

Funding allocation

Lack of funding is a critical issue for the development of PC in Palestine, where the MOH is entirely dependent on external donor funding and donations. Lack of funding was recognised as the most critical barrier to the provision of PC in most LMICs (Basu et al., 2013; Bingley & Clark, 2009; Donkor et al., 2018; McDermott et al., 2008; Zeinah et al., 2013b). The Palestinian government is relying on external funding, which makes planning difficult. Several strategies were adopted by LMICs, such as cost-sharing and health insurance funding provision (Bingley & Clark, 2009). Cost-sharing is not an applicable strategy in Palestine because almost all patients are living under the poverty line, which makes it difficult for them to purchase services. Thus, the government should collaborate with national and international organisations to secure funding for improving health care provision. The government should estimate and develop a cost database that will help in estimating PC cost.

10.5 Future work that should be done for a complete picture of palliative care development

We acknowledge that this doctoral research thesis did not assess other important components of the WHO Public Health PC Model, including the family needs of patients with advanced cancer and general public perspectives towards PC. It is imperative that the general public be knowledgeable about PC, and this is essential (McIlfatrick et al., 2021; Patel & Lyons, 2019). Sufficient knowledge will help patients and their families to make well-informed decisions and use PC properly. In addition, understanding general public knowledge about PC is vital in the development and sustainability of PC programmes (Patel & Lyons, 2019).

Because the data collection of this thesis was limited, the researcher has limited his focus to assessing the implementation of service needs, education and HCS, and policy-related issues considering countries' experiences. Also, there is no PC in Gaza. Thus, we anticipate that the general public's knowledge of PC will be limited. The general public awareness and family needs will be taken into account in the upcoming research work. The work will include educating the general public and families to make sure they understand what PC is and how to benefit from it. Educational intervention programmes are crucial for increasing the general public and families' knowledge of PC. Evidence has underscored the effectiveness of long- and short-term educational intervention on general public knowledge (Akiyama et al., 2016; Kozlov, McDarby, Reid, & Carpenter, 2017). Interventions can include flyers, booklets, posters, and public lectures (Kozlov, McDarby, et al., 2017) or brief videos on PC (Akiyama et al., 2016).

Discussing the topic around EoLC and a good death with the general public and families is important and should also assess their acceptance and knowledge of EoLC. Despite acknowledging the inevitability of death (Gire, 2014), people are still reluctant, and fear talking about death (Vanderveken, Schoenmakers, & De Lepeleire, 2019b). There are several methods used to enhance the discussion around death and bereavement: "Death over dinner conversations" (Lambert South & Elton, 2017) and a "Dying awareness week" (National council for palliative care, 2017). Notwithstanding the importance of these methods for discussing death and information about the PC role for patients at EoLC, both methods were developed in the UK, making it challenging to adopt both in the Muslim culture. Discussion around a good death in mosques, as an informal setting, may help enhance general public awareness and perception of PC.

Future research studies are also required to assess unmet service needs in other life-limiting illnesses that need further exploration, as they may differ in some ways from cancer service needs. For instance, patients with advanced chronic kidney disease experience a multitude of physical, psychological, and spiritual problems at the EOL (Sturgill & Bear, 2019). The prevalence of patients receiving dialysis is increasing due to improvements in dialysis patient survival rates. Thus, they desperately need to benefit from PC services, which should be incorporated into routine nephrology care (Sturgill & Bear, 2019). A high prevalence of unmet service needs is expected among patients with advanced chronic kidney disease, given the challenges that hinder professionals from addressing their patients' PC needs before dialysis (Tamura et al., 2018). The main challenge was underdeveloped PC models for patients with advanced chronic kidney disease (Tamura et al., 2018). Moreover, communications/conversations on health progress and future care plan options are not often conducted with patients with advanced chronic kidney disease (Brennan et al., 2017).

This thesis focused on PC for adult patients; pediatric PC services may need different approaches and configurations. Despite the uniqueness of paediatric PC, it shares some concepts with adult PC regarding the pain and suffering of patients and their families. However, significant differences were highlighted in terms of diagnosis, disease trajectory and prognosis, compared with adult patients (Drake & Chang, 2018). In addition, the roles of family and child during illness, prognosis, death, and bereavement also affect the provision of PC (Drake & Chang, 2018). Patient maturity and level of understanding also play a role in advanced care planning and making decisions. In paediatric PC, parents are responsible for making decisions, compared with adult PC. Thus, more research is needed for paediatric PC to assess patient needs, parents' views, and appropriate approaches for providing services.

10.6 Conclusion

Three main components of the WHO Public Health PC model were assessed (implementation of service needs, education and HCS, and policy-related issues) before the development of PC into the existing Palestinian HCS. The findings underscored that almost all advanced cancer patients in Palestine experience moderate to severe unmet supportive care needs and higher psychological distress than advanced cancer patients in other countries worldwide. High unmet supportive care needs are attributed to insufficient knowledge of PC and training of HCPs. High unmet needs obligate MOH to incorporate physical and psychological healthcare services within the routine delivery of care and have the potential to address patients' care needs and identify patients who need urgent help and assistance. Setting policies and laws for the integration of PC into Palestinian universities’ educational curricula as a compulsory subject, is essential to enhance professionals' knowledge, which will benefit both patients and their families.

Current PC healthcare services provided to Palestinian patients with life-threatening illnesses and their families are not comprehensive, limited to symptom control and pain management. Palestinian decision- and policymakers have pointed out PC at the top level of the Ministry's priorities, and it is clearly stated in the national strategic plan; however, the goals of development are not clearly defined in the plan, and capacity to implement the plan is inadequate. Education and training-related challenges are the frequent challenges in the GS, followed by funding allocation and the availability of medications. The Palestinian government should collaborate with national and international partners to overcome the challenges of PC provision and implement PC into the Palestinian HCS.

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APPENDICES

Appendix 1: Information Sheet for the Patient (English and Arabic)

INFORMATION SHEET

An Exploration of the Factors and Needs Associated with the Development of a Palliative Care Program into the Palestinian Healthcare System from Different Key Stakeholders' Perceptions

You are invited to participate in the above study supervised by Professor Alex Molasitiotis and Dr Justina Liu, and conducted by Mr. Hammoda ABU-ODAH, who is a Ph.D. student at the School of Nursing, The Hong Kong Polytechnic University. Prior to your decision, it is significant for you to understand why the research will conduct and what it will involve. Take your time reading the below information. If you have any unclear information, please do not hesitate to ask and we are happy to provide more explanation. Take time to decide whether you want to participate in this study or not. If you agree to participate in this study, you will need to sign a written informed consent. Please note that participation in this study is totally on a voluntary basis. Thank you for reading this.

The overall purpose of this study is to identify the unmet services needs of patients with advanced cancer before implementing PC services in Palestine. The objectives of this study are to determine the unmet palliative care needs of patients with advanced cancer; to assess the sociodemographic and clinical variables that influence unmet needs; and to examine the association between unmet needs and pain, symptoms, QOL, the spiritual well-being of patients' with advanced cancer.

You are invited to take part in this study, as you are a patient diagnosed with advanced cancer and treated at Palestinian Governmental hospitals. You are required to complete a questionnaire, which will take you about half an hour. As mentioned, you are free and have a right to withdraw from participation in this study at any time. If you prefer to withdraw or not to participate, this will not affect your treatment or stander of care received.

The information you provide as part of the project is the research data. Any research data from which you can be identified is known as personal data. Personal data does not include data where the identity has been removed (anonymous data). We will minimize our use of personal data in the study as much as possible. The researcher and supervisors (including Professor Alex Molasitiotis and Dr Justina Liu) will have access to personal data and research data for the purposes of the study. Responsible members of The Hong Kong Polytechnic University may be given access for monitoring and/or audit of the research.

All information related to you will remain confidential and will be identifiable by codes know only to the researches. All data retrieved will storage in a locked cabinet and can only be accessed by research teams. The information collected will be kept after project completion/publication. The Hong Kong Polytechnic University takes reasonable precautions to prevent the loss, misappropriation, unauthorized access or destruction of the information you provide.

You have every right to withdraw from the study before or during the measurement without penalty of any kind.

If you have any questions, you may ask our helpers now or later, even after the study has started.

You may contact Mr. Hammoda Abu-Odah (tel. no.: (00972) 56917 email: hammoda.abuodah@) or Prof. Alex Molassiotis (tel. no.: (852) 27666396 email: alex.molasiotis@) or Dr Justina Liu (tel. no.: (852) 27664097/ email: justina.liu@) of PolyU under the following situations:

a. if you have any other questions in relation to the study;
b. if, under very rare conditions, you become injured as a result of your participation in the study; or
c. if you want to get access to/or change your personal data before (the expiry date).

In the event you have any complaints about the conduct of this research study, you may contact the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in writing (c/o Research Office of the University) stating clearly the responsible person and department of this study as well as the HSESC Reference Number.

Thank you for your interest in participating in this study.

Principal Investigators

Prof. Alex Molassiotis, Dr Justina Liu, Mr. Hammoda Abu-Odah

THE HONG KONG
POLYTECHNIC UNIVERSITY
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ورقة المعلومات

استكشاف العوامل المرتبطة بالادخال الناجح لبرنامج الرعاية التلطيفية في نظام الرعاية الصحية الفلسطيني من وجهة نظر أصحاب المصلحة الرئيسيين

عزيزي المشارك/ـــة.

أنت مدعو للمشاركة في الدراسة المبينة أعلاه والتي يجريها الباحث حمودة محمد أبو عودة، طالب الدكتوراة في جامعة بوليتكنك هونغ كونغ ، وباشراف البروفيسور ألكس مولسيوتس ودكتورة جستينا ليو. من المهم قبل اتخاذك قرار المشاركة في هذه الدراسة أن تعرف لماذا نقوم بها وما محتواها. أرجو من سيادتكم أخذ الوقت المناسب لقراءة المعلومات المُبينة أدناه بتمعُن. إذا كانت لديك أي معلومات غير واضحة، فيرجى من سيادتكم عدم التردد في طرحها، ويسعدنا تقديم المزيد من التوضيح. خُذ وقتك الكافي وحدد إذا كنت ترغب في المشاركة في هذه الدراسة أم لا. في حالة الموافقة، فستحتاج منك التوقيع على اقرار الموافقة بالدراسة (صفحة 2). يرجى ملاحظة أن مشاركتك في هذه الدراسة طوعية ولك الحرية التامة بالإنسحاب عن المشاركة في أي وقت وبدون إعطاء مبررات. شكراً لقراءتك هذا.

تهدف هذه الدراسة، بشكل عام، إلي تحديد الحد الأدنى من الخدمات الصحية لتلبية احتياجات المرضى المصابين بالسرطان المتقدم قبل ادخال برنامج الرعاية التلطيفية في نظام الرعاية الصحية في فلسطين. بشكل خاص تهدف إلي تحديد احتياجات الرعاية غير الملباة للمرضى المصابين بالسرطان المتقدم؛ تقييم المتغيرات الاجتماعية والديموغرافية والسريرية التي تؤثر على الاحتياجات غير الملباة؛ ودراسة العلاقة بين الاحتياجات غير الملباة وبعض المتغيرات الأخرى كالألم والأعراض ونوعية الحياة والرفاهية الروحية.

يسرني دعوتك للمشاركة في الإجابة على أسئلة هذا الاستبيان. تم اختيارك كأحد من يمثلون المستفيدين من الخدمة الصحية في هذا المستشفى. لذلك أرجو من سيادتكم تعبئة الاستبيان والذي يتطلب حوالي 30 دقيقة لإستكماله. كما ذكرنا سابقاً، مشاركتك في هذه الدراسة طوعية ولك الحرية التامة بالإنسحاب عن المشاركة في أي وقت وبدون إعطاء مبررات وأن انسحابك لن يؤثر على علاجك أو الخدمة الصحية التي تتلقاها.

جميع المعلومات التي تقدمها كجزء من المشروع هي بيانات البحث. تُعرف البيانات البحثية التي يمكن التعرف عليك من خلالها بالبيانات الشخصية. لذلك لن تتضمن البيانات الشخصية أي بيانات توضح هويتك (كالاسم مثلاً). سنقلل من استخدامنا للبيانات الشخصية في الدراسة قدر المستطاع. سيتمكن الباحث والمشرفون من الوصول إلى البيانات الشخصية وبيانات البحث لأغراض الدراسة. كما سيُمنح الأعضاء المسؤولين في جامعة بوليتكنك هونغ كونغ إمكانية الوصول إلى بياناتك بهدف مراقبة أو تدقيق البحث. كما سيتم التعامل بالمعلومات المتعلقة بسيادتكم بسرية تامة وسيتم التعرف عليها من خلال رموز معرفة للباحثين. و سيتم الاحتفاظ بالمعلومات في مكان أمن وسيتم اتلافها فيما بعد حسب أنظمة جامعة بوليتكنك هونغ كونغ.

عزيزي المشارك/ـــة مشاركتك مهمة بالنسبة لي/ لذلك أرغب منك بدعمي في هذا الاستبيان. إذا كنت ترغب في الحصول على نسخة من نتيجة البحث أو كان لديك أسئلة بخصوصه، فيرجى الاتصال بنا من خلال وسائل الاتصال المذكورة أدناه. وفي حال كنت غير راضٍ عن الطريقة التي يتم اتباعها في هذه الدراسة فيمكنك الرفع بأي اقتراح أو اعتراض (بدون ذذكر اسمك إن رغبت في ذلك) الى المشرف على هذا البحث: البروفيسور ألكس مولسيوتس ودكتورة جستينا ليو.

البروفيسور ألكس مولسيوتس، تليفون: 852-27666396 – ايميل alex.molasiotis@

الدكتورة جستينا ليو، تليفون: 852-27664097 – ايميل justina.liu@

شكراً لوقتك ومشاركتك في الدراسة. عندما تُكمل تعبئة الاستبيان، الرجاء إعادته في الصندوق المخصص لاستلام الاستبيان.

مع خالص الاحترام والتقدير،

حمودة محمد أبو عودة، ايميل hammoda.abuodah@

الإتصال: فلسطين 00972-56917 – هونغ كونغ 852-27664520

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

Appendix 2: Written Informed Consent for the Patient (English and Arabic)

CONSENT TO PARTICIPATE IN RESEARCH

An Exploration of the Factors and Needs Associated with the Development of a Palliative Care Program into the Palestinian Healthcare System from Different Key Stakeholders' Perceptions

I ________________________ hereby consent to participate in the captioned study conducted by Mr. Hammoda ABU-ODAH, who is a Ph.D. student at the School of Nursing, The Hong Kong Polytechnic University.

Please read each statement and initial the box	**Please initial each box**
1. I confirm that I have read and understood the information sheet for the above study. I have been delivered a full explanation by the investigators of the nature, purpose and likely duration of the study, and of what I will be expected to do.	☐
2. I know that participation in this study is voluntary, and I am free to withdraw at any time without giving reason and without my medical care or legal rights being affected.	☐
3. I know that relevant sections of my medical records and data collected during the study may be looked at by individuals from the researcher's university. I permit for these individuals to have access to my data.	☐
4. I understand that any information given by me may be utilised in a future report, publications, or presentations by the research.	☐
5. I know that my name will not present in any reports, articles or presentations.	☐
6. I have been given adequate time to consider my participation, and I agree to take part in the above study.	☐

Name of participant ____

Signature of participant ____

Name of researcher Hammoda ABU-ODAH

Signature of researcher ____

Date ____

اقرار خطي

استكشاف العوامل المرتبطة بالادخال الناجح لبرنامج الرعاية التلطيفية في نظام الرعاية الصحية الفلسطيني من وجهة نظر أصحاب المصلحة الرئيسيين

أوافق أنا السيد/ة________________________ على إقرار المشاركة في الدراسة المبينة أعلاه التي يجريها الباحث حمودة أبو عودة، طالب الدكتوراة بكلية التمريض، جامعة بوليتكنك هونغ كونغ.

أرجو التمعن بقراءة كل بند قبل وضع علامة في المربع المخصص: **ضع اشارة في الصندوق**

1. أقر بأنني قرأت وفهمت ملف معلومات المشاركة في الدراسة المقدمة أعلاه. لقد تلقيت شرحاً كاملاً من قبل الباحث لطبيعة الدراسة والغرض منها والمدة المحتملة للدراسة، وقد تسنى لي استيعاب المعلومات وطرح الأسئلة التي تم الإجابة عليها. ☐
2. أعلم أن مشاركتي في هذه الدراسة طوعية ولي الحرية التامة بالإنسحاب عن المشاركة في أي وقت وبدون إعطاء مبررات، وأن انسحابي لن يؤثر على الخدمة الصحية التي أتلقاها. ☐
3. أقر بالسماح للباحث بالإطلاع على ملفي الطبي كجزء من الدراسة عن طبيعة المرض. وأُقر بأن المعلومات المعطاة خلال الدراسة سوف تُخزن في جامعة بوليتكنك هونغ كونغ وأُقر بأنني أمنحهم الموافقة بالإطلاع على معلوماتي المقدمة للبحث. ☐
4. أتفهم بأن المعلومات التي زودتها للباحثين ممكن أن تستخدم في أغراض البحث كالتقارير وورشات العمل والمنشورات البحثية. ☐
5. أتفهم أن المعلومات سوف تُستخدم بسرية تامة بدون ذكر أسماء في أي تقارير أو عروض تقديمية أو أوراق بحثية. ☐
6. لقد تم منحي الوقت الكافي لتحديد رغبتي في المشاركة في هذه الدراسة. أقر بالمشاركة في الدراسة المبينة أعلاه. ☐

أسم المشارك/ــة:____

التوقيع: ____

اسم الباحث: حمودة محمد أبو عودة

التوقيع:____

التاريخ:____

Appendix 3: Socio-demographic and Health/illness Characteristics of the Patients (English and Arabic)

Demographic characteristics

SN.	

Age		
Gender	Male / Female	

Marital Status	please tick
Single	
Married	
Divorced	
Separated	
Widowed	

Educational Background	please tick one box
None	
Primary level	
Secondary level	
Tertiary level	
Bachelor's degree or equivalent	
Postgraduate's degree or equivalent	

Employment Status	please tick one box
None	
Employee	
Housewife	

Monthly Income ($)	please tick one box
Less than 250	
250-500	
500-750	
More than 750	

Residency/living condition	please tick one box
Outside camp	
Inside camp	

Health/illness characteristics

Diagnosis/Type		please tick one box	
Breast cancer		Neurological cancer	
Haematological cancer		Gastro- intestinal cancer	
Lung cancer		Head and Neck cancer	
Renal/Urological cancer		Bone cancer	
Gynaecological cancer		Other (Specify)	
Skin cancer			

Stage	
III	
IV	

Duration since diagnosis		please tick one box	
Within the last month		Over 1 year – 3 years ago	
1-12 months ago,		Over 3 years ago	

Current treatment		please tick	
Chemotherapy		Biological/Immune therapy	
Radiotherapy		Transplantation	
Surgery		Other, please state………	
Hormone therapy			

الرقم المتسلسل ☐☐

المعلومات الديموغرافية

الرجاء التأشير على الاختيار المتطابق معك:

الجنس	1. ذكر	2. أنثى

العُمر بالسنوات	

الحالة الإجتماعية	1. أعزب	2. متزوج	3. منفصل	4. أرمل

المستوى التعليمي	1. ابتدائي فأقل	3. اعدادي	4. ثانوي	5. بكالوريوس	6. دراسات عليا

طبيعة العمل	1. لا يعمل	2. يعمل	3. ربة منزل

الدخل الشهري (بالدولار)	1. أقل من 250	2. 250-500	3. 501-750	4. أكثر من 750

مكان السكن	1. المدينة	2. القرية/الريف	3. المخيم

مكان تلقي العلاج	1. مستشفى الأوروبي	2. مستشفى الشفاء/الرنتيسي

المعلومات الصحية

التشخيص/النوع	1. سرطان الثدي	2. سرطان القولون	3. سرطان الرئة
	4. سرطان نخاع العظم	5. سرطان البروستاتا	6. سرطان المثانة
	7. سرطان الغدة الدرقية	8. سرطان الغدد الليمفاوية	9. سرطان الدماغ والعنق
	10. سرطان المعدة	أخرى، الرجاء التحديد...	

درجة المرض	1. الثالثة	2. الرابعة

مدة المرض منذ التشخيص	1. خلال الشهر الماضي	2. من شهرإلى 12
	3. من سنة إلى 3 سنوات	4. أكثر من 3 سنوات

العلاج الذي تتلقاه أو تلقيته	1. كيماوي	2. إشعاعي	3. جراحي	4. زراعة نخاع العظم
	أخرى، الرجاء التحديد..			

Appendix 4: Supportive Care Needs Survey – SF- 34 (English and Arabic)

INSTRUCTIONS

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Put a circle around the number which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

NO NEED	
	1. Not applicable – This was not a problem for me as a result of having cancer.
	2. Satisfied - I did need help with this, but my need for help was satisfied at the time.
SOME NEED	
	3. Low need- This item caused me concern or discomfort. I had little need for additional help
	4. Moderate need – This item caused me concern or discomfort. I had some need for additional help
	5. High need - This item caused me concern or discomfort. I had a strong need for additional help.

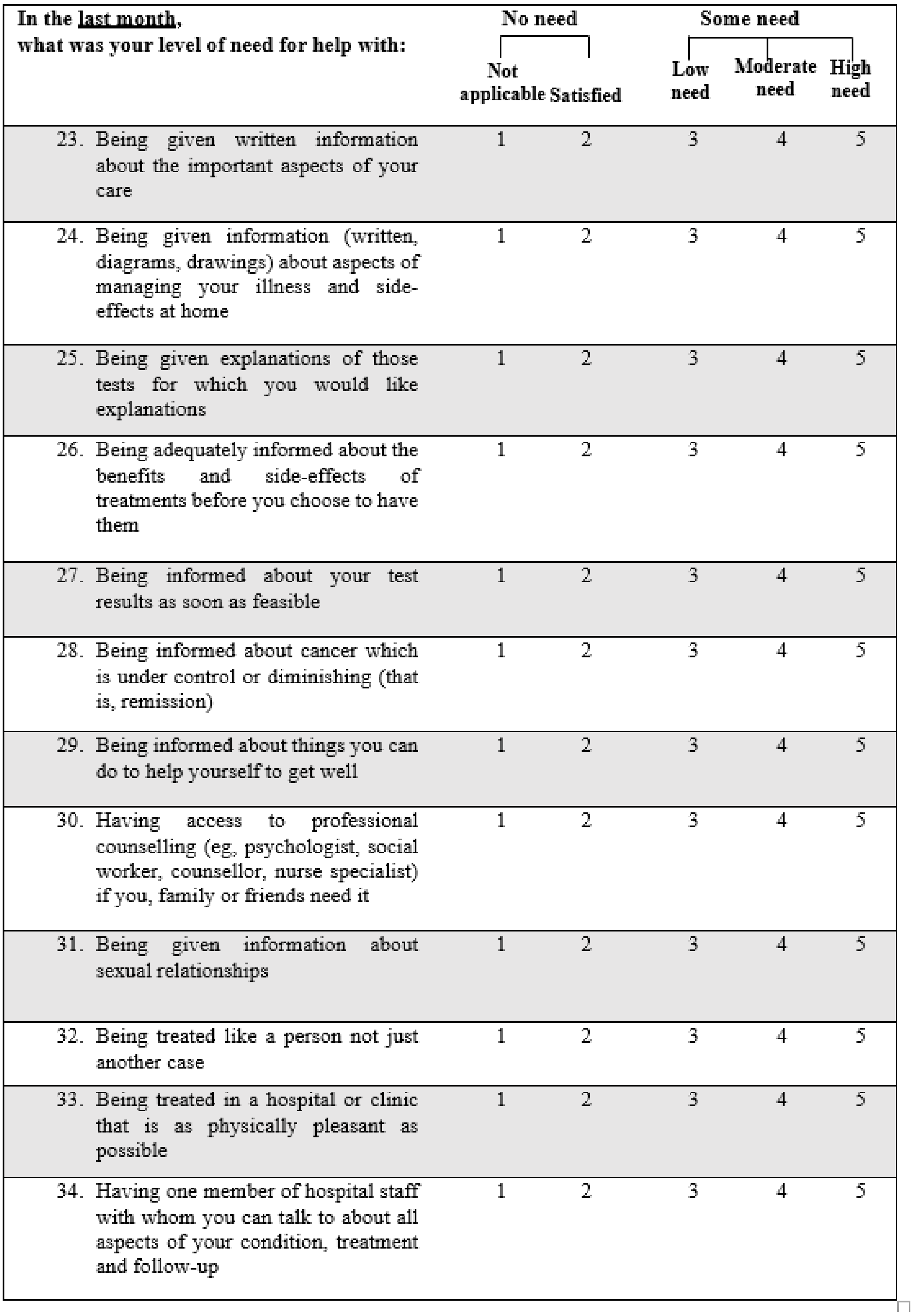
For Example

In the last month, what was your level of need for help with:	**No need**		**Some need**		
	Not applicable	**Satisfied**	**Low need**	**Moderate need**	**High need**
1. Being informed about things you can do yourself To get well	1	2	3	[✓ 4]	5

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

Now please complete the survey on the next 2 pages.

In the <u>last month</u>, **what was your level of need for help with:**	**No need**		**Some need**		
	Not applicable	**Satisfied**	**Low need**	**Moderate need**	**High need**
1. Pain	1	2	3	4	5
2. Lack of energy/tiredness	1	2	3	4	5
3. Feeling unwell a lot of the time	1	2	3	4	5
4. Work around the home	1	2	3	4	5
5. Not being able to do the things you used to do	1	2	3	4	5
6. Anxiety	1	2	3	4	5
7. Feeling down or depressed	1	2	3	4	5
8. Feelings of sadness	1	2	3	4	5
9. Fears about the cancer spreading	1	2	3	4	5
10. Worry that the results of treatment are beyond your control	1	2	3	4	5
11. Uncertainty about the future	1	2	3	4	5
12. Learning to feel in control of your situation	1	2	3	4	5
13. Keeping a positive outlook	1	2	3	4	5
14. Feelings about death and dying	1	2	3	4	5
15. Changes in sexual feelings	1	2	3	4	5
16. Changes in your sexual relationships	1	2	3	4	5
17. Concerns about the worries of those close to you	1	2	3	4	5
18. More choice about which cancer specialists you see	1	2	3	4	5
19. More choice about which hospital you attend	1	2	3	4	5
20. Reassurance by medical staff that the way you feel is normal	1	2	3	4	5
21. Hospital staff attending promptly to your physical need	1	2	3	4	5
22. Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	1	2	3	4	5



In the last month, what was your level of need for help with:	**No need**		**Some need**		
	Not applicable	**Satisfied**	**Low need**	**Moderate need**	**High need**
23. Being given written information about the important aspects of your care	1	2	3	4	5
24. Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
25. Being given explanations of those tests for which you would like explanations	1	2	3	4	5
26. Being adequately informed about the benefits and side-effects of treatments before you choose to have them	1	2	3	4	5
27. Being informed about your test results as soon as feasible	1	2	3	4	5
28. Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
29. Being informed about things you can do to help yourself to get well	1	2	3	4	5
30. Having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
31. Being given information about sexual relationships	1	2	3	4	5
32. Being treated like a person not just another case	1	2	3	4	5
33. Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
34. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5

Thank you for completing this survey

استبيان احتياجات الرعاية الداعمة:

تعليمات لتعبئـة الاستبيان / المسح:

لمساعدتنا في التخطيط لخدمات أفضل للمرضى الذين يتم تشخيصهم بالسرطان، نرغب في التعرُّف على احتياجاتك كمريض مُصاب بالسرطان.

تُعَّرف الاحتياجات على أنها نوع من المساعدة التي تتوقعها أوتأمل أن تحصل عليها لتتمكن من التعايش مع مرضك؛ إن الهدف من هذا الاستبيان هو تحديد مدى أو مقدار حاجتك للمسـاعدة والتعرف عليها، إذ يمكن أن تتنوع هذه الاحتياجات وتتفاوت. لذا ضع دائرة حول الرقم الأكثر تحديداً لمقدار حاجتك للمسـاعدة. هناك خمس إجابات محتملة يمكنك اختيار إجابة واحدة فقط منها:

لستُ بحاجة للمساعدة	1.	**لاينطبق:** ليست لدي أية مشكلة نتيجة إصابتي بالسرطان
	2.	**راض:** لقد احتجت للمساعدة وقد تمت تلبية حاجتي للمساعدة في حينه
أحتاج لبعض المسـاعدة	3.	**بسيطة :** أقلقني المرض أو أزعجني واحتجت لمساعدة إضافية بسيطة
	4.	**متوسطة:** أقلقني المرض أو أزعجني واحتجت لمسـاعدة إضافية بعض الشيء
	5.	**كبيرة:** أصابني قلق جرّاء إصابتي بالسرطان واحتجت لمسـاعدة إضافيـة كبيرة

مثال على ذلك:

ما مقدار حاجتك للمساعدة بـخصوص:	**لا أحتاج لأية مساعدة**		**أحتاج لبعض المساعدة**		
	لا ينطبق	**راض**	**بسيطة**	**متوسطة**	**كبيرة**
إطلاعك على الأشياء التي يمكنك القيام بها لتساعد نفسك على التحسُّن.	1	2	3	[✓ 4]	5
اذا وضعت دائرة حول رقم 4 حيث تراها الآن فإن ذلك يعني أنك لم تحصل على كل ما تحتاجه من المعلومات حول الأشياء التي يمكنك القيام بها لتساعد نفسك على التحسُّن، لذا فإنك بحاجة للمزيد من المعلومات.					

الأن الرجاء قم بتعبة الاستبيان

ما مقدار حاجتك للمساعدة فيما يتعلق بـــــ:	**لا أحتاج لأية مساعدة**		**أحتاج لبعض المساعدة**		
	لا ينطبق	راض	بسيطة	متوسطة	كبيرة
1. الألم	1	2	3	4	5
2. قلة النشاط / التعب	1	2	3	4	5
3. الشعور بالمرض معظم الوقت	1	2	3	4	5
4. العمل في أرجاء البيت	1	2	3	4	5
5. عدم مقدرتك على القيام بالأشياء التي اعتدت على القيام بها	1	2	3	4	5
6. القلق والتوتر	1	2	3	4	5

ما مقدار حاجتك للمساعدة فيما يتعلق بـــــ:	**لا أحتاج لأية مساعدة**		**أحتاج لبعض المساعدة**		
	لا ينطبق	راض	بسيطة	متوسطة	كبيرة
7. الشعور بالاكتئاب والإحباط	1	2	3	4	5
8. الشعور بالحزن	1	2	3	4	5
9. خوق من انتشار السرطان	1	2	3	4	5
10. قلق من أن نتائج العلاج خارج نطاق السيطرة	1	2	3	4	5
11. القلق والخوف من المستقبل	1	2	3	4	5
12. التعوُّد على الشعور بالسيطرة على وضعك	1	2	3	4	5
13. التمتع بنظرة إيجابية	1	2	3	4	5
14. مشاعر حول الموت والوفاة	1	2	3	4	5
15. التغيرات في المشاعر الجنسية	1	2	3	4	5
16. التغيرات في العلاقة الجنسية	1	2	3	4	5
17. القلق بشأن خوف المقربين منك أو أقاربك أو عائلتك عليك	1	2	3	4	5
18. توفر خيارات أكثر لك من أطباء الأورام لتراجعهم	1	2	3	4	5
19. توفر خيارات أكثر لأفضل العلاجات المتوفرة لمرضك	1	2	3	4	5
20. طمأنة الفريق الطبي لك بأن ما تشعر به هو أمر طبيعي	1	2	3	4	5
21. قيام موظفي المستشفى بتلبية احتياجاتك الجسمانية بسرعة	1	2	3	4	5
22. تقدير وحساسية موظفي المستشفى لمشاعرك واحتياجاتك النفسية	1	2	3	4	5
23. تزويدك بمعلومات مكتوبة حول الجوانب المهمة من رعايتك الصحية	1	2	3	4	5
24. تزويدك بمعلومات (مكتوبة وبيانية ورسومات) حول كيفية تدبر مرضك والاثار الجانبية في المنزل	1	2	3	4	5
25. تزويدك بشروح للفحوصات التي ترغب في أن تُشرح وتوضّح لك	1	2	3	4	5
26. إطلاعك جيداً على فوائد العلاجات واثارها الجانبية قبل أن تختار الخضوع لها	1	2	3	4	5
27. إطلاعك على نتائج الفحوصات الطبية في أقرب وقت ممكن	1	2	3	4	5
28. إبلاغك أنت لا غيرك بالسرطان وليس إبلاغ عائلتك أو أحد أقاربك	1	2	3	4	5
29. إطلاعك على أشياء يمكنك القيام بها لتساعد نفسك في التحسن	1	2	3	4	5
30. الحصول على استشارة تخصصية (أخصائي نفسي، أخصائي اجتماعي، مرشد نفسي، ممرضة متخصصة)، في حال احتجت أنت أو عائلتك أو أصدقائك لها.	1	2	3	4	5
31. تزويدك بمعلومات حول العلاقة الجنسية	1	2	3	4	5
32. معاملتك كشخص وليس كمجرد حالة مرضية أخرى	1	2	3	4	5
33. معاملتك في مستشفى أو عيادة راقية قدر الإمكان	1	2	3	4	5
34. وجود شخص من العاملين في المستشفى تستطيع التحدث معه حول جوانب مشكلتك الصحية والعلاج والمتابعة.	1	2	3	4	5

Appendix 5: Arabic Questionnaire for Symptom Assessment

Serial No.

المقياس العربي للأعراض
Arabic Questionnaire for Symptom Assessment (AQSA)

Date:

فضلاً: حددوا درجة شعوركم أو إحساسكم (الآن) بكل من الأعراض التالية:

١٠ = في غاية الشدة

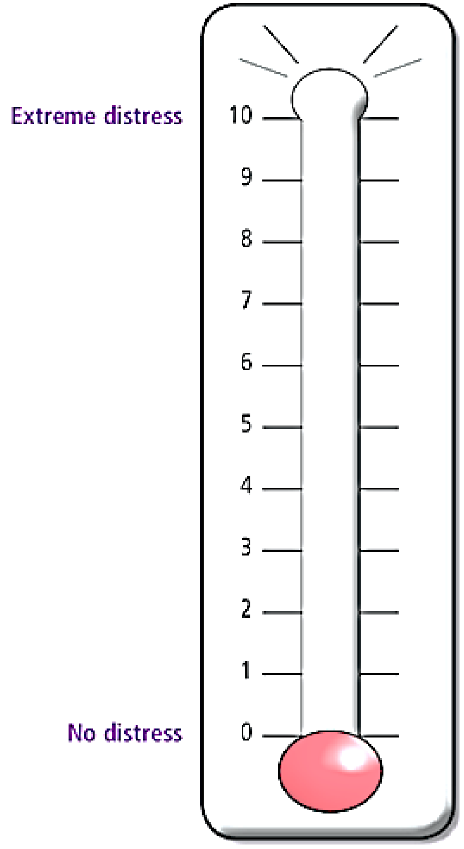
٥= متوسط الشدة

٠ = لا يوجد

Pain	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	ألم / وَجَع
Tiredness	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	إجهاد / تعب
Nausea/ Vomiting	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	غثيان / قيء
Anxiety	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	قلق
Depression	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	اكتئاب / حُزن
Shortness of breath	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	صعوبة التنفس
Drowsiness	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	نعاس
Insomnia	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	أرَق / قلة نوم
Dry mouth	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	جفاف الفم
Loss of appetite	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	ضعف الشهية
Confusion	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	ضعف التركيز / تشوش الذهن
Suffering	١٠ ٩ ٨ ٧ ٦ ٥ ٤ ٣ ٢ ١ ٠	المعاناة

Appendix 6: Distress Thermometer Questionnaire (English and Arabic)

Instructions: First, please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.



Second, please indicate if any of the following has been a problem for you in the past week, including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems
☐	☐	Child care
☐	☐	Housing
☐	☐	Insurance/financial
☐	☐	Transportation
☐	☐	Work/school
☐	☐	Treatment decisions
		Family Problems
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Ability to have children
☐	☐	Family health issues
		Emotional Problems
☐	☐	Depression
☐	☐	Fears
☐	☐	Nervousness
☐	☐	Sadness
☐	☐	Worry
☐	☐	Loss of interest in usual activities
☐	☐	**Spiritual/Religious Concerns**

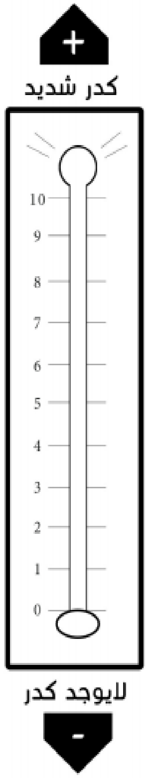
YES	NO	Physical Problems
☐	☐	Appearance
☐	☐	Bathing/dressing
☐	☐	Breathing
☐	☐	Changes in urination
☐	☐	Constipation
☐	☐	Diarrhea
☐	☐	Eating
☐	☐	Fatigue
☐	☐	Feeling swollen
☐	☐	Fevers
☐	☐	Getting around
☐	☐	Indigestion
☐	☐	Memory/concentration
☐	☐	Mouth sores
☐	☐	Nausea
☐	☐	Nose dry/congested
☐	☐	Pain
☐	☐	Sexual
☐	☐	Skin dry/itchy
☐	☐	Sleep
☐	☐	Substance abuse
☐	☐	Tingling in hands/feet

Other Problems: ____

____

مقياس الكدر (الكَرب، كَآبَةٍ وَحُزْنٍ، ضائقة نفسية)

أولاً : من فضلك ضع دائرة حول الرقم من (0 - 10)
التي تعطي أفضل وصف لحجم الكدر الذى أحسست به
خلال الأسبوع الماضي بما فيها هذا اليوم



ثانيا: يُرجى الإشارة إن مثلت لك أياً من الأمور التالية مشكلة في الأسبوع الماضي بما فيها هذا اليوم

من فضلك ضع علامة نعم أو لا لكل اختيار:

نعم	لا	المشاكل العملية
☐	☐	العناية بالطفل
☐	☐	المسكن
☐	☐	التأمين الطبي/الأمور المالية
☐	☐	المواصلات
☐	☐	العمل / الدراسة
☐	☐	القرارات العلاجية

نعم	لا	المشاكل العائلية
☐	☐	التعامل مع الأطفال
☐	☐	شريك الحياة
☐	☐	القدرة على الإنجاب
☐	☐	مشاكل صحية في العائلة

نعم	لا	المشاكل العاطفية
☐	☐	اكتئاب
☐	☐	مخاوف
☐	☐	سرعة الانفعال
☐	☐	الحزن
☐	☐	الهم
☐	☐	فقد المتعة في النشاطات المعتادة
☐	☐	أمور روحانية / دينية

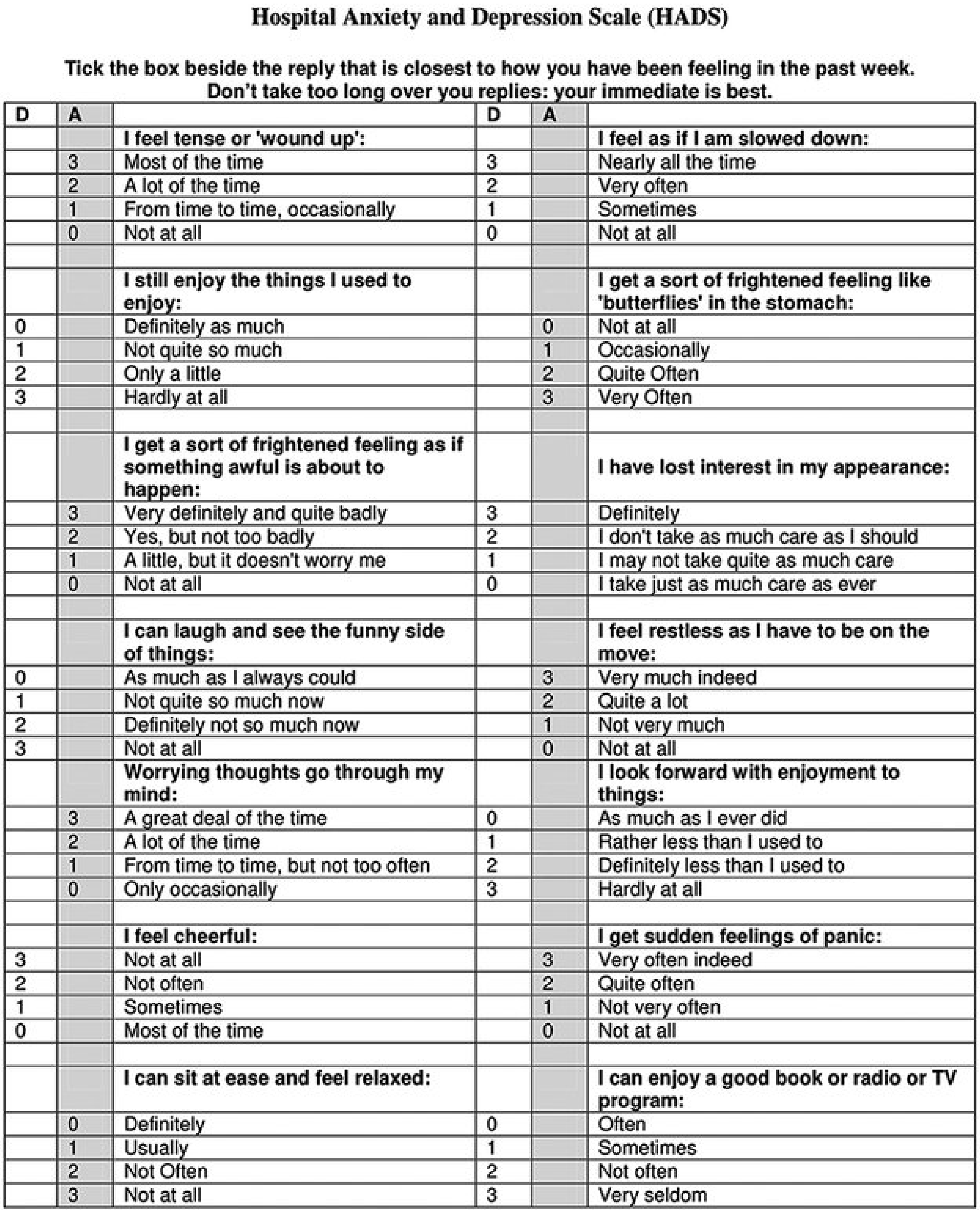
مشاكل اخرى (أذكرها) ....

....

نعم	لا	المشاكل الجسدية
☐	☐	المظهر
☐	☐	الاستحمام / ارتداء الملابس
☐	☐	التنفس
☐	☐	تغير في التبول
☐	☐	إمساك
☐	☐	إسهال
☐	☐	الأكل
☐	☐	التعب
☐	☐	شعور التورم والانتفاخ
☐	☐	حمى
☐	☐	التجول والحركة
☐	☐	عسر الهضم
☐	☐	الذاكرة/التركيز
☐	☐	تقرحات الفم
☐	☐	غثيان
☐	☐	جفاف الأنف أو احتقانه
☐	☐	ألم
☐	☐	الجنس
☐	☐	جفاف الجلد/حكة
☐	☐	إدمان المخدرات
☐	☐	تنميل في اليدين /القدمين

NCCN Distress Thermometer,V.2.2013. Cutoff score of DT ≥4. Alosaimi FD, et al. Validity and feasibility of the Arabic version of distress thermometer for Saudi cancer patients. PloS one. 2018.

Appendix 7: Hospital Anxiety and Depression Scale (English and Arabic)



Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:
Total score: Depression (D) ___________ Anxiety (A) ______________
0-7 = Normal
8-10 = Borderline abnormal (borderline case)
11-21 = Abnormal (case)

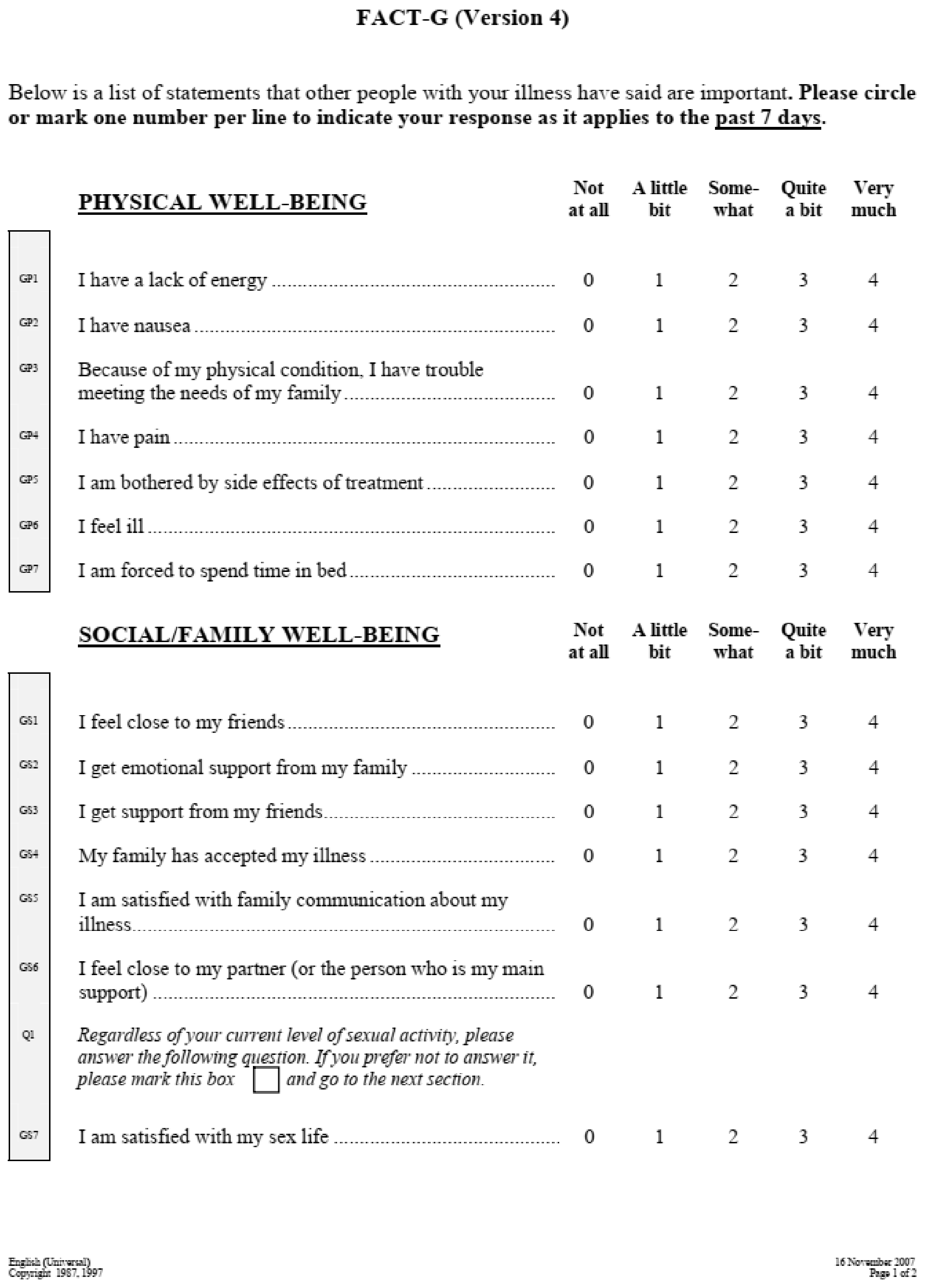
مقياس القلق والاكتئاب في المستشفى

هذا الاستبيان يساعد الطبيب لمعرفة مشاعرك وقراءة أحاسيسك ، لذا يرجى إحاطة الرقم الموازي لأفضل اختيار يصف حالتك خلال الأسبوع الماضي. ليس من المطلوب الاستغراق في التفكير لإختيار الإجابة، وإنما تفضل الإجابات العفوية التلقائية.

	من فضلك، قم بإختيار الإجابة المناسبة بوضع دائرة عليها:			Hospital Anxiety Depression Scale (HADS):	
	أحس بأنني هامد (فاقد للطاقة) :	D		أشعر بالتوتر الشديد:	A
3	• تقريباً في كل وقت		3	• أكثر الوقت	
2	• في كثير من الأحيان		2	• عدة مرات	
1	• في بعض الأوقات		1	• أحياناً	
0	• لا أشعر بذلك مطلقاً		0	• لا أشعر بذلك مطلقاً	
	يتنابني شعور بالخوف:	A		أنا لازلت أتمتع بالأشياء التي اعتدت أن أستمتع بها:	D
0	• لا ، على الإطلاق		0	• بالتأكيد، كما كنت	
1	• أحياناً		1	• ليس تماماً	
2	• كثيراً		2	• قليلاً	
3	• في أغلب الأوقات		3	• بالكاد، على الإطلاق	
	لقد فقدت الإهتمام بمظهري:	D		أشعر بنوع من الخوف, وكأن شيئا مروعا على وشك الحدوث:	A
3	• بالتأكيد فقدت كل الاهتمام		3	• بالتأكيد، وبشكل مزعج	
2	• أنا لا أهتم بمظهري كما يجب أن أهتم		2	• نعم، ولكن أقل سوءاً	
1	• قد لا أعتني بمظهري كما يجب		1	• قليلاً، لكنه لا يقلقني	
0	• أعتني بمظهري بشكل جيد كما كنت سابقا		0	• لا أشعر بذلك على الاطلاق	
	الإحساس بضيقة الصدر دون مجهود جسدي:	A		أستطيع الضحك و رؤية الجوانب الممتعة في الاشياء:	D
3	• في الواقع، كثيراً جداً		0	• كما كنت سابقا	
2	• كثيراً، لابأس به		1	• اقل مما كنت سابقا	
1	• أشعر بذلك قليلاً		2	• بالتأكيد، ليس كثيراً الآن	
0	• لا أشعر بذلك على الإطلاق		3	• لا أشعر بذلك على الإطلاق	
	أنا أتطلع للأشياء من حولي باستمتاع:	D		تأتيني دائما افكار مقلقة:	A
0	• بقدر ما يمكنني فعله		3	• أغلب الأوقات	
1	• نوعا ما أقل مما اعتدت على فعله		2	• معظم الأوقات	
2	• بالتأكيد أقل مما اعتدت على فعلة		1	• من وقت لآخر، ولكن ليس كثيراً	
3	• لا ، على الإطلاق		0	• أحيانا	
	ينتابني إحساس مفاجئ بالهلع:	A		أشعر بالبهجة:	D
3	• في الواقع، في كثير من الأحيان		3	• لا ، على الإطلاق	
2	• غالباً		2	• ليس كثيراً	
1	• ليس كثيراً		1	• في بعض الأحيان	
0	• لا أشعر بذلك على الإطلاق		0	• في أغلب الأوقات	
	يمكنني الإستمتاع بقراءة كتاب جيد أو مشاهدة البرامج التلفزيونية أو الإستماع إلى الإذاعة:	D		يمكنني الجلوس براحة و الشعور بالاسترخاء:	A
0	• غالباً		0	• بكل التأكيد	
1	• في بعض الأحيان		1	• عادة ما	
2	• ليس كثيراً		2	• ليس كثيراً	
3	• نادراً جداً		3	• لا يمكنني ذلك على الإطلاق	

Terkawi et al. Arabic version of (Hospital Anxiety Depression Scale "HADS") Page 1 of 1

Appendix 8: Functional Assessment Cancer Therapy General (FACT-G) (English and Arabic)



FACT-G (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.**

	<u>PHYSICAL WELL-BEING</u>	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	<u>SOCIAL/FAMILY WELL-BEING</u>	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

English (Universal)
Copyright 1987, 1997

16 November 2007
Page 1 of 2

FACT-G (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

التقييم الوظيفى لعلاج الأمراض المزمنة

FACT-G (Version 4.0)

هذه قائمة بالعبارات التي ذكر أشخاص بنفس علتك أنها مهمة بالنسبة لهم. **من فضلك ضع دائرة أو علامة على رقم واحد في كل سطر لبيان مدى انطباق إجابتك على حالتك في الأيام السبعة الأخيرة.**

	الكفاءة الجسمانية	**ليس على الإطلاق**	**مرات قليلة**	**نوعا ما**	**غالبا**	**كثيرا جدا**
GP1	أشعر بالوهن	0	1	2	3	4
GP2	أشعر بالغثيان (إ حساس بالقئ)	0	1	2	3	4
GP3	بسبب حالتي الصحية – لدي صعوبة في تلبية احتياجات أسرتي	0	1	2	3	4
GP4	أشعر بألم	0	1	2	3	4
GP5	أشعر بالضيق من الآثار الجانبية للعلاج	0	1	2	3	4
GP6	أشعر أنني عليل (مريض)	0	1	2	3	4
GP7	أنا مضطر لملازمة الفراش	0	1	2	3	4

	الكفاءة الاجتماعية و الأسرية	**ليس على الإطلاق**	**مرات قليلة**	**نوعا ما**	**غالبا**	**كثيرا جدا**
GS1	أشعر أنني قريب من أصدقائي	0	1	2	3	4
GS2	أحظى بتعاطف أسرتي	0	1	2	3	4
GS3	أجد كل الدعم من أصدقائي	0	1	2	3	4
GS4	لقد تقبلت أسرتي حالتي الصحية	0	1	2	3	4
GS5	أنا راض عن الكيفية التي تتعامل بها أسرتي مع مرضي	0	1	2	3	4
GS6	أشعر بالقرب من زوجي / زوجتي (أو الشخص الذي يمثل لي الدعم الرئيسي)	0	1	2	3	4
Q1	**بغض النظر عن حالتك الجنسية حاليا، من فضلك أجب عن هذا السؤال. إذا كنت لا ترغب في الإجابة من فضلك ضع علامة في هذا المربع ☐ ثم انتقل إلى السؤال التالي:**					
GS7	أنا راض عن حياتي الجنسية	0	1	2	3	4

FACT-G (Version 4.0)

من فضلك ضع دائرة أو علامة على رقم واحد في كل سطر لبيان مدى انطباق إجابتك على حالتك في الأيام السبعة الأخيرة.

الكفاءة العاطفية

		ليس على الإطلاق	مرات قليلة	نوعاً ما	غالبا	كثيرا جدا
GE1	أشعر بالحزن	0	1	2	3	4
GE2	أنا راض عن تقبلي لحالتي الصحية	0	1	2	3	4
GE3	أفتقد الأمل في مقاومتي لمرضي	0	1	2	3	4
GE4	أشعر بالعصبية	0	1	2	3	4
GE5	أنا قلق من الموت	0	1	2	3	4
GE6	أخاف أن تسوء حالتي	0	1	2	3	4

الكفاءة الوظيفية

		ليس على الإطلاق	مرات قليلة	نوعاً ما	غالبا	كثيرا جدا
GF1	أنا قادر على العمل (بما في ذلك العمل في المنزل)	0	1	2	3	4
GF2	عملي (بما في ذلك عملي في المنزل) يرضيني	0	1	2	3	4
GF3	أنا قادر على الاستمتاع بالحياة	0	1	2	3	4
GF4	لقد تقبلت مرضي	0	1	2	3	4
GF5	أنام جيدا	0	1	2	3	4
GF6	أستمتع بالأشياء التي أقوم بها للترفيه	0	1	2	3	4
GF7	أنا راض عن طبيعة حياتي الآن	0	1	2	3	4

Appendix 9: Functional Assessment Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp) (English and Arabic)

FACIT-Sp (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	ADDITIONAL CONCERNS	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
Sp1	I feel peaceful	0	1	2	3	4
Sp2	I have a reason for living	0	1	2	3	4
Sp3	My life has been productive	0	1	2	3	4
Sp4	I have trouble feeling peace of mind	0	1	2	3	4
Sp5	I feel a sense of purpose in my life	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort	0	1	2	3	4
Sp7	I feel a sense of harmony within myself	0	1	2	3	4
Sp8	My life lacks meaning and purpose	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs	0	1	2	3	4
Sp11	My illness has strengthened my faith or spiritual beliefs	0	1	2	3	4
Sp12	I know that whatever happens with my illness, things will be okay	0	1	2	3	4

التقييم الروحاني لعلاج الأمراض المزمنة

FACIT-Sp-12 (Version 4)

هذه قائمة بالعبارات التي ذكر أشخاص بنفس علتك أنها مهمة بالنسبة لهم. **من فضلك ضع دائرة أو علامة على رقم واحد في كل سطر لبيان مدى انطباق إجابتك على حالتك في الأيام السبعة الأخيرة.**

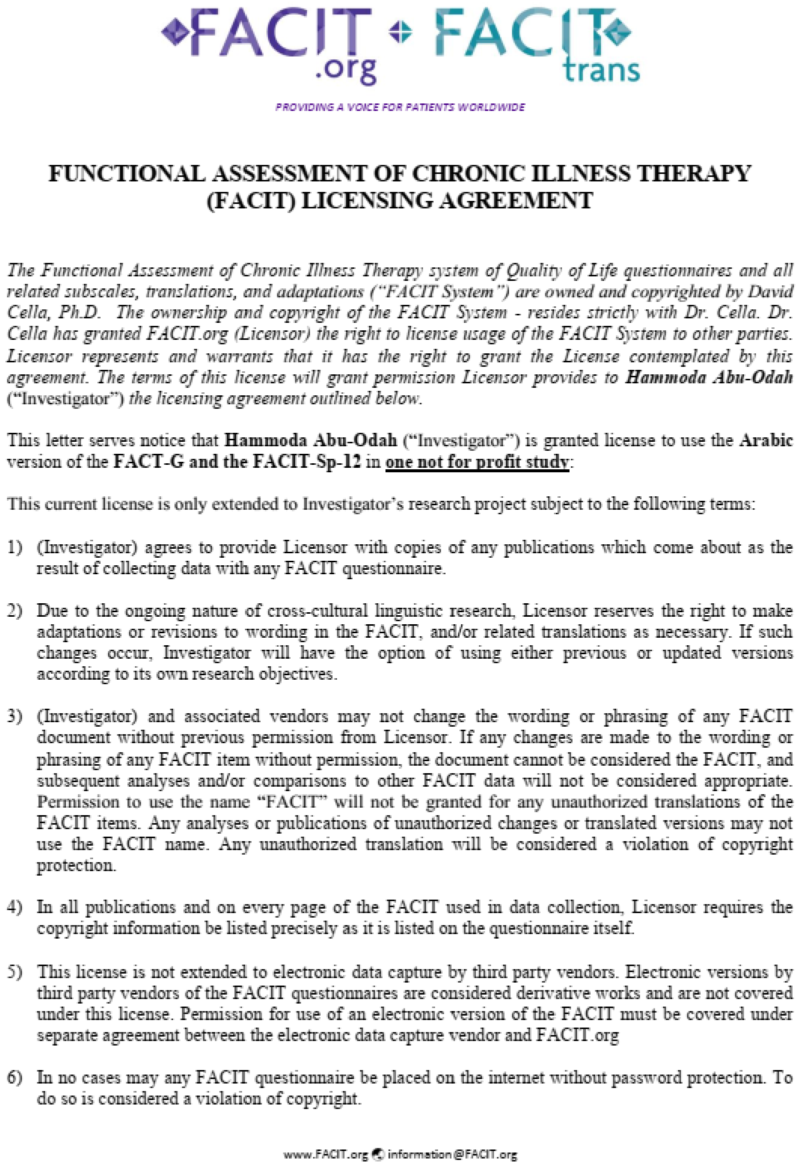
الكفاءة الروحانية/الدينية

		ليس على الإطلاق	مرات قليلة	نوعا ما	غالبا	كثيراً جداً
Sp1	أشعر بالسلام	0	1	2	3	4
Sp2	يوجد لدي سبب للعيش	0	1	2	3	4
Sp3	حياتي ما تزال منتجة...	0	1	2	3	4
Sp4	أواجه مشاكل في الإحساس براحة البال	0	1	2	3	4
Sp5	أشعر بشيء من الغاية في حياتي...	0	1	2	3	4
Sp6	أنا قادر على البحث عميقا في نفسي للوصول إلى الراحة	0	1	2	3	4
Sp7	أشعر بالانسجام مع نفسي...	0	1	2	3	4
Sp8	حياتي تفتقد للمعنى والهدف..	0	1	2	3	4
Sp9	أجد الراحة في إيماني أو في معتقداتي الدينية.................................	0	1	2	3	4
Sp10	أجد القوة في أيماني أو في معتقداتي الدينية..................................	0	1	2	3	4
Sp11	لقد عزز المرض من إيماني أو معتقداتي الدينية..............................	0	1	2	3	4
Sp12	أنا أعرف أنه مهما حصل مع مرضي، فإن الأمور ستكون على ما يرام ...	0	1	2	3	4

نشكرك على تخصيص بعض من وقتك لإكمال هذا الاستبيان.

ملاحظاتك وآرائك مهمة بالنسبة لنا

Appendix 10: Permission to use the instruments by the original author



FACIT.org FACIT trans
PROVIDING A VOICE FOR PATIENTS WORLDWIDE

FUNCTIONAL ASSESSMENT OF CHRONIC ILLNESS THERAPY (FACIT) LICENSING AGREEMENT

The Functional Assessment of Chronic Illness Therapy system of Quality of Life questionnaires and all related subscales, translations, and adaptations ("FACIT System") are owned and copyrighted by David Cella, Ph.D. The ownership and copyright of the FACIT System - resides strictly with Dr. Cella. Dr. Cella has granted FACIT.org (Licensor) the right to license usage of the FACIT System to other parties. Licensor represents and warrants that it has the right to grant the License contemplated by this agreement. The terms of this license will grant permission Licensor provides to ***Hammoda Abu-Odah*** ("Investigator") *the licensing agreement outlined below.*

This letter serves notice that **Hammoda Abu-Odah** ("Investigator") is granted license to use the **Arabic** version of the **FACT-G and the FACIT**-**Sp-12** in **one not for profit study**:

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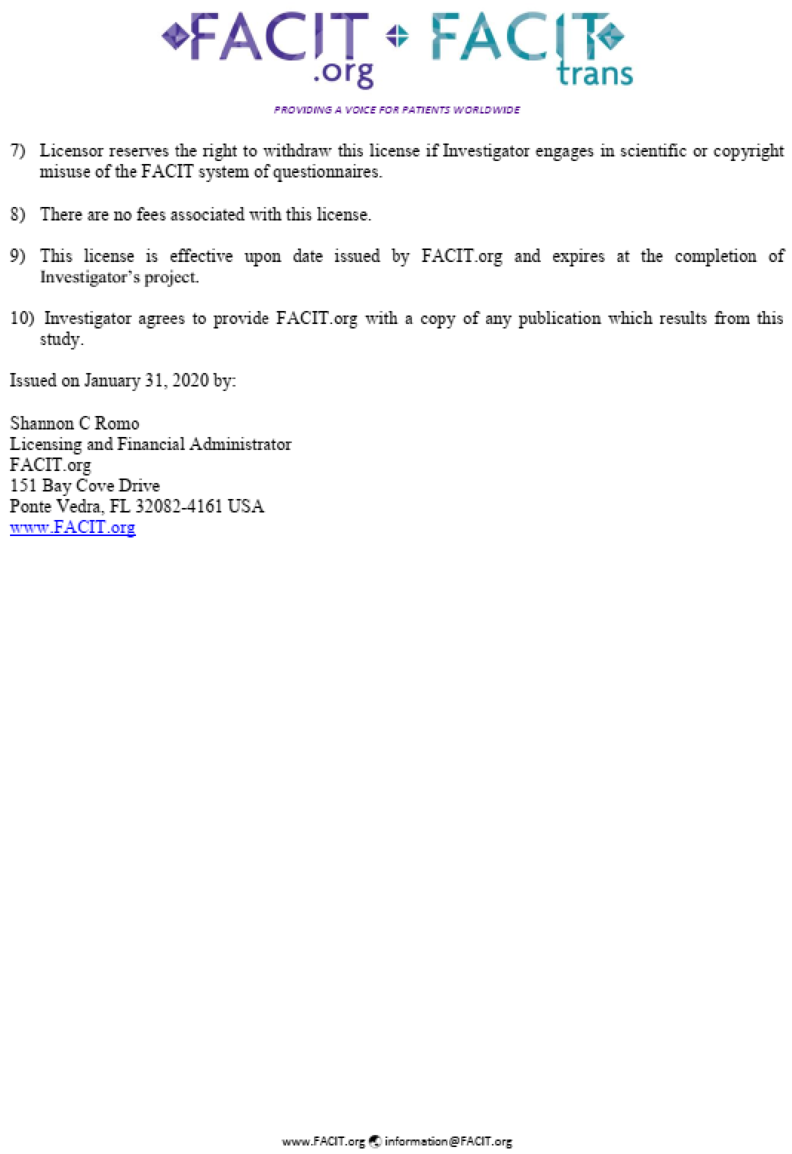

PROVIDING A VOICE FOR PATIENTS WORLDWIDE

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8) There are no fees associated with this license.

9) This license is effective upon date issued by FACIT.org and expires at the completion of Investigator's project.

10) Investigator agrees to provide FACIT.org with a copy of any publication which results from this study.

Issued on January 31, 2020 by:

Shannon C Romo
Licensing and Financial Administrator
FACIT.org
151 Bay Cove Drive
Ponte Vedra, FL 32082-4161 USA
www.FACIT.org

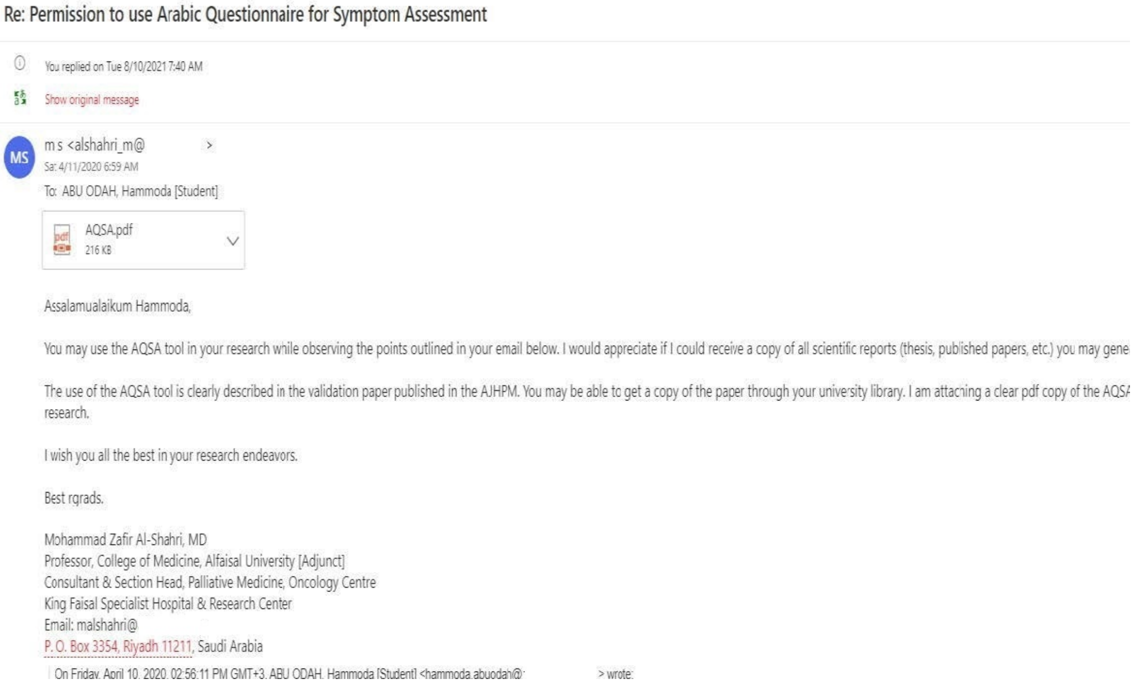
www.FACIT.org ◆ information@FACIT.org

Re: Validity and feasibility of the Arabic version of distress thermometer for Saudi cancer patients

Fahad Alosaimi <faalosaimi@ >
Thu 2/20/2020 9:00 AM
To: ABU ODAH, Hammoda [Student]

Definitely.
My pleasure.
You my find it in this link:
https://www.researchgate.net/profile/Fahad_Alosaimi/publication/330214289_mqyas_alkdr_lmrdy_alawram_mgnn_balrby_Arabic_NCCN_Distress_Thermometerpdf/data/5c55ea2c92851c22a3a3dd96/mqyas-alkdr-lmrdy-alawram-NCCN-Thermometer.pdf?orgin=publication_list

Sincere regards,
Fahad



Re: Permission to use Arabic Questionnaire for Symptom Assessment

You replied on Tue 8/10/2021 7:40 AM

Show original message

m s <alshahri_m@ >
Sat 4/11/2020 6:59 AM
To: ABU ODAH, Hammoda [Student]

AQSA.pdf
216 KB

Assalamualaikum Hammoda,

You may use the AQSA tool in your research while observing the points outlined in your email below. I would appreciate if I could receive a copy of all scientific reports (thesis, published papers, etc.) you may gene

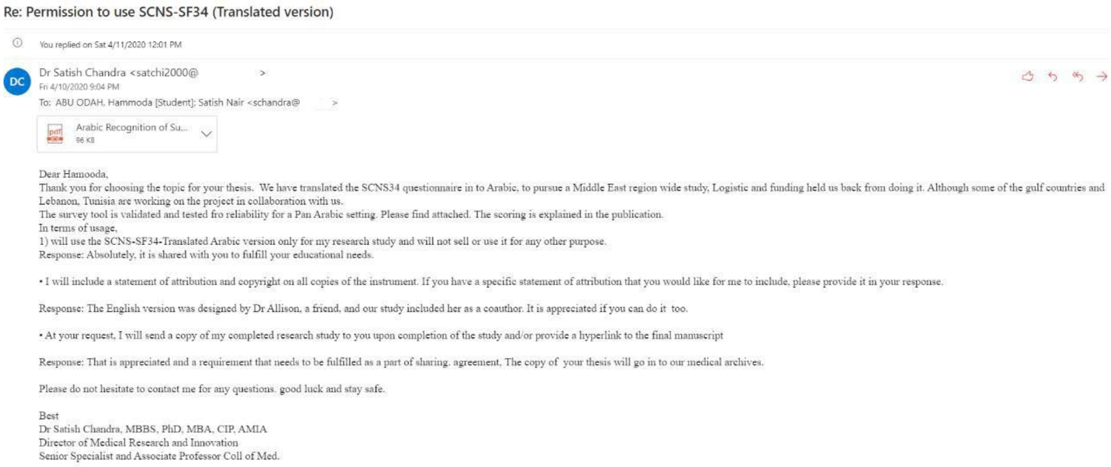
The use of the AQSA tool is clearly described in the validation paper published in the AJHPM. You may be able to get a copy of the paper through your university library. I am attaching a clear pdf copy of the AQS research.

I wish you all the best in your research endeavors.

Best rgrads.

Mohammad Zafir Al-Shahri, MD
Professor, College of Medicine, Alfaisal University [Adjunct]
Consultant & Section Head, Palliative Medicine, Oncology Centre
King Faisal Specialist Hospital & Research Center
Email: malshahri@
P. O. Box 3354, Riyadh 11211, Saudi Arabia

On Friday, April 10, 2020, 02:56:11 PM GMT+3, ABU ODAH, Hammoda [Student] <hammoda.abuodah@ > wrote:



Re: Permission to use SCNS-SF34 (Translated version)

You replied on Sat 4/11/2020 12:01 PM

Dr Satish Chandra <satchi2000@ >
Fri 4/10/2020 9:04 PM
To: ABU ODAH, Hammoda [Student]; Satish Nair <schandra@ >

Arabic Recognition of Su...
96 KB

Dear Hamooda,
Thank you for choosing the topic for your thesis. We have translated the SCNS34 questionnaire in to Arabic, to pursue a Middle East region wide study, Logistic and funding held us back from doing it. Although some of the gulf countries and Lebanon, Tunisia are working on the project in collaboration with us.
The survey tool is validated and tested fro reliability for a Pan Arabic setting. Please find attached. The scoring is explained in the publication.
In terms of usage,
1) will use the SCNS-SF34-Translated Arabic version only for my research study and will not sell or use it for any other purpose.
Response: Absolutely, it is shared with you to fulfill your educational needs.

• I will include a statement of attribution and copyright on all copies of the instrument. If you have a specific statement of attribution that you would like for me to include, please provide it in your response.

Response: The English version was designed by Dr Allison, a friend, and our study included her as a coauthor. It is appreciated if you can do it too.

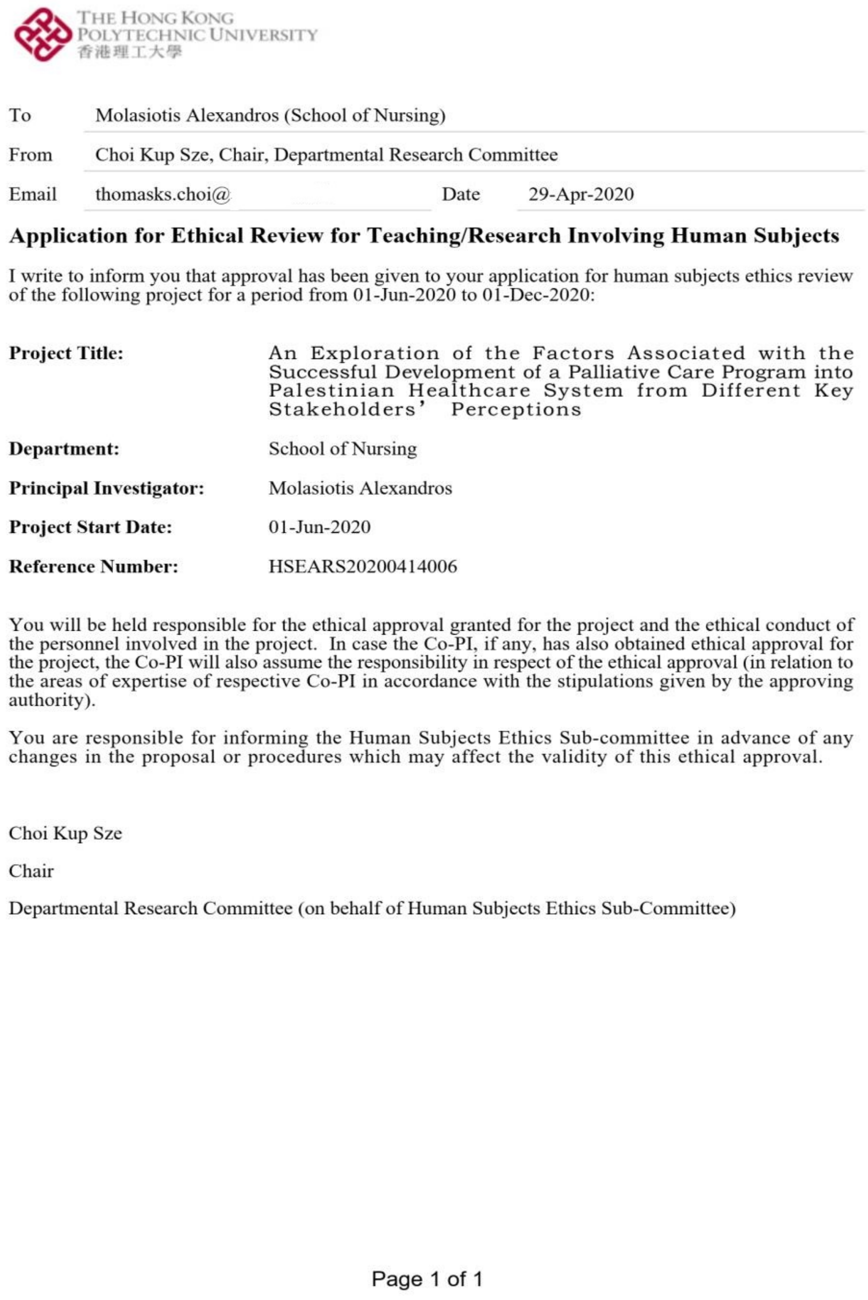
• At your request, I will send a copy of my completed research study to you upon completion of the study and/or provide a hyperlink to the final manuscript

Response: That is appreciated and a requirement that needs to be fulfilled as a part of sharing. agreement, The copy of your thesis will go in to our medical archives.

Please do not hesitate to contact me for any questions. good luck and stay safe.

Best
Dr Satish Chandra, MBBS, PhD, MBA, CIP, AMIA
Director of Medical Research and Innovation
Senior Specialist and Associate Professor Coll of Med.

Appendix 11: Letter approved by the Research Ethics committee of the Hong Kong Polytechnic University



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

To	Molasiotis Alexandros (School of Nursing)		
From	Choi Kup Sze, Chair, Departmental Research Committee		
Email	thomasks.choi@	Date	29-Apr-2020

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 01-Jun-2020 to 01-Dec-2020:

Project Title:	An Exploration of the Factors Associated with the Successful Development of a Palliative Care Program into Palestinian Healthcare System from Different Key Stakeholders' Perceptions
Department:	School of Nursing
Principal Investigator:	Molasiotis Alexandros
Project Start Date:	01-Jun-2020
Reference Number:	HSEARS20200414006

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.

Choi Kup Sze

Chair

Departmental Research Committee (on behalf of Human Subjects Ethics Sub-Committee)

Page 1 of 1

Appendix 12: Letter approved by the Palestinian Ministry of Health to conduct the study at two hospitals

State of Palestine
Ministry of health

دولة فلسطين
وزارة الصحة

السيد : رامي عيد سليمان العبادله المحترم

التاريخ:21/04/2020
رقم المراسلة 476303

مدير عام بالوزارة /الإدارة العامة لتنمية القوى البشرية ـ /وزارة الصحة

السلام عليكم ,,,

الموضوع/ تسهيل مهمة الباحث// حمودة أبو عودة

التفاصيل //
بخصوص الموضوع أعلاه، يرجي تسهيل مهمة الباحث/ **حمودة محمد أبو عودة**
الملتحق ببرنامج دكتوراه التمريض – جامعة هونغ كونج البوليتكنيك ـ هونغ كونغ في إجراء بحث بعنوان:ـ:ـ

An Exploration of the Factors Associated with the Successful Development of a Palliative“ Care Program into Palestinian Healthcare System from Different Key Stakeholders’ ”Perceptions

حيث الباحث بحاجة لتعبئة استبانة من عدد من مرضى الأورام وكذلك مقدمي الخدمات الصحية لهم إضافة لإجراء مقابلات معمقة مع عدد من أصحاب القرار في المستشفيات الحكومية، بما لا يتعارض مع مصلحة العمل وضمن أخلاقيات البحث العلمي، ودون تحمل الوزارة أي أعباء أو مسئولية.
وتفضلوا بقبول فائق الاحترام والتقدير،

ملاحظة / تسهيل المهمة الخاص بالدراسة أعلاه صالح لمدة 9 أشهر من تاريخه.

محمد ابراهيم محمد السرساوي
مدير دائرة/الإدارة العامة لتنمية القوى البشرية ـ

التحويلات

- محمد ابراهيم محمد السرساوي(مدير دائرة) ← رامي عيد سليمان العبادله(مدير عام بالوزارة) إجراءاتكم بالخصوص(21/04/2020)

المرفقات

- حمودة ابوعودة استبانة.pdf

غزة تلفون. (970+) 8–2846949
فاكس. (970+) 8–2826295

Gaza Tel. (+970) 8–2846949
Fax. (+970) 8–2826295

Appendix 13: Information Sheet for the Healthcare Professionals (English and Arabic)

INFORMATION SHEET

An Exploration of the Factors and Needs Associated with the Development of a Palliative Care Program into the Palestinian Healthcare System from Different Key Stakeholders' Perceptions

You are invited to participate in the above study supervised by Professor Alex Molasitiotis and Dr Justina Liu, and conducted by Mr. Hammoda ABU-ODAH, who is a Ph.D. student at the School of Nursing, The Hong Kong Polytechnic University. Prior to your decision, it is significant for you to understand why the research will conduct and what it will involve. Take your time reading the below information. If you have any unclear information, please do not hesitate to ask and we are happy to provide more explanation. Take time to decide whether you want to participate or not. If you agree to participate, you will need to sign a written informed consent (next page). Please note that participation in this study is totally on a voluntary basis.

The overall purpose of this study is to assess the educational issues or needs that physicians' and nurses' may face and how these affect the implementation of PC services. The objectives of this study are to assess the level of knowledge of physicians' and nurses' about palliative care; to explore the attitudes of physicians' and nurses' about palliative care; and to examine whether physicians' and nurses' knowledge and attitudes of palliative care differ.

You are invited to take part in this study because you are working at medical or oncology departments and are in more contact with cancer patients. You are required to complete a questionnaire, which will take about half an hour. You are free and have a right to withdraw from participation in this study at any time.

The information you provide as part of the project is the research data. Any research data from which you can be identified is known as personal data. Personal data does not include data where the identity has been removed (anonymous data). We will minimize our use of personal data in the study as much as possible. The researcher and supervisors will have access to your data for the purposes of the study. Responsible members of The Hong Kong Polytechnic University may be given access for monitoring and/or audit of the research.

All information related to you will remain confidential and will be identifiable by codes know only to the researches. All data retrieved will storage in a locked cabinet and can only be accessed by research teams. The information collected will be kept after project completion/publication. The Hong Kong Polytechnic University takes reasonable precautions to prevent the loss, misappropriation, unauthorized access or destruction of the information you provide.

You have every right to withdraw from the study before or during the measurement without penalty of any kind. If you have any questions, you may ask our helpers now or later, even after the study has started. You may contact Mr. Hammoda Abu-Odah (tel. no.: (00972) 56917 email: hammoda.abuodah@__________) or Prof. Alex Molassiotis (tel. no.: (852) 27666396 email: alex.molasiotis@______________) or Dr Justina Liu (tel. no.: (852) 27664097/ email: justina.liu@____________) of PolyU under the following situations:

d. if you have any other questions in relation to the study;

e. if, under very rare conditions, you become injured as a result of your participation in the study; or
f. if you want to get access to/or change your personal data before (the expiry date).

In the event you have any complaints about the conduct of this research study, you may contact the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in writing (c/o Research Office of the University) stating clearly the responsible person and department of this study as well as the HSESC Reference Number.

Thank you for your interest in participating in this study.

Principal Investigators
Prof. Alex Molassiotis, Dr Justina Liu, Mr. Hammoda Abu-Odah

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

ورقة المعلومات

استكشاف العوامل المرتبطة بالادخال الناجح لبرنامج الرعاية التلطيفية في نظام الرعاية الصحية الفلسطيني من وجهة نظر أصحاب المصلحة الرئيسيين

عزيزي المشارك/ـــة.

أنت مدعو للمشاركة في الدراسة المبينة آنفاً التي يجريها الباحث حمودة محمد أبو عودة، طالب الدكتوراه في جامعة بوليتكنك هونغ كونغ ، وبإشراف البروفيسور ألكس مولسيوتس ودكتورة جستينا ليو. من المهم قبل اتخاذك قرار المشاركة في هذه الدراسة أن تعرف لماذا نقوم بها وما محتواها. أرجو من سيادتكم أخذ الوقت المناسب لقراءة المعلومات المبينة أدناه بتمعن. إذا كانت لديك أي معلومات غير واضحة، فيرجى من سيادتكم عدم التردد في طرحها، ويسعدنا تقديم المزيد من التوضيح. خُذ وقتك الكافي وحدد إذا كنت ترغب في المشاركة في هذه الدراسة أم لا. في حالة الموافقة، فستحتاج منك التوقيع على إقرار الموافقة بالدراسة. يرجى ملاحظة أن مشاركتك في هذه الدراسة طوعية ولك الحرية التامة بالانسحاب عن المشاركة في أي وقت وبدون إعطاء مسوّغات. شكراً لقراءتك هذا.

تهدف هذه الدراسة، على نحوٍ عام، إلي تقييم القضايا أو الاحتياجات التعليمية التي قد يواجهها الأطباء والممرضون وكيف تؤثر على تنفيذ خدمات الرعاية التلطيفية. على نحوٍ خاص تهدف إلي تحديد مستوى معرفة الأطباء والممرضين لمفهوم الرعاية التلطيفية؛ استكشاف مواقف الأطباء والممرضين حول الرعاية التلطيفية؛ ودراسة ما إذا كانت معرفة ومواقف الأطباء والممرضين للرعاية التلطيفية مختلفة.

يسرني دعوتك للمشاركة في الإجابة عن أسئلة هذه الاستبانة. وقد تم اختيارك بوصفك أحد من يمثلون تقديم الخدمة الصحية في هذا المستشفى وعلى دراية بمرضى السرطان والخدمات المقدمة لهم. أرجو من سيادتكم تعبئة الاستبانة التي تتطلب نحو 30 دقيقةً لاستكماله. كما ذكرنا سابقاً، إنّ مشاركتك في هذه الدراسة طوعية ولك الحرية التامة بالانسحاب عن المشاركة في أي وقت وبدون إعطاء مسوّغات.

جميع المعلومات التي تقدمها بوصفها جزءاً من المشروع هي بيانات البحث. تُعرف البيانات البحثية التي يمكن تعرّفك من خلالها بالبيانات الشخصية. لذلك لن تتضمن البيانات الشخصية أي بيانات توضح هويتك (كالاسم مثلاً). سنقلل من استخدامنا للبيانات الشخصية في الدراسة قدر المستطاع. سيتمكن الباحث والمشرفون من الوصول إلى البيانات الشخصية وبيانات البحث لأغراض الدراسة. كما سيُمنح الأعضاء المسؤولون في جامعة بوليتكنك هونغ كونغ إمكانية الوصول إلى بياناتك بهدف مراقبة أو تدقيق البحث. كما سيتم التعامل بالمعلومات المتعلقة بسيادتكم بسرية تامة وسيتم تعرّفها من خلال رموز معرفة للباحثين. و سيتم الاحتفاظ بالمعلومات في مكان آمن وسيتم اتلافها فيما بعد حسب أنظمة جامعة بوليتكنك هونغ كونغ.

عزيزي المشارك/ـــة مشاركتك مهمة بالنسبة لي/ لذلك أرغب منك بدعمي في هذه الاستبانة. إذا كنت ترغب في الحصول على نسخة من نتيجة البحث أو كان لديك أسئلة بخصوصه، فيرجى الاتصال بنا من خلال وسائل

الاتصال المذكورة أدناه. وفي حال كنت غير راضٍ عن الطريقة التي يتم اتباعها في هذه الدراسة فيمكنك الرفع بأي اقتراح أو اعتراض (بدون ذكر اسمك إن رغبت في ذلك) إلى المشرف على هذا البحث: البروفيسور ألكس مولسيوتس ودكتورة جستينا ليو.

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شكراً لوقتك ومشاركتك في الدراسة

مع خالص الاحترام والتقدير،

حمودة محمد أبو عودة، ايميل hammoda.abuodah@

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THE HONG KONG
POLYTECHNIC UNIVERSITY
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Appendix 14: Written Informed Consent for the Healthcare Professionals (English and Arabic)

CONSENT TO PARTICIPATE IN RESEARCH

An Exploration of the Factors and Needs Associated with the Development of a Palliative Care Program into the Palestinian Healthcare System from Different Key Stakeholders' Perceptions

I ________________________ hereby consent to participate in the captioned study conducted by Mr. Hammoda ABU-ODAH, who is a Ph.D. student at the School of Nursing, The Hong Kong Polytechnic University

Please read each statement and initial the box	**Please initial each box**
1. I confirm that I have read and understood the information sheet for the above study. I have been delivered a full explanation by the investigators of the nature, purpose and likely duration of the study, and of what I will be expected to do.	☐
2. I understand that participation in this study is voluntary, and I am free to withdraw at any time without giving reason.	☐
3. I understand that any information given by me may be utilised in future report, publications, or presentations by the research	☐
4. I understand that my name will not appear in any reports, articles or presentations.	☐
5. I have been given adequate time to consider my participation and I agree to take part in the above study.	☐

Name of participant ______________________________

Signature of participant ______________________________

Name of researcher ______________________________

Signature of researcher ______________________________

Date ______________________________

اقرار خـطـي

استكشاف العوامل المرتبطة بالادخال الناجح لبرنـامج الرعاية التلطيفية في نظام الرعاية الصحية الفلسطيني من وجهة نظر أصحاب المصلحة الرئيسيين

أوافق أنا الزميل_____________________________ على إقرار المشاركة في الدراسة المبينة أعلاه التي يجريها الباحث حمودة أبو عودة، طالب الدكتوراة بكلية التمريض، جامعة بوليتكنك هونغ كونغ.

أرجو التمعن بقراءة كل بند قبل وضع علامة في المربع المخصص	**ضع اشارة في الصندوق**
1. أقر بأنني قرأت وفهمت ملف معلومات المشاركة في الدراسة المقدمة أعلاه. لقد تلقيت شرحاً كاملاً من قبل الباحث لطبيعة الدراسة والغرض منها والمدة المحتملة للدراسة، وقد تسنى لي استيعاب المعلومات وطرح الأسئلة التي تم الإجابة عليها.	☐
2. أعلم أن مشاركتي في هذه الدراسة طوعية ولي الحرية التامة بالإنسحاب عن المشاركة في أي وقت وبدون إعطاء مبررات.	☐
3. أتفهم بأن المعلومات التي زودتها للباحثين ممكن أن تستخدم في أغراض البحث كالتقارير وورشات العمل والمنشورات البحثية.	☐
4. أتفهم أن المعلومات سوف تُستخدم بسرية تامة بدون ذكر أسماء في أي تقارير أو عروض تقديمية أو أوراق بحثية.	☐
5. لقد تم منحي الوقت الكافي لتحديد رغبتي في المشاركة في هذه الدراسة. أقر بالمشاركة في الدراسة المبينة أعلاه.	☐

أسم المشارك/ـــة:____

التوقيع: ____

اسم الباحث:____

التوقيع:____

التاريخ:____

Appendix 15: Personal characteristics of the Healthcare Professionals (English and Arabic)

SN.	

Demographic characteristics

Gender	1. Male	2. Female
Age (Year)		

Level of education	please tick (√) one box
Diploma or less	
Bachelor	
Master or PhD or Board	

Professionals’ variables

Profession/Discipline	please tick one box
Physician	
Nurse	

Status/Rank	please tick one box
Head	
Sub-head	
Senior	
Staff	

Work setting/Clinical area	please tick one
Medical departments	
Oncology/haematology	

Hospital	please tick one
Al-Shifa	
European Gaza Hospital	

Working experience	Year
Duration of clinical experience	
Experience of working in oncology or medical	

Items related palliative care		
Did you receive training in PC?	Yes	No
If **(YES)**, what type/name of training did you		
How long did you receive this training?		
Where did you receive training?		

الرقم المتسلسل		

المعلومات الشخصية:

المعلومات الديموغرافية

الجنس	1. ذكر	2. أنثى
العُمر بالسنوات		

المستوى التعليمي	الرجاء وضع علامة (√) في مربع واحد
1. دبلوم فأقل	
2. البكالوريوس	
3. ماجستير أو دكتوراة أو بورد	

المعلومات المهنية/الوظيفية

الوظيفة	الرجاء وضع علامة (√) في مربع واحد
1. طبيب	
2. ممرض	

المستوى الوظيفي	الرجاء وضع علامة (√) في مربع واحد
1. رئيس قسم	
2. نائب رئيس القسم	
3. كبير الموظفين Senior	
4. موظف Staff	

مكان العمل (القسم)	الرجاء وضع علامة (√) في مربع واحد
1. أقسام الباطنة	
2. قسم الأورام/الدم	

المستشفى	الرجاء وضع علامة (√) في مربع واحد
1. م. الشفاء	
2. م. غزة الأوروبي	

الخبرة في مكان العمل	بالسنوات
1. الخبرة السريرية (العملية) / عدد سنوات الخبرة الكلي	
2. الخبرة العملية في قسم الباطنة أو الأورام	

بنود متعلقة بالرعاية التلطيفية		
1. هل تلقيت تدريب في مجال الرعاية التلطيفية	نعم	لا
إذا كانت الاجابة (**نعم**)، نوع التدريب/ اسم التدريب الذي تلقيته؟		
مدة التدريب ؟		
مكان التدريب؟		

Appendix 16: The Palliative Care Knowledge Test (English and Arabic)

■ **Please select the appropriate answer for each of the items listed below.**	**Correct**	**Incorrect**	**Unsure**
Philosophy			
Palliative care should only be provided for patients who have no curative treatments available.	1	2	3
Palliative care is exclusively for people who are in the last six months of life	1	2	3
Palliative care should not be provided along with anti-cancer treatments.	1	2	3
Palliative care is specifically for people with cancer	1	2	3
Pain			
One of the goals of pain management is to get a good	1	2	3
When cancer pain is mild, morphine should be used more often.	1	2	3
When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used.	1	2	3
Long-term use of opioids can often induce addiction.	1	2	3
Use of opioids does not influence survival time.	1	2	3
Some dying patients will require continuous sedation to alleviate suffering.	1	2	3
Dyspnea			
Morphine should be used to relieve dyspnea in cancer	1	2	3
When opioids are taken on a regular basis, respiratory depression will be common.	1	2	3
Oxygen saturation levels are correlated with dyspnea.	1	2	3
Anticholinergic drugs or scopolamine hydrobromide are effective for alleviating bronchial secretions of dying patients.	1	2	3
Psychiatric problems			
During the last days of life, drowsiness associated with electrolyte imbalance should decrease patient discomfort.	1	2	3
Benzodiazepines should be effective for controlling delirium.	1	2	3
Morphine is often a cause of delirium in terminally ill	1	2	3
Gastrointestinal problems			
At terminal stages of cancer, higher calorie intake is needed compared to early stages.	1	2	3
There is no route except central venous for patients unable to maintain a peripheral intravenous route.	1	2	3
Steroids should improve appetite among patients with	1	2	3
Intravenous infusion will not be effective for alleviating dry mouth in dying patients.	1	2	3

اختبار المعرفة للرعاية التلطيفية

يرجى اختيار الإجابة المناسبة لكل بند من البنود المدرجة أدناه.	**صح**	**خطأ**	**غير متأكد**
الفلسفة			
يجب توفير خدمات الرعاية التلطيفية فقط للمرضى الذين ليس لديهم علاجات شفائية متوافرة.	1	2	3
تقدم خدمات الرعاية التلطيفية خصيصاً للمرضى الذين لديهم أقل من ستة أشهر للعيش.	1	2	3
لا ينبغي تقديم خدمات الرعاية التلطيفية إلى جانب علاجات السرطان.	1	2	3
الرعاية التلطيفية مخصصة فقط لمرضى السرطان.	1	2	3
الألم			
الحصول على نوم جيد في أثناء الليل هو أحد أهداف إدارة الألم.	1	2	3
المورفين أكثر أنوع المواد المخدرة استخداماً عندما يكون الألم المرتبط بالسرطان خفيفاً.	1	2	3
لا ينبغي استخدام الأدوية غير الستيرويدية المضادة للالتهاب (NSAIDs) في حالة تناول المواد الأفيونية على نحوٍ منتظم.	1	2	3
يؤدي غالباً استخدام المواد الأفيونية لمدة طويلة إلى الإدمان.	1	2	3
لن يؤثر استخدام المواد الأفيونية على حياة المريض.	1	2	3
يحتاج بعض المرضى المحتضرين إلى تخدير مستمر لتخفيف الألم لديهم.	1	2	3
صعوبة التنفس			
يجب استخدام المورفين للتقليل من صعوبة التنفس لدى مرضى السرطان.	1	2	3
عند تناول المواد الأفيونية على نحوٍ منتظم ، فإن احتمالية صعوبة التنفس (تثبيط الجهاز التنفسي) شائعة.	1	2	3
يرتبط مستوى تشبع الأكسجين في الدمّ بضيق النَّفَس.	1	2	3
تعتبرعقارات مضاد إفراز الكولين (Anticholinergic drugs) فاعلة للتخفيف من إفرازات الشُعب الهوائِية للمرضى المحتضرين.	1	2	3
اضطرابات نفسية			
خلال الأيام الأخيرة من الحياة، يقلل النعاس الناتج عن عدم توازن الإلكتروليت (Electrolyte Imbalance) من اضطراب المريض.	1	2	3
البنزوديازبينات (Benzodiazepines) له تأثير فاعل في السيطرة على الهَذَيَان (Delirium).	1	2	3
المورفين يسبب غالباً الهَذَيَان لدى مرضى السرطان الميؤوس من شفائهم.	1	2	3
التغدية			
يجب تناول مواد ذات سعرات حرارية عالية في المراحل النهائية من السرطان مقارنة بالمراحل الباكرة.	1	2	3
الوريد المركزي (Central venous) هو المسار الوحيد للعلاج للمرضى الغير قادرين على المحافظة على أوردتهم الطرفية.	1	2	3
تُحسِن الستيرويدات (Steroids) شهية مرضى السرطان ذي المراحل المتقدمة من المرض.	1	2	3
لا يوجد فاعلية في نقل السوائل عن طريق الوريد في التخفيف من جفاف الفم لدى المرضى المحتضرين.	1	2	3

Appendix 17: Bradley Attitude Questionnaire about Care at End-of-Life (English and Arabic)

The meaning of the letters is: SD = Strongly Disagree; D = Disagree; U = Uncertain; A = Agree; SA = Strongly Agree

	Please circle the letter following each statement which corresponds to your own personal feelings about the attitude or situation presented.	**SD**	**D**	**U**	**A**	**SA**
1	Most of my physician (nurse) colleagues feel that when their patients receive palliative care, it reflects their own failure.					
2	Many of my physician (nurse) colleagues are uncomfortable discussing the option of palliative care with patients and their					
3	Physicians do not have a role in palliative care.					
4	Most elderly patients who are dying want their doctors to determine what care is best for them.					
5	Palliative care generally meets the needs of the family better than conventional care does.					
6	An interdisciplinary team approach interferes with patient					
7	I feel knowledgeable enough to discuss palliative care with patients and families.					
8	Most patients' symptoms, such as pain, shortness of breath, and nausea, are not controlled any better with palliative care than with conventional care they would otherwise receive.					
9	I usually order (request) as much pain medication as needed to keep terminally ill patients pain free.					
10	I usually tell patients that curative treatment is no longer successful as soon as I know.					
11	Most elderly patients do not want to be told if they are dying.					

استبيان برادلي للمواقف

	يرجى وضع (√) في المكان الذي يلي كل بند يتوافق مع مشاعرك الشخصية حول الموقف المقدم.	**غير موافق بشدة**	**غير موافق**	**لست متأكد**	**موافق**	**موافق بشدة**
1	شُعور معظم زملائي من الأطباء و الممرضين بفشلهم عندما يتلقى مرضاهم الرعاية التلطيفية.					
2	شُعور معظم زملائي من الأطباء و الممرضين بعدم الراحة عند مناقشة خيارات الرعاية التلطيفية مع المرضى وأسرهم.					
3	ليس للأطباء دور في الرعاية التلطيفية					
4	يطلب معظم المرضى المُسنين، الذين هم في مراحلهم المتأخرة من حياتهم، من أطبائهم تحديد الرعاية الأفضل لهم.					
5	بوجه عام ، تُلبي الرعاية التلطيفية إحتياجات الأسرة على نحوٍ أفضل من الرعاية التقليدية.					
6	يتعارض فريق متعدد التخصصات مع رعاية المرضى.					
7	أشعُر بالمعرفة الكافية لمناقشة الرعاية التلطيفية مع المرضى وأسرهم.					
8	من الصعب التحكم في أعراض معظم المرضى (مثل الألم وضيق التنفس والغثيان) على نحوٍ أفضل من خلال الرعاية التلطيفية مقارنة بالرعاية التقليدية التي قد يتلقونها.					
9	عادة ما أطلب أكبر قدر ممكن من مسكنات الألم لإبقاء المرضى الميؤوس من شفائهم دون ألم.					
10	عادة ما أخبر المرضى أن العلاج الشفائي غير فعال بمجرد معرفتي ذلك.					
11	لا يرغب معظم المرضى المسنين بإخبارهم بالموت.					

Appendix 18: Frommelt Attitudes Toward Care of the Dying Scale (English and Arabic)

The meaning of the letters is: SD = Strongly Disagree; D = Disagree; U = Uncertain; A = Agree; SA = Strongly Agree

	Please circle the letter following each statement which corresponds to your own personal feelings about the attitude or situation presented.	**SD**	**D**	**U**	**A**	**SA**
1	Giving care to the dying person is a worthwhile experience.					
2	Death is not the worst thing that can happen to a person.					
3	I would be uncomfortable talking about impending death with the dying person.					
4	Caring for the patient's family should continue throughout the period of grief and bereavement.					
5	I would not want to care for a dying person.					
6	The non-family care-givers should not be the one to talk about death with the dying person.					
7	The length of time required to give care to a dying person would frustrate me.					
8	I would be upset when the dying person I was caring for, gave up hope of getting better.					
9	It is difficult to form a close relationship with the dying					
10	There are times when death is welcomed by the dying person.					
11	When a patient asks, "Am I dying?", I think it is best to change the subject to something cheerful.					
12	The family should be involved in the physical care of the dying person if they want to.					
13	I would hope the person I'm caring for dies when I am not					
14	I am afraid to become friends with a dying person					
15	I would feel like running away when the person actually died.					
16	Families need emotional support to accept the behavior changes of the dying person.					
17	As a patient nears death, the non-family care-giver should withdraw from his/her involvement with the patient					
18	Families should be concerned about helping their dying member make the best of his/her remaining life.					
19	The dying person should not be allowed to make decisions about his/her physical care.					
20	Families should maintain as normal an environment as possible for their dying member.					
21	It is beneficial for the dying person to verbalize his/her					
22	Care should extend to the family of the dying person.					
23	Care-givers should permit dying persons to have flexible visiting schedules.					
24	The dying person and his/her family should be the in-charge decision makers					

	Please circle the letter following each statement which corresponds to your own personal feelings about the attitude or situation presented.	**SD**	**D**	**U**	**A**	**SA**
25	Addiction to pain relieving medication should <u>not</u> be a concern when dealing with a dying person.					
26	I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.					
27	Dying persons should be given honest answers about their					
28	Educating families about death and dying is <u>not</u> a non-family care-givers responsibility.					
29	Family members who stay close to a dying person often interfere with the professionals' job with the patient.					
30	It is possible for non-family care-givers to help patients prepare for death.					

**Non-family caregiver* is defined as anyone who is giving care to the dying person, professional or non-professional, who is not a member of the patient’s family.

مقياس فروميلت للمواقف

تنويه *يُعرف مقدم الرعاية من خارج الأسرة بأنه أي شخص يقوم برعاية الشخص المحتضر (Dying person)، سواء أكان محترفاً أو غير محترف ، وليس فرداً من أسرة المريض.

	يرجى وضع (√) في المكان الذي يلي كل بند يتوافق مع مشاعرك الشخصية حول الموقف المقدم.	**غير موافق بشدة**	**غير موافق**	**لست متأكد**	**موافق**	**موافق بشدة**
1	العناية بالشخص المحتضر تجربة جديرة بالاهتمام.					
2	الموت ليس أسوأ شيء يمكن أن يحدث لشخص ما.					
3	أشعُر بالاضطراب عندما أتحدث عن الموت الوشيك مع الشخص المحتضر.					
4	يجب أن تستمر رعاية أسرة المريض طوال مدة الحزن والفجيعة.					
5	لا أرغب في رعاية شخص يحتضر.					
6	يجب ألا يتحدث مزودو الرعاية من غير الأسرة عن الموت مع الشخص المُحتضر.					
7	طوال المدة الزمنية اللازمة لرعاية الأشخاص المحتضرين تصيبني بالإحباط.					
8	أنزعج عندما يتخلى الشخص الذي أهتم به عن الأمل في التحسن والشفاء.					
9	من الصعب تكوين علاقة وثيقة مع الشخص المُحتضر.					
10	هناك أوقات يُرحِب فيها الشخص المحتضر بالموت.					
11	عندما يسأل المريض، "هل أنا أموت؟"، أعتقد أنه من الأفضل تغيير الموضوع إلى شيء مبهج ومفرح.					
12	يجب اشراك الأسرة في الرعاية الجسدية للشخص المُحتضر إذا أرادوا ذلك.					
13	أتمنى عدم وجودي عند موت الشخص الذي أهتم به.					
14	أخشى أن أكون صديقاً لشخص يحتضر.					
15	أشعر بالرغبة في الهرب عندما يموت الشخص الذي اعتني به.					
16	تحتاج الأسر إلى الدعم العاطفي لِتقبُل التغيرات السلوكية للشخص المُحتضر.					
17	مع اقتراب المريض من الموت، يجب على مقدم الرعاية من غير أفراد الأسرة الانسحاب من مشاركته مع المريض					
18	يجب أن تهتم الأسرة بمساعدة الشخص المُحتضر للاستفادة من حياته المتبقية.					
19	يجب ألا يُسمح للشخص المُحتضر باتخاذ قرارات بشأن رعايته الجسدية.					
20	يجب أن تحافظ الأسرة على بيئة طبيعية ومناسبة قدر المستطاع للشخص المُحتضر.					
21	من المُفيد أن يُعبر الشخص المُحتضر عن مشاعره شفهياً.					
22	يجب أن تمتد الرعاية الصحية إلى أسرة الشخص المُحتضر.					
23	يجب أن يسمح مقدمو الرعاية للأشخاص المحتضرين بالحصول على جداول زيارة مرنة.					

	يرجى وضع (√) في المكان الذي يلي كل بند يتوافق مع مشاعرك الشخصية حول الموقف المقدم.	**غير موافق بشدة**	**غير موافق**	**لست متأكد**	**موافق**	**موافق بشدة**
24	الشخص المحتضر وأسرته هم المسؤولون عن اتخاذ القرارات.					
25	لا داعي للقلق من إدمان الشخص المحتضرعلى الأدوية التي تخفف من الألم عند التعامل معه.					
26	أشعُر بالاضطراب والتوتر إذا دخلت غرفة شخص مصاب بمرض ميئوس من شفائه ووجدته يبكي.					
27	يجب إعطاء الأشخاص المحتضرين إجابات صادقة عن حالتهم.					
28	تثقيف الأسر حول الموت والاحتضار ليس مسؤولية مقدمي الرعاية من غير الأسرة.					
29	غالباً، ما يتدخل أفراد الأسرة الملازمون للشخص المحتضر في عمل الطاقم الصحي.					
30	من الممكن لمقدمي الرعاية من غير الأسرة مساعدة المرضى على الاستعداد للموت.					

Appendix 19: Palliative Care Needs Assessment Questionnaire (English and Arabic)

> ***Palliative care is continuous supportive care offered to patients with life-threatening illness and their family to improve quality of life. Palliative care is provided throughout the continuum of illness considering patients' physical, psychological, social, and spiritual needs.***

Please read each of the following items and then indicate your response by ***circling*** *the appropriate number.*

		Not at all familiar	**Somewhat familiar**	**Very familiar**
1.	**How *familiar are you* with the concept of palliative care?** *(refer to definition above)*	0	1	2

Questions 2 and 3 ask about ***services and education in your setting.***

2.	**Are the following palliative care services present in your setting?**	**No**	**Yes**
2.1	Contractual relationship with a hospice or home care program	0	1
2.2	Palliative care team or consult service	0	1
2.3	Palliative care unit	0	1
2.4	Discharge planning for patients with chronic illness	0	1
2.5	Interdisciplinary care program for dying patients	0	1
2.6	Pain management consultative team or service	0	1
2.7	Bereavement program	0	1
2.8	Quality improvement for end-of-life-care	0	1
2.9	Quality improvement for pain management	0	1
2.10	Quality improvement for symptom management	0	1
2.11	Program to promote advance care planning (advance directives)	0	1
2.12	Program for staff support in caring for dying patients	0	1
2.13	Ethics committee	0	1
2.14	Nurses who are certified in hospice and palliative nursing	0	1
2.15	Physicians who are certified in hospice and palliative medicine	0	1
2.16	Professional education program on palliative care	0	1
2.17	Access to palliative care resources outside of your hospital	0	1
2.18	Communication among healthcare team related to palliative care	0	1

3.	**Have you attended an educational program on any of the following topics in your work setting over the past 2 years?**	**No**	**Yes**	**Has not been offered**
3.1	End of life care	0	1	NA
3.2	Pain management	0	1	NA
3.3	Symptom management	0	1	NA
3.4	Ethics issues at the end of life	0	1	NA

3.5	Community health resources	0	1	NA
3.6	Communications skills (e.g., goals of care discussion, family meetings, breaking bad news)	0	1	NA
3.7	Care for the caregivers – health care professionals	0	1	NA
3.8	Care for the caregivers – family and friends	0	1	NA
3.9	Discharge planning for patients with chronic illness	0	1	NA
3.10	How to use online resources available (e.g., health information system used in your institution, search engines, e-library)	0	1	NA
3.11	Other; if yes, please specify ________________________	0	1	NA

The following questions ask about your interest in and preferences for ***learning more about palliative care.***

		No	Yes
4.	**I wish to learn more about palliative care.** If yes, what would you like to learn more about?	0	1
5.	**I think our clinical staff would like to learn more about palliative care.**	0	1

6.	**Which ones of the following methods would you prefer to learn more about palliative care?**	**No**	**Yes**	**Not applicable**
6.1	Participating in web-based learning (course, self-study module) on palliative care	0	1	Not available
6.2	Attending a professional meeting or workshop where this is a topic	0	1	
6.3	Partnership with academic (teaching/university hospital) entity, if available	0	1	Not available
6.4	Partnership with local hospice or home care providers	0	1	Not available
6.5	Bringing in a palliative care consultant	0	1	
6.6	Taking an intensive course on palliative care	0	1	
6.7	Taking a physician or nurse certification course on palliative care with continuing education credits	0	1	
6.8	Integrating palliative care information into nursing or medical academic programs	0	1	
6.9	Other; if yes, please specify _________________________	0	1	

7. **If a palliative care class or course were offered, what would make it possible for you or your staff to attend?**

The following questions ask about the ***delivery*** *of palliative care* ***in your setting****.*

8.	**In your setting, how *satisfied* are you with the extent to which:**	**Not at all**	**A little bit**	**Quite a bit**	**Extremely**

8.1	Goals of care for patients with advanced illness are discussed?	0	1	2	3
8.2	Patients are informed of different care options that are in line with their goals of care?	0	1	2	3
8.3	Patients understand the information they are told about their condition and treatment approaches?	0	1	2	3
8.4	Patients get the help they need to make decisions about care alternatives?	0	1	2	3
8.5	Ethical issues in a patient's care are discussed by health care professionals?	0	1	2	3
8.6	Pain management is provided?	0	1	2	3
8.7	Symptom management is provided?	0	1	2	3
8.8	Advance directives are addressed?	0	1	2	3
8.9	Effective transitions for plan of care are provided at discharge?	0	1	2	3
8.10	Religious or Spiritual care is provided?	0	1	2	3
8.11	Psychosocial support and care are provided to the patient?	0	1	2	3
8.12	Family support is provided?	0	1	2	3

9.	**The following items are possible barriers to providing optimal palliative care to patients. To what extent is each a *barrier in your setting*?**	**Not at all**	**Somewhat**	**Severe**
9.1	Lack of knowledge about palliative care by health care professionals	0	1	2
9.2	Health care professionals' personal discomfort with death	0	1	2
9.3	Health care professionals' fear of causing addiction by administering pain medications	0	1	2
9.4	Patients'/families' avoidance of issues around dying	0	1	2
9.5	Cultural, religious, and/or spiritual beliefs influencing end-of-life care	0	1	2
9.6	Patients'/families' fear of addiction to pain medications	0	1	2
9.7	Lack or inadequacy of written policies and procedures about palliative care	0	1	2
9.8	Differences in opinion among health care professionals about palliative care	0	1	2
9.9	Lack of access to hospice services	0	1	2
9.10	The patient/family is not part of the decision-making process	0	1	2
9.11	Fear of legal action by leadership or government	0	1	2
9.12	Communication difficulties among health care professionals, patients, and/or families	0	1	2
9.13	Personnel shortages/time constraints	0	1	2
9.14	Lack of designated beds for palliative care services	0	1	2
9.15	Lack availability of medications/opioids (narcotics)	0	1	2
9.16	Improper communication among interdisciplinary team	0	1	2
9.17	Lack of volunteers in community	0	1	2
9.18	Lack of policy and guidance availability	0	1	2
9.19	Lack of home care availability	0	1	2

9.20	Lack of training for staff related to palliative care	0	1	2
9.21	Lack of community awareness related to palliative care	0	1	2
9.22	Lack of student nurse interest related to palliative care	0	1	2

		Never	**Sometimes**	**Frequently**	**Always**
10.	**Health care professionals in my setting are able to recognize the active dying process.**	0	1	2	3
11.	**Once a patient is identified as dying in my setting, I believe staff is comfortable knowing what to do for the patient.**	0	1	2	3
12.	**Palliative care is integrated into the care plan for seriously ill patients in my setting.**	0	1	2	3
13.	**I am comfortable talking about limited prognosis with patients and families.**	0	1	2	3

14. **Please tell us what your setting is doing well to provide palliative care:**

____

15. **What resources exist in your setting and community that could be used to help improve palliative care (e.g., people, agencies, community resources, nongovernmental organizations [NGOs])?**

____

No **Yes**

16.	**Are there any particular patient populations (e.g., age related [elderly, pediatric], diagnosis, ethnic groups, low literacy, language barrier) with whom you need more assistance?** If yes, please specify: ____	0	1

Thank you for taking the time to complete this survey.
Your input and opinions are important to us.

تقييم احتياجات الرعاية التلطيفية

الرعاية التلطيفية هي الرعاية الداعمة المستمرة التي تُقدم للمرضى الذين يعانون من أمراض تهدد حياتهم وعائلاتهم لتحسين نوعية الحياة لديهم. تقدم الرعاية التلطيفية خلال مدة المرض مراعية احتياجات المرضى الجسدية والنفسية والاجتماعية والروحية.

يرجى قراءة كل بند من البنود الآتية ثم بيان إجابتك بوضع دائرة حول الرقم المناسب.

		غير مألوف على الإطلاق	**مألوف إلى حد ما**	**مألوف جداً**
1	**ما مدى معرفتك بمفهوم الرعاية التلطيفية؟** *(راجع التعريف المذكور آنفاً)*	0	1	2

*يهتم السؤال 2 و3 **عن الخدمات والتعليم** في مؤسستك.*				
2	**هل خدمات الرعاية التلطيفية الآتية متوافرة في مؤسسك؟**	**لا**	**نعم**	
2.1	تعاقد مع برنامج الرعاية المنزلية	0	1	
2.2	فريق رعاية تلطيفية أو خدمات استشارية	0	1	
2.3	وحدة عناية تلطيفية	0	1	
2.4	تخطيط الخروج (Discharge planning) لمرضى الأمراض المزمنة	0	1	
2.5	برنامج رعاية متعدد التخصصات للمرضى المحتضرين	0	1	
2.6	فريق أو خدمة استشارية لإدارة الألم	0	1	
2.7	برنامج فُقْدان، الفجيعة (Bereavement program)	0	1	
2.8	تحسين الجودة لرعاية نهاية الحياة	0	1	
2.9	تحسين الجودة لإدارة الألم	0	1	
2.10	تحسين الجودة لإدارة الأعراض	0	1	
2.11	برنامج لتعزيز تخطيط الرعاية المسبقة (التوجيهات المسبقة)	0	1	
2.12	برنامج لدعم الموظفين الذين يقومون برعاية المرضى المحتضرين	0	1	
2.13	لجنة الأخلاقيات	0	1	
2.14	ممرضون حاصلون على شهادة في الرعاية التلطيفية	0	1	
2.15	أطباء حاصلون على شهادة في الرعاية التلطيفية	0	1	
2.16	برنامج تعليم مهني في الرعاية التلطيفية	0	1	
2.17	الوصول إلى موارد الرعاية التلطيفية خارج المستشفى	0	1	
2.18	التواصل بين فريق الرعاية الصحية فيما يتعلق بالرعاية التلطيفية	0	1	
3	**هل سبق لك أن حضرت برنامجاً تعليمياً عن أي من المواضيع الآتية في عملك خلال السنتين الماضيتين؟**	**لا**	**نعم**	**لم يتم عرضه**
3.1	الرعاية في مرحلة الاحتضار(End-of-life care)	0	1	NA
3.2	إدارة الألم	0	1	NA

3.3	إدارة الأعراض	0	1	NA
3.4	قضايا الأخلاق في رعاية نهاية الحياة	0	1	NA
3.5	الموارد الصحية للمجتمع	0	1	NA
3.6	مهارات الإتصالات (مثلاً، أهداف مناقشة الرعاية، الاجتماعات الأسرية، وكيفية التعامل مع الأخبار السيئة العاجلة)	0	1	NA
3.7	رعاية مقدمي الرعاية - مختصو الرعاية الصحية	0	1	NA
3.8	رعاية مقدمي الرعاية - الأسرة والأصدقاء	0	1	NA
3.9	تخطيط الخروج (Discharge planning) لمرضى الأمراض المزمنة	0	1	NA
3.10	كيفية استخدام الموارد المتاحة عبر الإنترنت (مثل نظام المعلومات الصحية المستخدم في مؤسستك ومحركات البحث والمكتبة الإلكترونية)	0	1	NA
3.11	أخرى؛ إذا كانت الإجابة نعم، من فضلك وضح..........................	0	1	NA

*تطرح الأسئلة الآتية معلومات تتعلق باهتمامك وتفضيلاتك **لتعلم المزيد عن الرعاية التلطيفية**.*			
		لا	**نعم**
4	**أرغب في معرفة المزيد عن الرعاية التلطيفية.** إذا كانت الإجابة بنعم ، فما الذي تود معرفة المزيد عنه؟	0	1
5	**أعتقد أن فريقنا الصحي يرغب في معرفة المزيد عن الرعاية التلطيفية.**	0	1

6	**أي من الطرق الآتية تفضلها للتعلم من خلالها عن الرعاية التلطيفية؟**	**لا**	**نعم**	**غير متاح**
6.1	المشاركة في التعلم عبر شبكة الإنترنت حول الرعاية التلطيفية.	0	1	غير متاح
6.2	حضور اجتماع أو ورشة عمل مهنية يكون فيها هذا الموضوع.	0	1	
6.3	الشراكة مع جهة أكاديمية (التدريس / المستشفى الجامعي) ، إن وجدت.	0	1	غير متاح
6.4	الشراكة مع مقدمي الرعاية المنزلية أو مقدمي الرعاية التلطيفية.	0	1	غير متاح
6.5	استقدام استشاري رعاية تلطيفية.	0	1	
6.6	أخذ دورة مكثفة في الرعاية التلطيفية.	0	1	
6.7	أخذ دورة مرخصة في الرعاية التلطيفية معتمدة من التعليم المستمر.	0	1	
6.8	دمج معلومات الرعاية التلطيفية في البرامج الأكاديمية للتمريض أو الطب.	0	1	
6.9	أخرى؛ إذا كانت الإجابة نعم، من فضلك وضح..........................	0	1	
7. اذا اتيجت لك فرصة لحضور دورة أو درس في الرعاية التلطيفية، ما الذي يدفعك أنت أو موظفيك للموافقة للحضور؟				

*تطرح الأسئلة الآتية معلوماتٍ تتعلق **بتقديم** الرعاية التلطيفية **في مؤسستك**.*

8	**في مؤسستك، ما مدى رضاك عن:**	غير راض على الإطلاق	قليلاً	ألى حد ما	راض تماماً
8.1	مناقشة أهداف رعاية المرضى الذين يعانون من مراحل متقدمة في المرض؟	0	1	2	3
8.2	إبلاغ المرضى بخيارات الرعاية المختلفة التي تُماشي أهدافهم في الرعاية؟	0	1	2	3
8.3	فهم المرضى للمعلومات التي تُزود لهم عن حالتهم وطرق العلاج؟	0	1	2	3
8.4	حصول المرضى على المساعدة التي يحتاجونها لاتخاذ قرارات بشأن بدائل الرعاية؟	0	1	2	3
8.5	مناقشة القضايا الأخلاقية في رعاية المرضى من قبل مقدمي الخدمة الصحية؟	0	1	2	3
8.6	توفير إدارة للألم؟	0	1	2	3
8.7	توفير إدارة الأعراض؟	0	1	2	3
8.8	التعامل مع التوجيهات المسبقة (Advanced directives)؟	0	1	2	3
8.9	توفير انتقال فعال لخطة الرعاية عند خروج المريض؟	0	1	2	3
8.10	تقديم الرعاية الدينية أو الروحية؟	0	1	2	3
8.11	توفير الدعم والرعاية النفسية والاجتماعية للمريض؟	0	1	2	3
8.12	توفير دعم للأسرة؟	0	1	2	3

9	**فيما يلي بعض البنود المحتملة التي يمكن أن تشكل عقبات أمام توفير الرعاية التلطيفية المثلى للمرضى، إلى أي مدى يشكل كل بند *عقبة في مؤسستك؟***	ليس على الإطلاق	ألى حد ما	تماماً
9.1	نقص المعرفة بشأن الرعاية التلطيفية من جانب العاملين في مجال الرعاية الصحية.	0	1	2
9.2	عدم الارتياح الشخصي لمقدمي الرعاية الصحية للتحدث عن الوفاة أو الاحتضار.	0	1	2
9.3	خوف مقدمي الرعاية الصحية من التسبب في إدمان المرضى عن طريق إعطاء مسكنات الألم.	0	1	2
9.4	تجنب المرضى / الأسر للقضايا المتعلقة بالموت والاحتضار.	0	1	2
9.5	تأثير المعتقدات الثقافية والدينية و/أو الروحية على الرعاية في نهاية الحياة.	0	1	2
9.6	خوف المرضى/الأسر من الإدمان على أدوية الألم.	0	1	2
9.7	عدم وجود سياسات وإجراءات مكتوبة حول الرعاية التلطيفية.	0	1	2
9.8	اختلاف الأراء بين مقدمي الرعاية الصحية حول الرعاية التلطيفية.	0	1	2
9.9	عدم القدرة على الوصول إلي خدمات الرعاية المنزلية	0	1	2
9.10	عدم اعتبار المريض/العائلة جزءاً من عملية صنع القرار.	0	1	2
9.11	الخوف من الإجراءات القانونية من قبل القيادة أو الحكومة	0	1	2
9.12	صعوبات في الاتصال بين العاملين في مجال الرعاية الصحية والمرضى و/أوالأسر.	0	1	2
9.13	نقص الموظفين / قيود وضيق الوقت.	0	1	2
9.14	عدم توفر أسِرة مخصصة لخدمات الرعاية التلطيفية.	0	1	2
9.15	عدم توفر الأدوية / المواد الأفيونية.	0	1	2
9.16	عدم التنسيق بين الفريق متعدد التخصصات.	0	1	2
9.17	نقص المتطوعين في المجتمع.	0	1	2
9.18	عدم توافر السياسات والتوجيهات.	0	1	2
9.19	عدم توافر خدمات الرعاية المنزلية.	0	1	2
9.20	نقص تدريب الموظفين فيما يتعلق بالرعاية التلطيفية.	0	1	2
9.21	نقص الوعي المجتمعي المتعلق بالرعاية التلطيفية.	0	1	2
9.22	عدم اهتمام الطالب (طبيب-ممرض) بالرعاية التلطيفية.	0	1	2

		أبداً	أحياناً	في كثير من الأحيان	دائماً
10	مقدمو الرعاية الصحية في مؤسستي قادرون على إدراك عملية الموت والاحتضار.	0	1	2	3
11	بمجرد تحديد المريض في مؤسستي على أنه في مرحلة الاحتضار والموت، أعتقد أن الموظفين يشعرون بالراحة لمعرفتهم بما يجب فعله للمريض.	0	1	2	3
12	يتم دمج مرضى الرعاية التلطيفية في خطة رعاية المرضى الذين يعانون من أمراض خطيرة في مؤسستي؟	0	1	2	3
13	أشعر بارتياح عندما أتحدث مع المرضى وأسرهم عن التطور المرضي المحدود؟	0	1	2	3

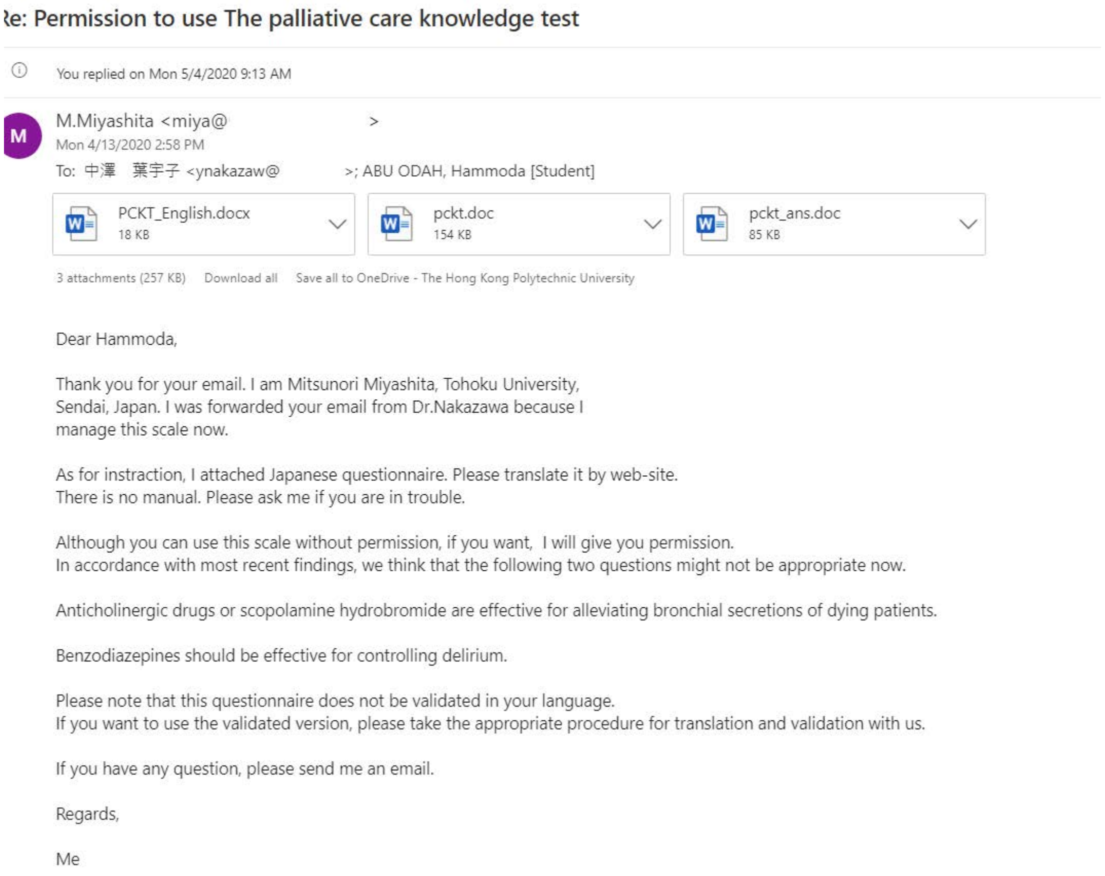
14. الرجاء إخبارنا عما تقوم به مؤسستك من أجل توفير/إدخال/دمج الرعاية التلطيفية:

15. ما هي الموارد الموجودة في مؤسستك ومجتمعك التي يمكن إستخدامها للمساعدة في تحسين الرعاية التلطيفية (مثل، الناس، مؤسسات، موارد المجتمع المحلي، المنظمات غير الحكومية)؟

نشكرك على تخصيص بعض من وقتك لإكمال هذه الاستبانة.

ملاحظاتك وآراؤك مهمة بالنسبة لنا

Appendix 20: Permission to use the study’s two instruments by original author



Re: Permission to use The palliative care knowledge test

You replied on Mon 5/4/2020 9:13 AM

M.Miyashita <miya@ >
Mon 4/13/2020 2:58 PM
To: 中澤 葉宇子 <ynakazaw@ >; ABU ODAH, Hammoda [Student]

PCKT_English.docx 18 KB
pckt.doc 154 KB
pckt_ans.doc 85 KB

3 attachments (257 KB) Download all Save all to OneDrive - The Hong Kong Polytechnic University

Dear Hammoda,

Thank you for your email. I am Mitsunori Miyashita, Tohoku University, Sendai, Japan. I was forwarded your email from Dr.Nakazawa because I manage this scale now.

As for instraction, I attached Japanese questionnaire. Please translate it by web-site.
There is no manual. Please ask me if you are in trouble.

Although you can use this scale without permission, if you want, I will give you permission.
In accordance with most recent findings, we think that the following two questions might not be appropriate now.

Anticholinergic drugs or scopolamine hydrobromide are effective for alleviating bronchial secretions of dying patients.

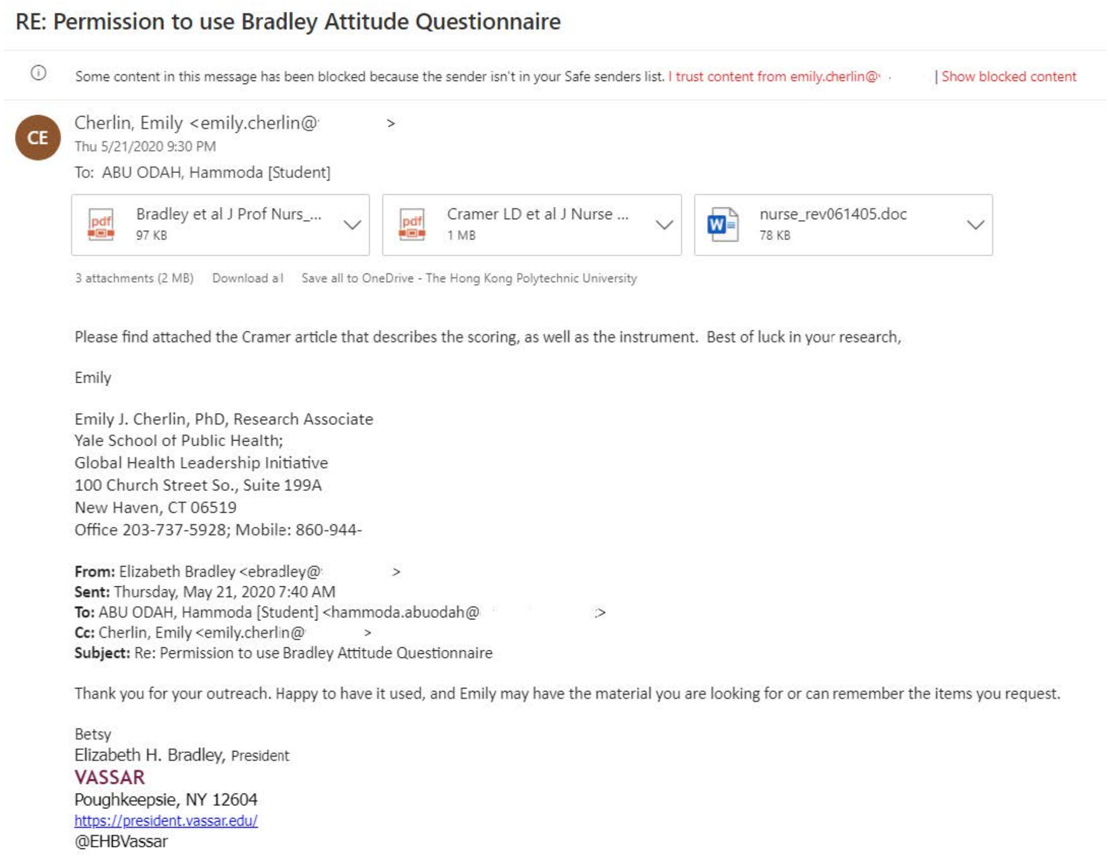
Benzodiazepines should be effective for controlling delirium.

Please note that this questionnaire does not be validated in your language.
If you want to use the validated version, please take the appropriate procedure for translation and validation with us.

If you have any question, please send me an email.

Regards,

Me



RE: Permission to use Bradley Attitude Questionnaire

Some content in this message has been blocked because the sender isn't in your Safe senders list. I trust content from emily.cherlin@ | Show blocked content

Cherlin, Emily <emily.cherlin@ >
Thu 5/21/2020 9:30 PM
To: ABU ODAH, Hammoda [Student]

Bradley et al J Prof Nurs_... 97 KB
Cramer LD et al J Nurse ... 1 MB
nurse_rev061405.doc 78 KB

3 attachments (2 MB) Download all Save all to OneDrive - The Hong Kong Polytechnic University

Please find attached the Cramer article that describes the scoring, as well as the instrument. Best of luck in your research,

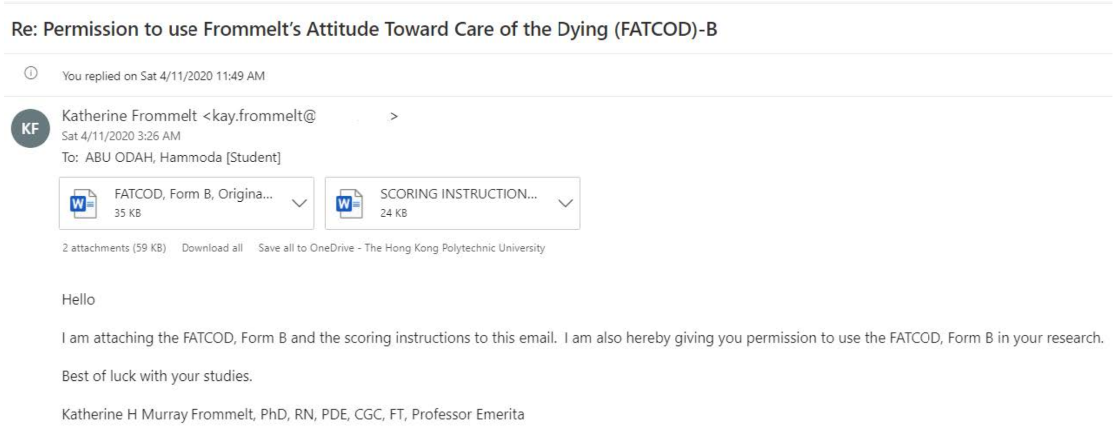
Emily

Emily J. Cherlin, PhD, Research Associate
Yale School of Public Health;
Global Health Leadership Initiative
100 Church Street So., Suite 199A
New Haven, CT 06519
Office 203-737-5928; Mobile: 860-944-

From: Elizabeth Bradley <ebradley@ >
Sent: Thursday, May 21, 2020 7:40 AM
To: ABU ODAH, Hammoda [Student] <hammoda.abuodah@ >
Cc: Cherlin, Emily <emily.cherlin@ >
Subject: Re: Permission to use Bradley Attitude Questionnaire

Thank you for your outreach. Happy to have it used, and Emily may have the material you are looking for or can remember the items you request.

Betsy
Elizabeth H. Bradley, President
VASSAR
Poughkeepsie, NY 12604
https://president.vassar.edu/
@EHBVassar



Re: Permission to use Frommelt's Attitude Toward Care of the Dying (FATCOD)-B

You replied on Sat 4/11/2020 11:49 AM

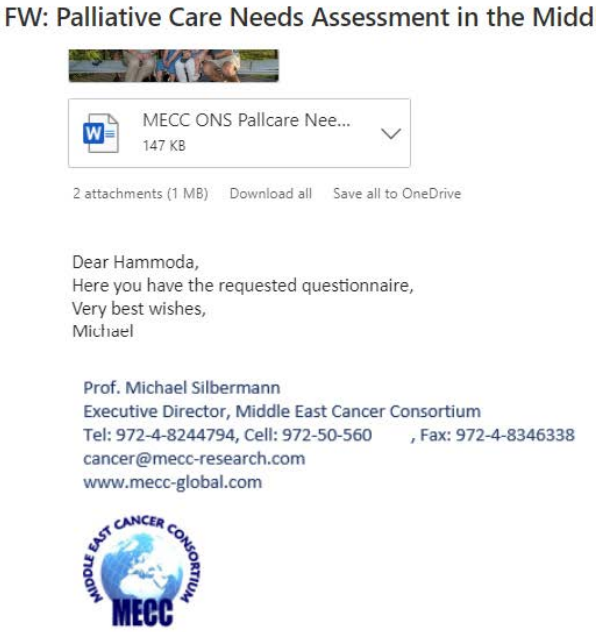
Katherine Frommelt <kay.frommelt@ >
Sat 4/11/2020 3:26 AM
To: ABU ODAH, Hammoda [Student]

Hello

I am attaching the FATCOD, Form B and the scoring instructions to this email. I am also hereby giving you permission to use the FATCOD, Form B in your research.

Best of luck with your studies.

Katherine H Murray Frommelt, PhD, RN, PDE, CGC, FT, Professor Emerita



FW: Palliative Care Needs Assessment in the Middle East

Dear Hammoda,
Here you have the requested questionnaire,
Very best wishes,
Michael

Prof. Michael Silbermann
Executive Director, Middle East Cancer Consortium
Tel: 972-4-8244794, Cell: 972-50-560 , Fax: 972-4-8346338
cancer@mecc-research.com
www.mecc-global.com

Appendix 21: Information Sheet for Decision and Policymakers (English)

INFORMATION SHEET

An Exploration of the Factors and Needs Associated with the Development of a Palliative Care Program into the Palestinian Healthcare System from Different Key Stakeholders' Perceptions

Dear Dr…………………………………………………..

You are invited to participate in the above study supervised by Professor Alex Molasitiotis and Dr Justina Liu, and conducted by Mr. Hammoda ABU-ODAH, who is a Ph.D. student at the School of Nursing, The Hong Kong Polytechnic University. Prior to your decision, it is significant for you to understand why the research will conduct and what it will involve. Take your time reading the below information. If you have any unclear information, please do not hesitate to ask and we are happy to provide more explanation. Take time to decide whether you want to participate or not. If you agree to participate, you will need to sign a written informed consent (next page). Please note that participation in this study is totally on a voluntary basis.

The overall purpose of this study is to comprehensively explore policies-related issues from decision-and policymakers before developing palliative care programs with the Gaza healthcare system. The objectives of this study are understand the extent to which palliative care has been identified as a priority from policymakers' perspectives; to discuss with the policymakers' the existing and new policies that support the integration of palliative care into the structure of national healthcare systems; to explore the policymakers' perspective about policies/work been done regarding strengthening human resources and to identify which essential medicine for pain and symptom management are available in the healthcare system, their cost, and prescribing related-issues from policymakers' point view.

You are invited to take part in this study as you have a policy-making role in the healthcare system and are responsible for making executive and legislative decisions about matters related to services (including PC). The interview will take about an hour. You are free and have a right to withdraw from participation in this study at any time.

The information you provide as part of the project is the research data. Any research data from which you can be identified is known as personal data. Personal data does not include data where the identity has been removed (anonymous data). We will minimize our use of personal data in the study as much as possible. The researcher and supervisors will have access to your data for the purposes of the study. Responsible members of The Hong Kong Polytechnic University may be given access for monitoring and/or audit of the research.

All information related to you will remain confidential and will be identifiable by codes know only to the researchers. All data retrieved will storage in a locked cabinet and can only be accessed by research teams. The information collected will be kept after project completion/publication. The Hong Kong Polytechnic University takes reasonable precautions to prevent the loss, misappropriation, unauthorized access or destruction of the information you provide.

You have every right to withdraw from the study before or during the interview. If you have any questions, you may ask our helpers now or later, even after the study has started. You may contact Mr. Hammoda Abu-Odah (tel. no.: (00972) 56917 email: hammoda.abuodah@_____________) or Prof. Alex Molassiotis (tel. no.: (852) 27666396 email: alex.molasiotis@____________) or Dr Justina Liu (tel. no.: (852) 27664097/ email: justina.liu@_______________) of PolyU under the following situations:

g. if you have any other questions in relation to the study;
h. if, under very rare conditions, you become injured as a result of your participation in the study; or
i. if you want to get access to/or change your personal data before (the expiry date).

In the event you have any complaints about the conduct of this research study, you may contact the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in writing (c/o Research Office of the University) stating clearly the responsible person and department of this study as well as the HSESC Reference Number.

Thank you for your interest in participating in this study.

Principal Investigators

Prof. Alex Molassiotis, Dr Justina Liu, Mr. Hammoda Abu-Odah

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

Appendix 22: Written Informed Consent for the Decision and Policymakers (English and Arabic)

CONSENT TO PARTICIPATE IN RESEARCH

An Exploration of the Factors and Needs Associated with the Development of a Palliative Care Program into the Palestinian Healthcare System from Different Key Stakeholders' Perceptions

I ________________________ hereby consent to participate in the captioned study conducted by Mr. Hammoda ABU-ODAH, who is a Ph.D. student at the School of Nursing, The Hong Kong Polytechnic University

Please read each statement and initial the box

Please initial each box

1. I confirm that I have read and understood the information sheet for the above study. I have been delivered a full explanation by the investigators of the nature, purpose and likely duration of the study, and of what I will be expected to do. ☐

2. I understand that participation in this study is voluntary, and I am free to withdraw at any time without giving reason. ☐

3. I understand that any information given by me may be utilised in future report, publications, or presentations by the research ☐

4. I understand that my name will not appear in any reports, articles or presentations. ☐

5. I have been given adequate time to consider my participation and I agree to take part in the above study. ☐

Name of participant ____

Signature of participant ____

Name of researcher ____

Signature of researcher ____

Date ____