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**DEVELOPMENT AND EVALUATION OF A LIFE REVIEW PROGRAM  
FOR CHINESE ADVANCED CANCER PATIENTS**

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**Ph.D**

**The Hong Kong Polytechnic University**

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**THE HONG KONG POLYTECHNIC UNIVERSITY**

**SCHOOL OF NURSING**

**DEVELOPMENT AND EVALUATION OF A LIFE REVIEW PROGRAM**

**FOR CHINESE ADVANCED CANCER PATIENTS**

**XIAO HUI MIN**

**A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE**

**REQUIREMENTS FOR THE DEGREE OF**

**DOCTOR OF PHILOSOPHY**

**September 2010**

## **CERTIFICATE OF ORIGINALITY**

I hereby declare that this thesis entitled “Development and evaluation of a life review program for Chinese advanced cancer patients” 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.

\_\_\_\_\_(signed)

Xiao Hui Min

**Abstract of thesis entitled “Development and evaluation of a life review  
program for Chinese advanced cancer patients”**

submitted by Xiao Hui Min

for the degree of Doctor of Philosophy

at The Hong Kong Polytechnic University in September 2010

**Background**

Empirical data have supported that a life review is an effective psycho-spiritual intervention, particularly with the elderly. However, no life review programs have been specifically designed for Chinese patients with advanced cancer and their views on the life review therefore remain unknown.

**Aim**

This study aimed to develop a life review program for Chinese advanced cancer patients and test its effects on a sample of advanced cancer patients in Fuzhou, China.

**Method**

There were two phases in this study. Phase one was the development of a life review program for Chinese advanced cancer patients. Based on Erikson’s eight stages of psychosocial development, Confucian thoughts on human development, a previous study of this research team, and the literature, the program was designed, including reviewing a life and formulating a life review booklet. Phase two was the evaluation of this program with a randomized controlled trial design. Subjects were recruited from April 2009 to January 2010 in the Fujian Hospice. Eighty subjects were randomly assigned to the control and experimental groups.

The subjects in the experimental group received the program, which was performed once a week for three weeks by the student researcher at the subjects' own homes. The QOL data measured by the Single Item Scale and the quality of life concerns in the end of life questionnaire, and assessed before the commencement of the program, immediately after , and three weeks after the completion of the program. The data about patients' perceptions of the program were collected through semi-structured interviews immediately after the program.

## **Results**

In the ITT sample, the patients in the experimental group demonstrated: (1) a significant improvement in the within-group, between-group, and interaction effects on overall QOL ( $F=32.881$ ,  $P=0.000$ ;  $F=52.615$ ,  $P=0.000$ ;  $F=40.555$ ,  $P=0.000$ , respectively), negative emotions ( $F=9.987$ ,  $P=0.000$ ;  $F=8.683$ ,  $P=0.000$ ;  $F=20.033$ ,  $P=0.000$ , respectively), existential distress ( $F=21.243$ ,  $P=0.000$ ;  $F=14.301$ ,  $P=0.000$ ;  $F=17.447$ ,  $P=0.000$ , respectively), and value of life ( $F=9.344$ ,  $P=0.000$ ;  $F=68.218$ ,  $P=0.000$ ;  $F=117.227$ ,  $P=0.000$ , respectively); (2) a significant increase in support in the interaction effects ( $F=6.330$ ,  $P=0.003$ ); (3) a significant improvement in healthcare concerns in the within-group ( $F=5.561$ ,  $P=0.005$ ) and between-group effect ( $F=4.766$ ,  $P=0.032$ ); and (4) a significant decline in sense of alienation in the between-group ( $F=9.191$ ,  $P=0.003$ ) and interaction effects ( $F=9.118$ ,  $P=0.000$ ).

The patients in the improved group perceived that the life review program helped them accept one's unique life, have feelings of emotional relief, achieve a sense of meaning in life, leave a personal legacy, and make future orientations. The perceptions of patients in the unchanged group were of struggling between accomplished tasks and unresolved conflicts; enhancing mood, leaving a

generativity booklet, and feeling difficulty in reviewing a life due to uncontrolled physical discomfort. The perceptions of patients in the decreased group involved being overwhelmed with negative feelings of encountering a painful life, and failing to freely share life experiences due to the presence of family members during the interviews.

## **Conclusion**

This study is a pioneer research project to develop a life review program for Chinese advanced cancer patients and test its effects in the context of China with a randomized controlled trial. The program not only provides Chinese nurses with a new approach to meeting the unique needs of patients approaching death, but also poses a challenge to customary beliefs about death. The program can be either used or modified as routine care for Chinese advanced cancer patients to enhance their QOL, particularly psycho-spiritual well-being. However, nurses should realize that physical discomfort, painful life experiences, and the presence of family members may interfere with the impact of the life review program.

## LIST OF PRESENTED AND PUBLISHED WORK

### Conference presentations

1. Xiao, H.M., Kwong, E., Mok, E. & Pang, S. (2010). Development of a life review program for Chinese advanced cancer patients. The 13<sup>th</sup> East Asian Forum of Nursing Scholars. Hong Kong. 19-20 February 2010.
2. Xiao, H.M., Kwong, E., Mok, E. & Pang, S. (2008). Quality of life concerns among advanced cancer patients in Fuzhou, China: a qualitative study. Singapore Palliative Care Conference 2008. Singapore. 29-30 August 2008.

### Publications

1. 肖惠敏, 邝惠容, 彭美慈, 莫孙淑冰. (2010). 晚期癌症患者人生回顾干预措施的构建. *中华护理杂志*, 45(7), 631-633.  
  
Xiao, H.M., Kwong, E., Pang, S. & Mok, E. (2010). Development of a life review program for Chinese advanced cancer patients. *Journal of Chinese Nursing*, 45(7), 631-633.
2. Xiao, H.M., Kwong, E., Pang, S. & Mok, E. (2011). Chinese advanced cancer patients' perceptions of participation in a life review program. *Journal of Clinical Nursing*. (In press)



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## **LIST OF ABBREVIATIONS**

*( in alphabetical order )*

CI	Confidence Interval
ICC	Intra-class Correlation Coefficient
ITT	Intention-to-treat
KPS	Karnofsky Performance Status
LREF	Life Review and Experience Form
PIF	Patient Information Form
PP	Per Protocol
QOL	Quality of Life
QOLC-E	Quality of life Concerns in the End of Life Questionnaire
RA	Research Assistant
RCT	Randomized Controlled Trial
SD	Standard Deviation
SIS	Single Item Scale
SPMSQ	Short Portable Mental Status Questionnaire
WHO	World Health Organization

# **CHAPTER 1**

## **INTRODUCTION**

This chapter provides an overview of this study. It presents the background of the study, the objectives of the study, the significance of the study, and the organizational structure of this thesis.

### **1.1 Background of the study**

#### **1.1.1 Incidence and mortality of cancer**

Cancer is a life-threatening disease that is growing annually around the world in incidence and mortality due to steadily aging populations, smoking, and unhealthy lifestyles (World Health Organization, 2007). In 1990, there were an estimated 8.1 million new cases and 5.2 million deaths (Parkin, Pisani & ferlay, 1999; Pisani, Parkin, Bray & Ferlay, 1999) globally from cancer that year. In 2000, the estimate was 10.1 million new cases, 6.2 million deaths, and 22 million people living with cancer (Parkin, 2001). The most recent figure, for 2008, suggests a total of 12.7 million new cases and 7.6 million deaths, and 24.6 million persons living with cancer (Jemal, pray, Center, Feday, Ward & Forman, 2011).

In China, the incidence and mortality rate of cancer is also, for the most part, increasing each year. In the 1990s, an estimated 1.3 million new cases and 1.6 million deaths occurred each year (Dong et al., 2000; Xu & Tong, 2003). A relatively recent estimate made in 2000 was 2 million new cases and 1.5 million deaths (National Health Ministry of China, 2004). Currently, cancer is the

leading cause of death in China, accounting for 27.01% of deaths among urban residents and 24.26% among rural residents (Ministry of Health of the People's Republic of China, 2010). Fujian is one of the provinces in China with a high incidence of cancer and a high rate of mortality from it. It has 80,000 new cases and 50,000 cancer deaths every year (Ying, 2007).

The high incidence and mortality rate of cancer is imposing a great burden on countries. It is resulting in an enormous loss in the labor force and in the huge consumption of medical resources. It brings emotional distress and financial strain to families. To the patients themselves, particularly those whose illness is at an advanced stage and who have little chance of being cured, it poses a great challenge.

### **1.1.2 Impact of advanced cancer on patients**

Advanced cancer puts patients in the final stage of their life. They are faced in advance with their final growth and development. According to Erikson's (1950) eight stages of psychosocial development, if patients are able to complete the final stage of development, they will achieve ego integrity, accepting the inevitable in their life, and finding meaning in life. Otherwise, they will become preoccupied by despair, feel regrets, and fear death.

However, not many patients can achieve the final stage of growth and development. They struggle with worsening physical symptoms, such as pain and fatigue, and declining physical functions (Chui et al., 2009). They have difficulty in responding psychologically to the illness, and therefore experience



anxiety, depression, and even thoughts of suicide (Jia et al., 2000; Cathcart, 2006; Lin & Shen, 2006). They may also suffer spiritual distress triggered by concerns over death, such as a feeling of meaningless, a feeling of hopelessness, a self-perceived burden to others, loss of social roles, powerlessness, and dependency (Hench & Danielson, 2009).

Physical symptoms can often be relieved, while psycho-spiritual distress becomes more pronounced among advanced cancer patients approaching death (Lo et al., 2002). Fu et al. (2006) found that the need for psycho-spiritual care is more prominent than that for physical care among Chinese patients with advanced cancer. Similarly, in our previous study in Fuzhou, China, we found that the greatest crisis faced by advanced care patients is not always over physical symptoms. Instead, psycho-spiritual distress is their most significant challenge (Xiao, Kwong, Pang & Mok, 2008). Such distress hinders psychological functioning, impairs the quality of life (QOL), and enhances end-of-life despair among advanced cancer patients (Peterman, Fitchett, Bray, Hernandez & Cella, 2002; McClain, Rosenfeld & Breitbart, 2003; Pandey, Devi, Ramdas, Krishnan & Kumar, 2009).

### **1.1.3 The Chinese situation in care for advanced cancer patients**

#### **1.1.3.1 Improper distribution of health resources**

Over the past decades, the Chinese government and society emphasize prevention, treatment and rehabilitation of diseases. Most of health resources concentrate on hospitals while few resources on hospices (Shang, 2011). The mainstream of the hospitals is to cure diseases and save lives. Various

departments of the hospitals therefore often shut the door on palliative care patients at the end of life except the emergency department. On the other hand, the hospices are not a pleasant choice of advanced cancer patients due to the limited hospices, traditional filial piety, customary on death, and medical insurance system (Wang, Xiao & Feng, 2006). Therefore, the patients usually stay at home and family members are their major caregivers.

#### **1.1.3.2 Unreasonable construction of palliative care teams**

A multi-disciplinary team providing integrative care is necessary to meet advanced cancer patients' needs in terms of physical, psychosocial and spiritual aspects. In mainland China, a palliative care team consists of a physician and a nurse without the involvement of social workers, psychologists, and chaplains (Lan *et al.*, 2006). Recently, volunteers begin to join palliative care teams in some cities, such as Fuzhou. However, most of them are lack of specific training in palliative care. In spite of their working enthusiasm, they are not able to provide high-quality services.

#### **1.1.3.3 Inadequate care for advanced cancer patients**

As mentioned above, most advanced cancer patients take their last journey at home. However, community health professionals only visit the patients who need specific physical care, such as wound care, injections. Meanwhile, several home-based palliative care teams is distributed over the whole country. Generally, the services for those patients at home focus on physical care and emotional support; while psycho-spiritual interventions targeting at their unique needs are not available (Liu & Yu, 2011).

#### **1.1.4 Life review**

Life review has been considered an effective psycho-spiritual intervention for people who are faced with the challenge of death (Jones, Lyons & Cunningham, 2003; Davis, 2004; Ando & Tsuda, 2006). Life review is a process of recalling, evaluating, and integrating life experiences in order to facilitate the achievement of ego integrity at the final stage of life (Butler, 1963). It has been widely applied to older people and was first used on palliative care patients overseas. Research on life review covers a wide spectrum of subjects, including the elderly (Haight, 1988; Hanaoka & Okamura, 2004; Chiang, Lu, Chu, Chang & Chou, 2008), cancer patients (Ando & Tsuda, 2006; Ando, Tsuda & Morita, 2007; Ando, Morita, Okamaoto & Ninosaka, 2007), patients with acquired immune deficiency syndrome (AIDS) (Erlen, Mellors, Sereika & Cook, 2001), patients with cerebral vascular diseases (Davis, 2004), and young men with critical diseases (Jones et al., 2003). These studies have demonstrated that life review yields therapeutic results, including enhancing life satisfaction, self-esteem, spiritual well-being, psychological well-being, and QOL, and reducing depression and hopelessness.

Despite its effectiveness, only a few studies on life review have been conducted in Chinese communities (Lau, 1994; Chiang et al., 2008; Liao & Lin, 2008). These studies have focused on the elderly in Hong Kong or Taiwan. To our knowledge, no life review program has been specifically designed for Chinese patients with advanced cancer, and its effect upon such patients is therefore unknown.

## **1.2 Objectives of the study**

The purpose of this study is to develop a life review program and evaluate its effects with a sample of Chinese patients with advanced cancer in Fuzhou. The objectives of this study are:

1. To design a life review program for Chinese patients with advanced cancer.
2. To examine the effect of the life review program on the QOL of Chinese patients with advanced cancer.
3. To elicit perceptions of the life review program among Chinese patients with advanced cancer who participated and completed the program.

## **1.3 Significance of the study**

Research on palliative care in mainland China has concentrated on the investigation of health problems, correlations of QOL and factors, and instrument validation, while a few reports have addressed intervention studies, such as the use of psycho-education. To our knowledge, there is no research literature on psycho-spiritual intervention for advanced cancer patients in mainland China. Life review as a psycho-spiritual intervention has recently been applied overseas in palliative care. However, there has been no study on the use of life review among Chinese patients with advanced cancer, particularly in mainland China.

This study is a pioneer research on life review in palliative care. To meet the challenge of underdeveloped palliative care and the need that patients have for psycho-spiritual care, this study produces a specific life review program for

Chinese patients with advanced cancer. The effectiveness of this program will be new evidence showing that life review can improve the QOL of advanced cancer patients. This program provides nurses in mainland China a new approach to delivering psycho-spiritual care for patients with advanced cancer in various palliative care settings. This study can serve as a starting point to lead nurses in mainland China to play a role in promoting the development of palliative care, particularly psycho-spiritual care. In addition, this study should enhance the body of knowledge on psycho-spiritual care in field of palliative care.

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

This thesis consists of ten chapters. Chapter One, the current chapter, provides an overview of this study and its justification. Chapter Two is a review of the literature on the QOL of patients with advanced cancer and about knowledge gaps in previous research on life review. Chapter Three discusses how to design a life review program for Chinese patients with advanced cancer. Chapter Four discusses the conceptual framework for this study. Chapter Five presents the methodology of this study. Chapter Six reports a pilot study. Chapter Seven delineates the quantitative results relating to the effect of the life review program on the QOL of advanced cancer patients. Chapter Eight describes the qualitative results relating to patients' perceptions of participating in the life review program. Chapter Nine discusses these quantitative and qualitative results. Chapter Ten discusses the implications and limitations of this study and offers recommendations for future studies. The thesis then ends with a conclusion.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter begins with a review of advanced cancer and palliative care. It is followed by a discussion of the QOL among advanced cancer patients and life review as an intervention. The final section reports the life review and its effects.

#### **2.1 Advanced cancer**

Cancer encompasses hundreds of different types of malignant tumors characterized by the proliferation of abnormal cells. When a cell escapes the normal constraints placed on its growth, it begins to divide, proliferate, and differentiate in an unregulated fashion, and then a cancer arises. Cancer cells in the primary site are able to invade the adjacent connective tissue, gain access to the blood or lymph circulation, and become transported to distant sites to establish a new separate tumour, the metastasis (Kearney & Richardson, 2006).

Advanced cancer refers to cancer that has spread to other places in the body and that usually cannot be cured or controlled with treatment (United States National Cancer Institutes, NCI, 2008). Clinical symptoms depend on the site of the primary cancer and the vital structure or organs that are involved (Huether & McCance, 2008). At an early stage of the cancer, patients may be asymptomatic, with only a rise in blood cancer-markers or/and a tumour detected by medical equipment. As the disease progresses, they may encounter various clinical symptoms. For example, patients with liver cancer often suffer from oedema, ascites, nausea, and vomiting. When cancer comes to its terminal stage, the

functions of the organs that are involved decline quickly and previous symptoms become worse.

The goal of treatments for advanced cancer is to alleviate suffering and improve the QOL of patients (National Comprehensive Cancer Network, NCCN, 2010). Thus, palliative care is best recommended for advanced cancer patients. Unfortunately, palliative care in mainland China is still at an early stage.

## **2.2 Palliative care in mainland China**

### **2.2.1 Development of palliative care**

Although the concept of hospice care was first introduced in mainland China in 1988, palliative care has not undergone a great deal of development over the past 30 years (Liu, 2007; Shang, 2011). Only 120 palliative care organizations have been established in a country with a population of 1.3 billion. This figure includes hospices and palliative care units in hospitals (Lu & Bai, 2007).

#### ***Hospice-based palliative care***

Palliative care was initially provided by hospices in mainland China. Since the 1990s, hospices have been established by the Chinese government or local organizations, such as the Shanghai Nan Hui Hospice and the Beijing Song Tang Hospice. Hospice-based services are limited to terminally ill people living in hospices. The services are delivered by a team consisting of a physician, a nurse, and volunteers, who have not received formal education in palliative care. Therefore, the services focus on managing symptoms and providing emotional support (Hua, Yuan & Xu, 2007).

### ***Hospital-based palliative care***

Hospital-based palliative care has been growing since 1994 due to the fact that most patients die in hospitals. Palliative care units are established in hospitals for terminally ill patients, but no specific palliative care professionals are assigned to deliver palliative care. Thus, hospital-based palliative care involves giving physical care, medical care, health education, and general emotional support, while the provision of specific psycho-spiritual care targeted at the dying has received little attention (Cheng, 2000; Lan et al., 2006; Liu & Yu, 2011).

### ***Home-based palliative care***

Recently, home-based palliative care programs are being developed because they are relatively cost-effective. In particular, Mr. Li Ka Shing (LKS), a Hong Kong tycoon renowned for his entrepreneurial flair, has promoted palliative care in mainland China by developing 30 hospices (LKS Foundation, 2010). In these hospices, a multidisciplinary team including a physician, a nurse, and volunteers is trained to provide home-based palliative care for advanced cancer patients. The services cover symptom management, psychosocial care, and spiritual support. However, the psycho-spiritual support that is given is generally unplanned and inadequate. It is possible that health providers lack the time and/or ability to provide psycho-spiritual care. It is also likely that patients do not seek out professional psycho-spiritual care.

### **2.2.2 Barriers to the development of palliative care**

The literature indicates that the barriers to the development of palliative care in mainland China involve customary beliefs about death, filial piety, and the



realities of the health system (Li, 2005; Chen, Luo & Xie, 2005; Wang, Xiao & Feng, 2006; Shang, 2011). In Chinese culture, death is associated with mystery, misery, and fear. People believe that talking about “death” will cause bad luck or increase the likelihood of its occurrence (Chan & Chow, 2006). This belief in death prevents people from communicating issues relating to death, thereby obstructing the development of palliative care (Chen et al., 2005; Wang et al., 2006).

The traditional notion of filial piety also influences the delivery of palliative care. When a patient is diagnosed with an incurable disease, the patient’s family often has to face an ethical and practical dilemma. Cognitively, they realize that the patient’s prognosis is limited. Ethically, they feel the difficult of accepting the transition from curative to palliative care for the patient. Practically, to show their filial piety, they prefer to seek possible treatments for curing the patient, rather than accept palliative care (Li, 2005; Wang & Wang, 2011).

In addition, the health care system in mainland China has not created a favorable environment for the development of palliative care. Currently, mainstream health care is about curing diseases or saving patients, while palliative care attracts less attention. In terms of attitudes, knowledge, and skills, most health providers are inadequately prepared to deal with those who are facing death (Chen et al., 2005; Lu & Bai, 2007; Xu, 2011).

### **2.3 Life review**

Life review is a naturally occurring universal process characterized by the return of memories and past conflicts (Butler, 2000). It is an everyday activity starting in childhood with the development of autobiographical memory. The impulse to review one's life can be particularly strong in those who realize that they are approaching death (Butler, 1963). Although a life review can occur spontaneously, when it is used as a therapeutic intervention, it is no longer spontaneous. Life review was originally developed as a means of resolving old conflicts for helping elderly persons prepare for death (Pickrel, 1989). For various reasons, life review has been extended to the field of palliative care (Borden, 1989; Brady, 1999; LeFavi & Wessels, 2003; Trueman & Parker, 2004, 2006; Jenko, Gonzalez & Seymour, 2007). First, life review is a natural intervention for palliative care patients. According to Butler (1963), a review of one's life is often prompted by the realization of one's approaching death. Clinical experiences also indicate that many palliative care patients need to reflect upon the failures and achievements of their life (Trueman & Parker, 2004; Jenko et al., 2007). Second, life review is an effective psycho-spiritual intervention. Various studies have demonstrated that life review is able to improve life satisfaction, self-esteem, spiritual well-being, and QOL, and to reduce depression and feelings of hopelessness among people approaching death (Erlen et al., 2001; Davis, 2004; Ando et al., 2007a, 2007b). Finally, life review is cost-effective. It yields psychologically therapeutic functions, but its implementer is not necessarily a psychologist (Haight, 1989; Haight & Dias, 1992; Mastel-Smith et al., 2006). Nurses or other health providers with adequate training are able to perform a life review intervention.

### **2.3.1 Theoretical basis of life review**

#### **2.3.1.1 Erikson's eight stages of psychosocial development**

Erikson (1950) extended Sigmund Freud's work on childhood development by adding thoughts about a person's development in the second half of life. Erikson proposed the view that the life span of an individual consists of eight stages of development, as shown in Figure 2.1. Each stage is marked by a particular crisis, arising from one's level of physiological maturation and the social demands on the person at that stage. Each crisis includes both a positive and a negative component (i.e., trust vs. mistrust). The optimal development of personality is expressed in terms of a favorable ratio of the positive to negative component for each crisis. If the conflict is successfully resolved, the positive component is largely absorbed into the emerging ego and establishes the basic area of psychosocial strength at that stage. If the conflict is unsuccessfully resolved, the developing ego in a particular area is impaired and further adversely affects the resolution of future crises but does not completely prevent them. Therefore, these crises are epigenetic, arising out of a maturational ground plan and eventually coming together to form the whole individual.

**Trust vs. mistrust (Birth-1 year):** The first psychosocial stage is the development of trust during infancy. For Erikson, a sense of trust is the cornerstone of a healthy personality. An infant's trust in other people and in the world depends on the quality of the maternal care that the baby receives. If a mother is able to give her baby a sense of familiarity, consistency, and sameness of experience, the infant will successfully develop trust, feeling safe and secure in the world. If the quality of maternal care is unreliable, inadequate, and

rejective, the infant will fail to develop trust and hold an attitude of fear, suspicion, and apprehension towards the world.

Old Age								Integrity vs. Despair, Disgust: Wisdom
Adulthood							Generativity vs. Self-Absorption: Care	
Young Adulthood						Intimacy vs. Isolation: Love		
Adolescence					Identity vs. Identity Confusion: Fidelity			
School Age				Industry vs. Inferiority: Competence				
Play Age			Initiative vs. Guilt: Purpose					
Early Childhood		Autonomy vs. Shame, Doubt: Will						
Infancy	Trust vs. Mistrust: Hope							
	1	2	3	4	5	6	7	8

**Figure 2.1 Erikson's psychosocial stages of life**

Source: adopted from Erikson, E. (1978). Adulthood (p. 25). New York: Norton.

**Autonomy vs. shame and doubt (1-3years):** The second stage is the development of a greater sense of autonomy. Erikson believed that learning to control one's bodily functions leads to a feeling of control and a sense of independence. Toilet training is a vital part of this process. Other important events include gaining more control over food choices, toy preferences, and clothing selection. If the choices are supported by others, the child will develop

self-esteem and autonomy. If the choices are denied, the child will doubt himself or herself, feel shame, and lack confidence.

**Initiative vs. guilt (3-6 years):** The third stage is the development of initiative. At this stage, the child is faced with developing appropriate objectives, and planning and undertaking various tasks to achieve those objectives. If the child's self-initiated activities are encouraged, the sense of initiative will be reinforced. If the child is not allowed to complete his or her own tasks or receives excessive punishment, the child will be left with a sense of guilt, self-doubt, and lack of initiative.

**Industry vs. inferiority (6-12 years):** The fourth stage relates to the period when a child is of school age. This period of life is to develop a work ethic and competency. A child who is encouraged and commended by parents and teachers will develop a feeling of competence and belief in his or her skills. The child who receives little or no encouragement from parents, teachers, or peers will doubt his or her abilities and develop low self-esteem.

**Ego identity vs. role confusion (12-19 years):** The fifth stage is the period of adolescence. The adolescent is confronted with integrating various self-images into a personal identity, which is affected by society, particularly peer groups. Belonging helps the adolescent develop his or her identity and test fidelity to the groups. Not belonging will cause the adolescent to feel confused about himself or herself.

**Intimacy vs. isolation (20-25 years):** The sixth stage is associated with young adulthood. The person is involved in courtship, marriage, and early family life. The person seeks identity through relationships with others. Those who are capable of intimacy will develop close and committed relationships with other people. In contrast, those who are not able to enter into comfortable and intimate personal relationships will feel loneliness, social emptiness, and isolation.

**Generativity vs. stagnation (26-64 years):** The seventh stage corresponds to that of middle adulthood. The person is faced with the crisis of generativity versus stagnation. Generativity literally means to produce things or people that symbolize one's continued existence after death. According to Erikson, generativity can be expressed by being productive in one's work, by being creative or most directly by having children, caring for them and raising them to become adults. If the person fails to establish a sense of generativity, s/he will fall into a sense of self-absorption that predominantly concerns his or her personal needs.

**Ego integrity vs. despair (64-death):** The eighth stage is the final stage of life. The person is confronted with the crisis of "ego-integrity versus despair." Successful resolution of "ego-integrity versus despair" is essential to psychological adjustment and well-being in later life. If the person can integrate his/her entire life through a retrospective accounting of his/her life to date, s/he will attain "the acceptance of one's one and only life cycle as something that had to be and that, by necessity, permitted of no substitutions" (Erikson 1963, p. 268). Achieving ego-integrity also implies that one is able to give order and meaning

to one's life. Conversely, if a person fails to do this, s/he is filled with despair, "feeling that the time is now short, too short for the attempt to start another life and try out alternate roads to integrity" (Erikson 1963, p. 269).

### **2.3.1.2 Butler's life review process**

Butler's life review process has been said to be a crucial extension of Erikson's theory in that he postulates the life review process as the way to achieve ego integrity (Kaminisky, 1984).

Before Butler, reminiscence by the old had too often been devalued. It was regarded as aimless wondering of the mind or living in the past (Kovach, 1991). In 1963, Butler first proposed the term "life review" in his seminal article entitled "The life review: an interpretation of reminiscence in the aged." He defined life review as "a naturally occurring universal process, characterized by the progressive return to consciousness of past experiences, in particular, the resurgence of unresolved conflicts which can now be surveyed and integrated" (p. 66). Butler believed that life review occurs in people of all ages at various times, but is prompted by the realization of approaching dissolution and death. Butler further suggested that psychotherapy capitalizes on this natural process, and developed life review therapy as a technique for helping the elderly integrate life experiences and resolve old conflicts. This integration helps the elderly to find new and significant meaning in life, mitigate fear, and prepare for death (Butler, 1974).

### **2.3.2 Linchpins of a successful life review**

Based on empirical research and expert experiences, four critical characteristics have been identified to ensure therapeutic success in a life review (Haight & Dias, 1992; Haight & Haight, 2007). They are evaluation, structure, individuality, and duration.

#### **2.3.2.1 Evaluation**

Evaluation is probably the most important characteristic of a life review (Haight & Dias, 1992). Evaluation refers to the process in which a reviewer assesses, weighs, and values life events (Haight & Haight, 2007). There are three modes of evaluation: reinterpreting past actions in terms of present knowledge, evaluating sensitive issues free from earlier frameworks, and analyzing past actions in terms of environmental and historical constraints (Webster & Young, 1988). In an evaluation, the reviewer is encouraged to express what s/he feels about life events and what s/he thinks about life experiences. S/he is facilitated to bolster positive experiences, such as contributions and achievements. S/he is also guided to reconcile negative experiences through viewing them from different perspectives and getting insights into their context. Finally, the reviewer is facilitated to integrate various life experiences into a more acceptable or meaningful whole one.

Although evaluation in life review resembles other psychiatric interventions, life review is different from those psychotherapies. In a life review, the facilitator helps a reviewer wrap up life's garbage and take it out; while the psychiatrist in psychotherapy helps a reviewer search through the garbage and look for meaning



in it (Haight & Dias, 1992). In other words, a life review only deals with issues brought up by the reviewer, whereas psychotherapies attempt to find deep-seated issues in the reviewer (Haight & Burnside, 1993). Thus, apart from psychological professionals, nurses and other health providers with adequate training can also act as facilitators of a life review.

#### **2.3.2.2 Structure**

Structure means that a life review covers all stages of life from childhood to the present. Haight's life review and experiencing form (LREF) often serves as a guideline to reinforce the structure of a life review. The LREF was developed on the basis of Erikson's eight stages of psychosocial development (Haight & Bahr, 1984). The LREF includes 63 probing questions addressing great life themes at each stage of life. The LREF ensures that a life review addresses all stages of life.

The structured life review has been challenged for its strict organization. However, it should not be a concern if a facilitator fully understands the purpose of the structure and uses the questions in the LREF sensitively and intelligently. The LREF is meant to protect the structure of the life review. However, it does not require a reviewer to review a life by exactly following the sequence of the questions in the LREF. The reviewer is allowed to move back and forth from one life stage to another, as s/he talks about his or her life. Therefore, the LREF structures the life review process but allows for spontaneity, flexibility, and individual differences. Generally, the reviewer controls his or her life stories; and

the facilitator ensures that his or her review covers all stages of life (Haight & Haight, 2007).

#### **2.3.2.3 Individuality**

Individuality refers to the fact that a life review is carried out between a facilitator and a reviewer. The individual approach provides privacy and confidentiality, which gives the reviewer a sense of safety. The reviewer also has a chance to receive full attention and more feedback from the facilitator than would be the case in a group approach. A special sense of intimacy and bonding may possibly develop between the facilitator and the reviewer. As a result, the reviewer may reveal and reconcile more painful details of his or her life (Hendricks, 1995). Emphasizing individuality does not mean devaluing group work. Groups play a very important role in establishing new social networks, although they possibly keep the reviewer from revealing his or her innermost secrets (Haight, Coleman & Lord, 1995). Different approaches to a life review may be effective for different purposes. If the therapeutic function is the purpose of a life review, the individual approach is preferred (Haight & Dias, 1992).

#### **2.3.2.4 Duration**

Duration is suggested as another critical characteristic of a life review since it often makes a measurable difference in achieving good outcomes. Clearly, a reviewer and a facilitator need enough time to forge trust, establish a relationship, and discuss life experiences. It has been demonstrated that the optimum amount of time for a structured life review for older people is six to eight one-hour sessions (Haight & Haight, 2007). Until now, the duration of a life review for

palliative care patients has been uncertain. In the existing literature, it varies from two to six sessions and 30 minutes to one hour per session (Erlen et al., 2001; Davis, 2004; Ando & Tsuda, 2006; Ando et al., 2007a, 2007b). However, there is a consensus that for palliative care patients the life review should be short because the patients are in poor physical condition. Nevertheless, the duration of an interview, whether two or eight sessions are involved, is limited. Therefore, the reviewer should be encouraged to use the interval between visits to review his or her life experiences (Garland & Garland, 2001).

### **2.3.3 Life review versus reminiscence**

A search of the literature indicates confusion regarding life review and reminiscence, with the two terms often being used interchangeably. Clarifying these two interventions will give directions for implementing them and evaluating their effectiveness. The life review is a process of recalling, evaluating, and synthesizing the experiences of one's entire life (Webster & Young, 1988). Reminiscence is a means of recalling past events that are personally significant (Burnside, 1994). According to the above definitions, both life review and reminiscence employ the past and memory to construct the process of the intervention. Recalling memories offers participants the chance to relive past happy moments, but may also evoke painful memories, leading to negative emotions or psychological distress (Lashley, 1993; Jones & Lyons, 2003). These commonalities are perhaps the reason for the confusion between the two interventions and the interchangeable use of the terms.

However, there are more differences than similarities between the two interventions. They serve different purposes and have different requirements for implementation (Burnside & Haight, 1992). The goal of reminiscence is to increase an individual's socialization, while a life review aims to help individuals achieve ego integrity (Lin, Dai, Hwang, 2003). Regarding the process, reminiscence is often spontaneous, focuses on positive experiences, and involves some parts of the whole life. In contrast, a life review is more structured, explores both positive and negative life experiences, and covers the entire span of a person's life. More importantly, a life review must contain evaluative and integrative components, whereas reminiscence does not (Haight & Burnside, 1993; Burnside & Haight, 1992).

As for the association of life review with reminiscence, some authors believe that reminiscence is a part of a life review (Merriam, 1989; Burnside & Haight, 1992). Others regard a life review as a type of reminiscence. For example, Wong and Watt (1991) proposed the view that there are six types of reminiscence: integrative reminiscence (similar to a life review), instrumental reminiscence, transmissive reminiscence, escapist reminiscence, obsessive reminiscence, and narrative reminiscence. Despite their different orientations, there is a consensus that life review is not equal to reminiscence.

## **2.4 Quality of life of advanced cancer patients**

### **2.4.1 Concept of quality of life**

The past decade has witnessed a growing interest in employing "quality of life" (QOL) as an endpoint in clinical trials beyond the traditional biologic marker of

health care outcome. This concept is especially important in palliative care. Since the physical and functional status of palliative care patients declines inexorably, traditional measures concerning cure and prolonged survival rarely provide meaningful data (Fayers & Machin, 2007).

Despite the widespread use of the term “quality of life,” agreement over the definition of QOL is lacking. There is a consensus that QOL is a subjective sense of well-being or life satisfaction (Richards & Ramirez, 1997). For example, Young and Longman (1983) viewed QOL as “the degree of satisfaction with present life circumstances perceived by the person” (p.220). Meeberg (1993) stated that QOL is “the feeling of overall life satisfaction, as determined by the mentally alert individual whose life is being evaluated” (p.37). The WHOQOL group (1995) defined QOL as “individuals’ perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards, and concerns” (p.1405).

In the definition of QOL, subjectivity is considered to be one fundamental component. Subjectivity means that QOL can only be understood from the patient’s perspective (Cella, 1994). When patients are asked how they feel, the response is influenced by their current expectations, and therefore only partially relates to their observable behaviors or conditions.

Dimension is the other component of the definition of QOL. QOL is viewed as either uni-dimensional or multi-dimensional (Woolsey, 1989). Regarding uni-dimensional QOL, some authors have endorsed a simplistic notion that

Karnofsky performance status (KPS) is an estimate of overall QOL (Karnofsky & Burchenal, 1949; Zubrod et al., 1960); others have devised a single-item scale to estimate overall QOL (Gough, Furnival, Schilder & Grove, 1983; Bernheim & Buyse, 1984; Cohen, Hassan, Lapointe & Mount, 1996). These approaches are easy to administer to get an overall sense of QOL, but they fail to provide specific information on dimensions of QOL. This leads to the concept of multi-dimensional QOL. Although various areas are incorporated under the notion of QOL, most can be grouped into one of four related but distinct areas: physical, psychological, social, and spiritual/existential well-being (The WHOQOL Group, 1995; Sloan et al., 2002). Multi-dimensional QOL is able to provide information about various dimensions of QOL. However, its validity for measuring overall QOL has been questioned, because of a bias in the selection of the dimensions of QOL (Cohen & Mount, 1992). Therefore, it is suggested that QOL might best be measured by directly asking patients to rate both their overall QOL and various dimensions that affect their QOL (Gill & Feinstein, 2010).

#### **2.4.2 Measurement of quality of life**

A number of questionnaires have been developed and applied to assess QOL, including generic and disease-specific questionnaires. The aim of generic questionnaires is to cover a wide range of conditions, and their advantage is that they enable comparisons to be made among patients with different diseases. For their part, disease-specific instruments address issues of particular concern to patients with a disease, and are sensitive to detecting differences resulting from treatments (Fayers & Machin, 2007). Therefore, to evaluate the effect of an

intervention on the QOL of a specific group, disease-specific QOL instruments are preferable.

Five disease-specific QOL instruments applied in advanced cancer patients are compared here. They are the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993), the Functional Assessment of Cancer Therapy-general (FACT-G) (Cella, Tulskey & Gray, 1993), the Hospice Quality of Life Index (HQLI) (McMillan & Weitzner, 1998), the McGill quality of life questionnaire (MQOL) (Cohen, Mount, Strobel & Bui, 1995), and the Quality-of-Life Concerns in the End-of-life Questionnaire (QOLC- E) (Pang et al., 2004; 2005).

These instruments can be self-administered, are multidimensional in structure, and have good validity and reliability. However, their contents are different, showing the four aspects of physical well-being, psychological well-being, social well-being, and spiritual/existential well-being. Physical well-being represents a combination of disease symptoms, treatment side-effects, and general physical well-being, as perceived by the patient (Cella, 1994). Among these questionnaires, EORTC QLQ-C30 and HQLI contain detailed questions to assess symptoms. Cohen et al. (1996) criticized such questionnaires as being excessively focused on the physical domain. By contrast, MQOL and QOLC-E ask patients to list their most uncomfortable symptoms, instead of all possible physical symptoms. This approach sounds more appropriate for collecting data on symptoms from advanced cancer patients because it addresses their unique physical concerns and the questionnaire is less burdensome to complete.

Psychological well-being is bipolar, reflecting positive and negative affects. Usually, patients with advanced cancer have experienced emotional distress, but some may accept the fact that they have the disease and go through their last days in peace. Therefore, a comprehensive health-related QOL assessment should measure both sides of this spectrum (Cella, 1994). However, most questionnaires only involve negative feelings, including QLQ-C30, HQLI, and QOLC-E. It has been shown that this limitation is recognized in FACT-G and MQOL, which include in the questionnaires queries about the positive and negative emotional reactions of patients approaching death.

Social well-being refers to how individuals carry on relationships with family, friends, colleagues at work, and the general community. It is a resource for patients to draw upon to cope with, and adapt to, illness; therefore, it is also an important aspect of QOL. The content of social well-being is diverse, including perceived social support, the maintenance of leisure activities, family functioning, and intimacy (Cella, 1994). However, most of these questionnaires that have been applied in advanced cancer patients have either contained no questions on their social domain, or ask very few global items about their overall level of social functioning. Concretely, MQOL asks no questions about this domain; QLQ-C30 and QOLC-E respectively involve two items about social functioning; only FACT-G, HQLI covers social support, activities with family and friends, and support from a health care team.

The spiritual/existential domain is a major determinant of the overall QOL for patients whose physical health and functional status are inexorably declining



(Merriman, 2002). However, QLQ-C30 and FACT-G do not involve this aspect. HQLI has questions related to religious belief, but religious concern is not equivalent to spiritual or existential concerns. Religion refers to supernatural constraints, sanctions, or religious practices; while spirituality is a boarder concept than religion and encompasses a person's search for meaning, and for relationships with a higher power, with nature, and with other people (Zerwekh, 2006). The core existential aspect is personal existential meaning, whether material or spiritual. MQOL is the first instrument involving the spiritual/existential domain (Salek, Pratheepawanit, Finaly & Luscombe, 2002). QOLC-E also emphasizes this domain by including existential distress and value of life as subscales.

In short, these QOL instruments have three major shortcomings in their dimensions. First, some QOL instruments tend to overemphasize the physical domain so that other important domains, psychosocial or existential domains, are underrepresented, such as EORTC QLQ-C30, FACT-G and HQLI. Second, most QOL measures, with the exception of MQOL and QOLC-E, do not include the existential/spiritual domain although this area is very important for advanced cancer patients. Third, with the exception of FACT-G, MQOL, and QOLC-E, QOL instruments focus on measuring a list of problems of life rather than on achieving a balance between positive and negative influences on life. Therefore, MQOL and QOLC-E sound more suitable for use in assessing the QOL of advanced cancer patients.

When selecting a QOL instrument, cultural issues also need to be taken into consideration. MQOL has been translated into Chinese and validated in a Chinese setting. The results revealed that, due to cultural differences, most Chinese patients have difficulty in understanding one item related to life control. It has been suggested that some items relating to Chinese culture, including concepts of face and practices and attitudes related to food and sex, be added to MQOL (Lo et al., 2001). Conversely, QOLC-E was derived in the context of China and therefore subtle differences in social-cultural context are addressed. It is well known that an easily understood instrument is vital to ensure the quality of the assessment and its completion.

#### **2.4.3 Challenges in assessing quality of life**

There are some challenges in assessing the QOL of palliative care patients. First, QOL should be assessed by patients since it is subjective. However, patients with poor KPS have a much lower response to QOL instruments than those with good KPS, which leads to enrolment or non-response bias (Brasel, 2010). When patients themselves may not be able to answer questions, proxies may be considered as an alternative or complementary source of information. This raises two challenges: locating people who can provide information about the patient's experiences and evaluating the validity of the patient's answers (Fowler, Coppola & Teno, 1999). Usually, those who are fully involved in the patient's care, such as health professionals or informal carers, will take up the role of proxy. However, an assessment from a proxy should be clearly distinguished from a patient-based assessment. Research has found that proxies seem to

overestimate a patient's psychological distress, but underestimate pain and other symptoms (Kaasa & Loge, 2003).

Second, it has been suggested that QOL is best captured when measured over time. Three data points are recommended: baseline, during therapy, and at follow-up (Osoba, 1996). Clinch and Schipper (1996) proposed the view that the operational properties of the QOL assessment should not impose any limitations on the frequency of measurement or on the duration of the follow-up. However, too frequent assessments may be a burden to palliative care patients, and lead to diminishing returns in the collecting of data. Furthermore, although there is a consensus that the period of recall of a QOL measurement should be fairly short—two to four weeks, this may be a too long timespan for palliative care patients, whose condition could change rapidly (Morgan, 2000).

Last, but not least, patients' QOL concerns at the end of life are sensitive. It is highly challenging to explore areas of QOL, such as negative emotions, alienation from family, existential distress, and feelings about the value of life. A QOL assessment may stir up emotional pain in patients and bring up undisclosed problems (Grant & Sun, 2010). Therefore, assessors using QOL instruments must be empathetic and sensitive.

#### **2.4.4 Quality of life among advanced cancer patients**

Advanced cancer is an incurable disease. Physically, psychosocially, and spiritually/existentially, the disease has a great impact on patients, which interferes with their QOL.

Physically, advanced cancer patients frequently experience multiple symptoms, such as pain, anorexia, insomnia, cough, dyspnea, dry mouth, nausea, vomiting, and constipation. Symptoms may be directly related to the disease, may be caused by the treatment, or may be due to the failure of the organ involved and to metabolic abnormalities (Mercadante, Casuccio & Fulfaro, 2000). The prevalence of symptoms in patients with advanced cancer varies considerably. Potter, Hami, Bryan, and Quigley (2003) observed that the five most prevalent symptoms of patients referred to palliative care services in the UK were pain (64%), anorexia (34%), constipation (32%), weakness (32%), and dyspnea (31%). Lo, Ding, Chung, and Woo (1999) reported that the most common symptoms of Chinese patients with advanced cancer on admission to palliative care units were fatigue (52%), pain (50%), dyspnea (32%), cough (32%), and anorexia (24%); the five most severe physical symptoms were dysphagia, ascites, pain, dyspnea, and fatigue. Although patients may have a common pathway in the last days of life, the clinical evidence suggests that the frequency and intensity of symptoms change during the course of the disease. Mercadante, Casuccio, and Fulfaro (2000) found that, as the disease progresses, some symptoms, such as nausea and vomiting, dry mouth, gastric pyrosis, and diarrhea, reached a peak in frequency and severity, and then decreased; other symptoms, such as dyspnea, drowsiness, weakness, and confusion tended to further increase among advanced cancer patients receiving home-based palliative care. Recently, Tsai, Wu, Chiu, Hu, and Chen (2006) conducted a study involving longitudinal evaluations of symptom severity from admission to the palliative care unit, to one week later, and two days before death among Chinese patients with advanced cancer in a palliative care unit. The findings revealed that five physical

symptom change patterns: A: continuous static (restless/heat, abdominal fullness, constipation, dizziness, and insomnia); B: static-increase (fatigue, weakness, nausea/vomiting, taste alteration, dysphagia, diarrhea, dry mouth, and night sweats); C: decrease-static (pain); D: decrease-increase (anorexia and dyspnea); E: static-decrease (aggression). It can be seen that some physical symptoms were not well managed in spite of palliative care. The uncontrolled symptoms distressed patients and impaired all aspects of QOL, including emotional and spiritual well-being, social relationships, and functional abilities (Chiu, Hu & Chen, 2000; McMillan & Small, 2002; Lloyd-Williams, Dennis & Taylor, 2004, Mystakidou et al., 2004).

Apart from the physical influence, advanced cancer also puts patients at the risk of psychosocial distress. Psychosocial problems are distinct from the physical effects of advanced cancer, but are inextricably linked to the physicality of the illness. As the disease progresses, patients gradually lose their health, the ability to care for themselves, their independence, relationships, roles, identity, and the sense that they have a future (Zerwekh, 2006). Each of these losses may trigger psychosocial distress.

Cathcart (2006) states that the common forms psychosocial distresses in patients with advanced cancer are anxiety, depression, and suicide ideation. For advanced cancer patients, anxiety concerning dependence, family or social-role functioning, and financial issues may wane toward the end of life, while worries about suffering and death may increase (Roth & Massie, 2007). Patients with depression tend to become disinterested in activities and in their loved ones, have

an inability to experience pleasure, express feelings of worthlessness, feel persistent guilt and a sense of hopelessness, have poor concentration, show indecisiveness, and wish for death (Fitch, 2003). Thoughts of suicide may arise, due to a feeling of profound despair. Although few patients act on such thoughts, many patients do consider suicide at one or more times preceding death (Cathcart, 2006). The psychosocial distress may become more pronounced towards the end of life. Hwang and colleagues (2003) found that psychological symptoms, including feeling sad, worried, irritable, or nervous, dramatically increase among advanced cancer patients during the last month of life. In China, more than 37% of advanced cancer patients were found to be in psychosocial distress (Li, Hao, Zhang & Chen, 2001). The greatest percentage of patients suffered from anxiety, followed by depression and, last of all, somatisation (Li et al., 2001; Wang & Xue, 2006). Our previous study found that advanced cancer patients worried about their family and perceived themselves as being a burden on their families (Xiao et al., 2008). In a number of western and Chinese studies, psychosocial distress has been shown to increase physical symptoms, impair social functions, destroy the feeling that life has meaning, and to interfere with the QOL of advanced cancer patients (Chen, Jiang, Liu, Liu & Li, 2002; Smith & Gomm, 2003; Mystakidou et al., 2005; Liu, Wu & Chen, 2006; McCoubrie & Davies, 2006; Yao, Tao, Liu, Chen & Xu, 2007).

Spirituality/existentiality is another significant aspect of a patient's life that is affected by advanced cancer. Following the diagnosis of the disease, an awareness of one's imminent death often initiates thoughts about one's mortality and purpose in life (Rummans et al., 2006; Lichtenthal et al., 2009). Such

thoughts can lead to responses ranging from a normative awareness of one's existence to a persistent state of demoralization (Lee, 2008). An integrative literature review showed that existential concerns involved the "struggle to maintain self-identity" and "threats to self-identity" (Henoch & Danielson, 2009). When values of life are threatened, patients struggle to cope either by redefining the situation or by forming helpful relationships to protect their self-identity. When patients lose values and relationships, are overwhelmed by suffering, and unable to cope with the situation, they indulge in despair. Murata and Morita (2006) proposed the view that existential distress is caused by the loss of components essential to the being and the meaning of human beings: the loss of relationships (with others), loss of autonomy (independence, control over future, continuity of self), and loss of temporality (the future). Various studies have revealed that advanced cancer patients encounter apparent spiritual/existential distress, including a feeling of dependency, a sense of meaninglessness in their present life, feelings of hopelessness, the sense that they are a burden on others, the loss of social role functioning, powerlessness, and irrelevant feelings (Morita, Tsunoda, Inoue & Chihara, 2000; Morita et al., 2004; LeMay & Wilson, 2008; Henoch & Danielson, 2009). In China, a Hong Kong study (Pang et al., 2005) has found that the value of life and existential distress are the first three concerns among Chinese patients with advanced cancer. Such distress is an obstacle patients in bolstering psychological functioning, adjusting to illness, and protecting against end-of-life despair (Peterman et al., 2002; McClain et al., 2003; Sherman et al., 2005; Balboni et al., 2010).

## **2.5 Life review and its effects**

### **2.5.1 Life review for non-Chinese people facing the challenge of death**

#### ***Life review for older people***

The earliest interest in the life review was stimulated by the desire to help old people to reconcile unresolved conflicts and achieve ego integrity. Since Butler first proposed the therapeutic role of life review/reminiscence in 1963, diverse activities have been suggested to augment its process, such as memory props, topics/themes, guided autobiography, music, dance/movement, and art (Lewis & Butler, 1974; Serrano et al., 2004).

From the 1960s to the early 1980s, the literature on life review was essentially anecdotal in nature. Clinicians employing art life review therapy, dance/movement therapy, and life history claimed various benefits to the elderly resulting from these programs. According to a literature review, only two studies had objectively documented positive effects. Neither of them adopted a control group to determine if such effects were specific to the life review group or merely the result of increased attention or stimulation. No studies had attempted to experimentally clarify the following essential features of life review: the optimal time; ideal frequency of sessions; type of content; which processes lead to what kinds of outcomes; which elderly can benefit from a life review; and whether or not the nature of a life review group experience differs according to chronological age or cohort (Molinari & Reichlin, 1984).

To address the above issues, a great deal of research has been carried out over the past years to explore specific life review programs and their effects. Most life



review programs, including group and individual programs, have centered on older people. The early group life review programs typically consisted of memory stimulation and discussion with group members (Fielden, 1990; Arian et al., 1993; Cook, 1998; Jones, 2003; Arkoff, Meredith & Bubanoski, 2004). Themes /topics and props, such as old photos, scrapbooks, and personal memorabilia, were employed to inspire memories from childhood to the present. A psychologist or other health providers (e.g., a nurse) usually led the programs, which ranged from six to 16 weekly sessions, (the exception was the study of Jones, in which the sessions were held twice a week), with one to two hours for each session. Some limitations existed in these studies. Most studies were lacking in randomization and had a sample size of less than 40 (Fielden, 1990; Jones, 2003; Arkoff et al., 2004). Moreover, the results of these studies were inconsistent. Some studies showed that the group life review programs yielded positive results, such as increased life satisfaction (Fielden, 1990; Cook, 1998) and decreased depression (Arian et al., 1993; Jones, 2003); while Arkoff et al.'s (2004) study indicated that no significant difference occurred in psychological well-being after the program.

The above review-centered life review programs can be regarded as the early group life review programs. With a deeper understanding of the role of autobiographical retrieval in developing a sense of coherence, guided autobiography began to be used in the 1990s to facilitate group life review programs (de Vries, Birren & Deutchman, 1995). The recent group life review programs have shifted from review only to a combination of review and writing. Such life review programs have three sections: (1) the facilitator presented that

day's topics; (2) the subjects were encouraged to contemplate and write their recollections; (3) the subjects shared and discussed their stories (Steven-Ratchford, 1993; Watt & Cappeliez, 2000; Hanaoka & Okamura, 2004; Mastel-Smith, McFarlane, Sierpina, Malecha & Haile, 2007). These programs ranged from six to 10 weekly sessions, with one to two hours per session, which were led by an occupational therapist, psychological therapist, and gerontological nurse. Some studies were conducted to examine the effects of these programs. For example, Stevens-Ratchford's (1993) study on 24 older adults living in a retirement community found that there was no significant difference in depression and self-esteem after a six-session group life review program. Similarly, Hanaoka and Okamura (2004) also found that the older people who participated in an eight-session group life review did not demonstrate a significant improvement in life satisfaction, self-esteem, and reduction in depression, compared with the control group. In the investigation of Arkoff et al. (2004), there was no significant improvement in psychological well-being between the experimental and control elderly groups after a 14-session group life review. Contrarily, Watt and Cappeliez's (2000) six-session group life review and Mastel-Smith et al.'s (2007) 10-session group life review were demonstrated to be effective in decreasing depression in older adults.

In brief, the effect of the group life review programs on psycho-spiritual well-being is uncertain. The major advantage of the group life review programs is to establish new peer relationships or adjust better to a new communal housing site or institutional settings (Haber, 2006). However, due to a lack of confidentiality

and privacy, innermost thoughts and painful memories may not be revealed by group members.

To address the above concerns, the trend is to take an individual approach to conducting a life review. Instead of being surrounded by members of a group, older people in these programs reviewed their life one-on-one with a facilitator. In 1984, Haight and Bahr first proposed an individual life review program for the elderly, based on Erikson's theory. The program included six visits. Essentially, the first two visits covered the years of childhood and adolescence; the second two visits were concerned with the adult years; and the last two visits consisted of a summing up evaluation of the span of the individual's life. The LREF was developed to structure the process of a life review. The program was demonstrated to be feasible and effective in increasing life satisfaction in the elderly. Since then, many researchers have directed their interest towards individual life review programs for the elderly (Haight 1988; Haight, Michel & Hendrix, 1998; Haight, Michel & Hendrix, 2000; Serrano et al., 2004; Mastel-Smith et al., 2006). The programs in their studies consisted of six weekly sessions, with the exception of the study of Serrano et al. (2004) which used four weekly sessions, and each session lasted 30 to 60 minutes. Usually, a nurse or a home worker led the life review process as a facilitator, using the LREF. The design of some studies was not rigorous enough, such as having a small sample size of less than 30 (Haight & Bahr, 1984) and a lack of randomization (Mastel-Smith et al., 2006). The most robust studies were those of Haight et al. (1998, 2000), which adopted the Solomon four experimental design with 256 nursing home residents. Nevertheless, all of these studies consistently found that these

programs were able to improve life satisfaction, psychological well-being, and self-esteem, as well as decrease depression and hopelessness among older people. Additionally, Haight et al. (2000) found that the effects of the life review program on depression, life satisfaction and self-esteem were extended over three years in nursing home residents. They also observed that life review had the potential to help prepare people for the end of life and a good death. A recent qualitative study elicited the perceptions of those who participated in an individual life review program delivered by a home care worker (Binder et al., 2009). The qualitative analysis revealed five themes: someone was there to listen to my story; it was a special time; a valued interaction with the home care worker developed; remembering was meaningful and pleasurable; and integration with one's lived experiences was healing. Compared with group life review programs, the most significant point of the individualized life review program might be the potential for the patient to reconcile more painful memories and experience greater effectiveness in achieving ego-integrity.

To conclude, some features of life review programs for older people have been revealed by studies over the decades. First, the programs have begun to include writing as a component, rather than only a review and discussion. Second, the programs can be conducted in groups and individually. However, the effect of group life review programs is inconsistent. By contrast, all individual life review programs have been demonstrated to improve the psycho-spiritual well-being of older people, such as by increasing life satisfaction, self-esteem, and psychological well-being, as well as decreasing depression and hopelessness. Third, the programs are flexible in duration, ranging from six to 16 sessions.

Most programs are six sessions in length, particularly individual life review programs. The available studies did not indicate that more sessions in a life review achieve better outcomes. Finally, aside from a psychologist, life review programs for older people are led by an occupational therapist, a nurse, or a home worker.

### ***Life review for palliative care patients***

Optimization of QOL is the primary goal in palliative care. To achieve this goal, the structure and delivery approach of life review programs have undergone some changes in the past decades. In the early years, Haight's six-session individual life review program was duplicated for young men with critical illness by Jones et al. (2003). This was a case study design with six subjects for each group, including a life review group, a home visit group, and a no-intervention group. The data were collected at the baseline and six months after the program. The quantitative results revealed an upward trend in optimism and self-esteem, and a downward trend in depression over six months in the life review group, compared to the situation in the other two groups. The qualitative results indicated three unique themes for the life review group: integration and accepting lifestyle challenges, feeling special and unique and having a positive self-appraisal, and reflecting upon parental qualities with insight. Although this was qualitative study, the positive results further confirmed the value of a life review for patients with critical diseases.

Some researchers modified Haight's six-session individual life review program for palliative care patients by shortening the sessions but retaining the contents

(Davis, 2004; Ando & Tsuda, 2006; Ando et al., 2007a). In Davis' study, a shortened life review program with three sessions was tested with a randomized control trial (RCT) involving 14 patients with right hemisphere cerebral vascular damage in a rehabilitation centre. The findings showed that the experimental group had a significantly lower level of depression and a higher degree of life satisfaction. In Ando and Tsue's (2006) comparison study, the four-session life review program was examined in a study involving 36 cancer patients undergoing chemotherapy or radiation therapy. The results indicated that the experimental group experienced a significant reduction in depression and improvement in self-esteem. Ando et al. (2007a) applied the four-session life review program to 12 terminally ill cancer patients in a palliative care unit. The pre-post study revealed that this programme was able to improve the overall QOL of these patients, and some QOL domains including spiritual well-being, orientation, and mood. However, one problem was encountered in this study: 9 of 21 patients failed to complete the study because their physical condition had deteriorated. Despite some limitations in these studies, such as a small sample size, no control group, non-randomization, or a high drop-out rate, all of the studies indicated that a shortened life review program produced positive results in palliative care patients. Another significant point is that these studies began to expand traditional outcome measures of the life review, such as depression, self-esteem, and life satisfaction, to QOL.

The other modified version of Haight's six-session individual life review program was the combination of shortening life review sessions and adding new life themes/topics to the contents. Erlén et al. (2001) applied such a program to

people living with AIDS. Haight's program was shortened to four sessions, addressing childhood, adolescence, adulthood, and a life summary, respectively. Furthermore, the experience of living with HIV/AIDS was added to the topics on adulthood. In this study, 20 people living with AIDS were randomly assigned to the structured life review program or to usual care. Two registered nurses with a certain amount of training led the program of four weekly sessions with approximately one to two hours per session. The patients had the option of coming to the School of Nursing for the life review and/or data collection or having the nurse facilitator travel to their home for these sessions. The outcome measurement was conducted immediately post-treatment, three months post-treatment, and one year post-treatment. The findings indicated that the treatment group had improved overall QOL and self-esteem, and less depressive symptoms over one year, and a greater purpose in life at three months. The sample size of this study was small, with only 10 in each group; thus, the results can only be considered as tentative. However, the positive impact on quality of life, self-esteem, depressive symptoms, and purpose in life confirmed the benefits of conducting a life review for palliative care patients.

To address the high drop-out rate, Ando et al. (2007b) designed a one-week short-term life review interview for terminally ill cancer patients based on Haight's structured life review and Chochinov's dignity therapy (Chochinov & Chan, 2005; Chochinov, Hack, Hassrs, Kristjanson & McClement, 2005). Guiding questions for helping patients to review their lives were employed from the RLEF and Chochinov's dignity therapy. In the first session, the patients reviewed their lives, and then the review was recorded and edited. After the first

session, the therapist made an album, in which key words or phrases used by the patient were recorded as often as possible. Both positive and negative experiences and feelings were included in the album. Photos or drawings from books or magazines that were associated with the patient's words were also pasted in the album to make it more beautiful and memory provoking. In the second session, the patient and the therapist viewed the album, and confirmed the contents with appreciation. The patients who participated in the program demonstrated a significant improvement in spiritual well-being and happiness, and a decrease in anxiety, depression, and suffering. Since the study adopted a pre-post one group design, the lack of a control group made it difficult to conclude that this improvement was a result of their participation in the program. The most valuable aspect of this study was that the making of an album was included in the program, which left something tangible to serve as a personal legacy and which enhanced the effect of the life review (Oleson, 1989).

Another innovative life review program that has tried is the "life preparation and completion" programme aimed at improving the functioning and QOL of eligible hospice patients (Steinhauser et al., 2008). To promote discussions on the completion of life and preparing for this event, the life review included forgiveness, and heritage and legacy as components in the program. This program began with a discussion of the past, involving a biographical context, accomplishments, proudest moments, and cherished times. One week later, the program extended the content of the life review to exploring issues about forgiveness, things they would have done differently, and things left unsaid or undone. In the final session, the program targeted lessons learned, heritage, and



legacy and therefore ending up with a future orientation. Eighty-two eligible hospice patients with cancer, heart disease, lung disease, or others were randomly assigned to the life preparation and completion group, the non-guided relaxation meditation group, or the no intervention group. The program was carried out individually at each patient's own home, with three sessions once every two weeks and 45 minutes to one hour for each session. The findings indicated no significant differences in functional status, anxiety, depression, and preparation for end of life between the three groups and within each group. The authors attributed insignificant difference to the fact that the final sample size was small due to a 50% withdrawal rate. However, compared with other life review programs, this life review program established the importance of discussing legacy for a future orientation.

To sum up, other than older people, life review has been applied to palliative care patients. Life review programs have undergone some changes since their initial application to palliative care patients. There are four main changes: (1) the move from at least six sessions to shorter sessions, varying from two to six sessions. (2) the move from reviewing a human being's common life themes to an emphasis on life-threatening illness experiences; (3) the move from review only to combining the review with a tangible personal legacy; (4) the move from traditional outcomes, such as depression, hopelessness, self-esteem, and life satisfaction, to QOL. It is worth mentioning that these traditional outcomes are all associated with QOL (Kermode & Maclean, 2001; Mystakidou et al., 2005; Gustavsson-Lilius, Julkumnen & Hietanen, 2007; Strine, Chapman, Balluz, Moriarty & Mokdad, 2008).

Regarding the effect of life review programs for palliative care patients, the available studies have consistently indicated that a life review yields positive results, such as increased life satisfaction, self-esteem, spiritual well-being, and QOL, as well as decreased depression. Most of these studies encountered some methodological limitations including a small sample size, the lack of a control group, or non-randomization. An RCT is necessary to confirm its effect. In addition, except for the work of Binder et al. (2009), there have been no studies exploring the participants' perceptions of the life review program.

### **2.5.2 Life review for Chinese people facing the challenge of death**

Several studies have reported a life review program and/or its effect among a Chinese population. These studies have focused on elderly Chinese in Hong Kong and Taiwan. Lau (1994) first adopted Haight's six-session individual life review for Chinese older people and examined its effect in Hong Kong using an RCT. Outcome data was collected both immediately and one month after the program. A significant improvement in life satisfaction and self-esteem and reduction in depression over time was observed in the life review participants. However, the small sample size of the study, with only 15 subjects for each group, limits the generalization of the findings.

Haight's six-session life review program has recently been modified for Chinese older people by reorganizing contents and sessions (Chiang et al., 2008). The modified program consists of eight sessions. Each session respectively addresses childhood, adolescence, family, job, friends, and accomplishments, except for the summary (two sessions). In this study, 75 Chinese elderly males from a

veteran's home in Taiwan were randomly assigned to the experimental group and the control group. A nurse led the program once a week for eight weeks, with each session lasting 1 to 1.5 hours, and held in groups. The study found the modified life review program to be effective in improving life satisfaction and self-esteem among Chinese elderly males. Although the modified program emphasized certain life themes, such as family, job, friends, and accomplishments, Chinese cultures have not yet received adequate attention with respect to what should be addressed in a life review. Furthermore, this study targeted elderly males; therefore, the findings could not be generalized to female elderly.

Liao and Lin (2008) reported that through a four-session life review, an elderly stroke patient expressed acceptance of his life, reduced his feelings of powerlessness, and achieved the integration of his ego with his life. One limitation of this study is that the description of the life review program is unclear. Furthermore, the design of this study was case study, which is unable to test whether the finding result is attributed to the program or not.

In brief, there have been very few studies on the life review concerning Chinese people. Those studies that exist have either adopted or modified Haight's structured life review for Chinese elderly. However, none of the studies have taken Chinese cultures into account when designing the life review programs. Despite some problems of research design, such as a small sample size and the use of the case study approach, these studies have consistently demonstrated that the programs are effective in improving life satisfaction and self-esteem, and

reducing depression and powerlessness. Table 2.1 shows a review of research on the life review for people faced with the challenge of death.

## **2.6 Summary**

This chapter reviewed literature primarily related to the QOL of advanced cancer patients and life review. Advanced cancer patients are at the final stage of life, and are experiencing various kinds of suffering, particularly the psycho-spiritual aspects. Various studies have demonstrated that undertaking a life review yields positive effects on QOL, life satisfaction, self-esteem, spiritual well-being, psychological-well-being, depression, and hopelessness in the elderly or palliative care patients. However, most of these studies did not investigate how life review help to improve psycho-spiritual well-being, with the exception of Binder et al.'s (2009) study exploring older people's perceptions of the life review program.

To our knowledge, no study has reported a life review program for Chinese patients with advanced cancer. Although Haight's (1984) individual life review program and Chiang et al.'s (2008) group life review program have been found to produce positive results among Chinese older people, they are not applicable to Chinese patients with advanced cancer. This is because these two programs do not address major themes in the patients' present life, such as cancer and cancer-related issues. In contrast, Ando et al. (2007b) were aware of the characteristics of cancer patients and developed a short-term life review program for Japanese terminal cancer patients. However, their program focused on generally summarizing and evaluating the whole life in one session, without exploring life

experiences at each stage. This design may fail to help patients integrate the previous stages of life. Furthermore, the above three programs did not pay adequate attention to cultural sensitivities. Therefore, there is a need to specifically design a life review program for Chinese patients with advanced cancer and test its effect.

**Table 2.1 Review of research on the life review for people faced with the challenge of death**

Study	Sample	Design	Intervention	Measurement	Outcome
<b>Studies with a non-Chinese sample</b>					
Fielden (1990)	31(sheltered housing residents)	Quasi-experimental study EG: LR CG: A current life focus	9 group sessions 1 to 1.5 hrs per session Once a week Facilitator: a clinical psychologist	Life satisfaction	The EG showed a significant improvement in life satisfaction compared with the CG.
Stevens-Ratchford et al. (1993)	24 (older people living in a retirement community)	RCT EG: LR CG: no intervention	6 group sessions 2 hrs per session Frequency: not available Facilitator: not available	Self-esteem Depression	No significant effects on self-esteem and depression.
Arean et al. (1993)	75 (older people with depressive disorder living in community)	Quasi-experimental study EG: LR CG1: problem-solving therapy(PST) CG2: a waiting-list control (WLC)	12 group sessions 1.5 hrs per session Once a week Facilitator: not available	Depression Social problem-solving ability Integration of life events	PST and LR produced significant reductions in depressive symptoms at post-treatment and the three-month follow-up.
Cook (1998)	36 (female nursing home residents)	RCT EG: LR CG1: a current life focus CG2: no treatment	16 group sessions 1 hr per session Once a week Facilitator: not available	Life satisfaction	The EG showed a significant improvement in life satisfaction compared with the CG.

Watt et al. (2000)	26 (older people with depression)	Quasi-experimental study EG: LR CG1: Instrumental reminiscence (IR) CG2: active socialization group	6 group sessions 1.5 hrs per session Once a week Facilitator: a psychological therapist	Depression	Both LR and IR led to a significant reduction in depression immediately after and three months after the intervention.
Jones (2003)	30 (women in an assisted living facility)	Quasi-experimental study EG: LR CG: reminiscence therapy	6 group sessions 45 minutes per session Twice a week Facilitator: a nurse	Depression	The EG showed a significant decrease in depression compared with the CG.
Hanaoka et al. (2004)	80 (older people in a nursing home)	RCT EG: life review CG: discussion activities about health	8 group sessions 1 hr per session Once a week Facilitator: an occupational therapist	Life satisfaction Self-esteem Depression Hopelessness	No significant difference in life satisfaction and self-esteem between the EG and CG. A significant reduction in hopelessness and depression at post-treatment and three months post-treatment between the EG and CG.
Arkoff et al. (2004)	36 (community-dwelling older women)	Quasi-experimental study EG: LR CG: no treatment	14 group sessions 2 hrs per session Once a week Facilitator: a psychologist	Psychological well-being	No significant changes in psychological well-being between the two groups. The EG showed a significant pre-post improvement in psychological well-being.
Mastel-Smith et al. (2007)	53 older adults	RCT EG: LR and writing CG: Usual care	10 group sessions 2 hrs per session Once a week Facilitator: a nurse	Depression	The EG had a significantly lower level of depressive symptoms compared with the CG.

Haight et al. (1984)	12 (elderly people)	Quasi-experimental study EG: LR CG: no intervention	6 individual sessions 6 times within 30 days Facilitator: a nurse	Life satisfaction	The EG showed a significant improvement in life satisfaction compared with the CG.
Haight (1988)	60 (homebound elderly)	RCT EG: LR CG1: friendly visits CG2: no intervention	6 individual sessions 1 hr per session Once a week Facilitator: a nurse	Psychological well-being Life satisfaction	The EG showed a significant improvement in life satisfaction and psychological well-being compared with the CG.
Haight et al. (1998)	256 (older people in a nursing home)	Solomon Four research design EG: LR CG: friendly visits	6 individual sessions 1 hr per session Once a week Facilitator: a nurse	Depression Hopelessness Suicide ideation Life satisfaction Self-esteem Psychological well-being	The EG showed less depression; the decrease was noted immediately after the intervention. The EG showed less depression and hopelessness, and higher life satisfaction and psychological well-being one year after the program.
Haight et al. (2000)	52 (older people in a nursing home)	Solomon Four research design EG: LR CG: friendly visits	6 individual sessions 1 hr per session Once a week Facilitator: a nurse	Depression Hopelessness Suicide ideation Life satisfaction Self-esteem Psychological well-being	The EG showed a significant decrease in depression, and improvement in life satisfaction and self-esteem over three years.
Serrano et al. (2004)	43 (elderly people with depression)	RCT EG: LR CG: no treatment	4 individual sessions Duration per session (not available) Once a week Facilitator: a psychologist	Depression Hopelessness Life satisfaction Autobiographical memory test	The EG demonstrated significantly fewer depressive symptoms, less hopelessness, improved life satisfaction, and were able to retrieve more specific events, compared to the CG.



Mastel-Smith et al. (2006)	20 (home-dwelling older women)	Quasi-experimental study (Pre-post one group design)	6 individual sessions 40 minutes per week Once a week Facilitator: a home worker	Depression	A significant decrease in depression over 20 weeks after the intervention.
Binder et al. (2009)	13 (older women)	Qualitative study	6 individual sessions 40 minutes per week Once a week Facilitator: a home worker	Not applicable	Five themes: (1) someone was there to listen to my story; (2) it was a special time; (3) a valued interaction with the home care worker developed; (4) remembering was meaningful and pleasurable; (5) integration with one's lived experiences was healing.
Jones et al. (2003)	18 (young men with a critical illness)	A Case study EG: LR CG1: home visit CG2: no intervention	6 individual sessions 1 hr per session Once a week Facilitator: not available	Depression Optimism Self-esteem	Quantitative results: there was an upward trend in optimism and self-esteem, and a downward trend in depression over six months in the EG, compared to the other two groups.  Qualitative results (three themes for the EG): integration and accepting lifestyle challenges, feeling special and unique and having a positive self-appraisal, and reflecting upon parental qualities with insight.

Davis et al. (2004)	14 (individuals with right hemisphere cerebral vascular accidents)	RCT EG: LR CG: view neutral video and a follow-up discussion	3 individual sessions 1 hr per session Once a week Facilitator: not available	Depression Life satisfaction	The EG showed a significantly lower level of depression and a higher degree of life satisfaction, compared to the CG.
Ando et al. (2006)	36 (cancer patients)	Quasi-experimental study EG: LR CG: no treatment	4 individual sessions 1 hr per session Once a week Facilitator: a psychologist	Depression Self-esteem	The EG showed a significant decrease in depression and improvement in self-esteem, compared to the CG.
Ando et al. (2007)	12 (terminally ill cancer patients)	Quasi-experimental study (Pre-post one group design)	4 individual sessions Duration per session (not available) Once a week Facilitator: a psychologist	QOL	The overall QOL, mood, orientation, and spiritual well-being significantly improved after the life review.
Ando et al. (2007)	30 (terminally ill cancer patients)	Quasi-experimental study (Pre-post one group design)	2 individual sessions Duration per session (not available) Twice a week Facilitator: a psychologist	Spiritual well-being Anxiety Depression Happiness Suffering	Spiritual well-being, anxiety, depression, happiness, and suffering significantly improved after the life review.
Erlen et al. (2001)	20 (people with AIDS)	RCT EG: LR CG: usual care	4 individual sessions 1 to 2 hrs per session Once a week Facilitator: a nurse	Depression Self-esteem Purpose in life QOL	The EG showed an improved overall QOL, self-esteem, and fewer depressive symptoms over 12 months, and a greater purpose in life at three months, compared to the CG.

Steinhauser et al. (2008)	82 (eligible hospice patients with cancer, heart, or lung disease)	RCT EG: Preparation and Completion intervention involving LR CG1: no intervention Attention CG2: Non-guided relaxation meditation	3 individual sessions 45 minutes to 1 hour Once every two weeks	Functional status Depression Anxiety QOL	The EG showed an improvement in functional status, depression, anxiety, and preparation for the end of life, compared to the CG, which did not reach a statistical level.
<b>Studies with a Chinese sample</b>					
Lau (1994)	31(depressed institutionalized elderly)	RCT EG: life review CG: friendly visits	6 individual sessions 1hr per session Once a week Facilitator: a psychological research student	Depression Life satisfaction Self-esteem	The EG demonstrated significantly lower depression and higher life satisfaction and self-esteem, compared to the CG.
Chiang et al. (2008)	75 (elderly males from a veteran's home)	RCT EG: life review CG: usual activities	8 group sessions 1-1.5 hrs per session Once a week Facilitator: a nurse	Self-esteem Life satisfaction	The EG had higher self-esteem and life satisfaction at post-treatment and one month post-treatment, compared to the CG.
Liao et al. (2008)	1 (elderly stroke patient)	Case report	4 individual sessions 1-2 hrs per session Frequency: not available Facilitator: a nurse	Powerlessness	The client expressed acceptance of his life, reduced his feelings of powerlessness, and achieved the integration of his ego with his life.

EG: experimental group; CG: control group.

## **CHAPTER 3**

### **DESIGN OF A LIFE REVIEW PROGRAM FOR CHINESE ADVANCED CANCER PATIENTS**

This study addresses the development and evaluation of a life review program for Chinese patients with advanced cancer. This chapter discusses the design of the life review program based on Erikson's theory, Confucian thoughts on human development, our previous study, and the literature.

#### **3.1 Aims of the life review program**

The purpose of the whole life review program, including reviewing a life and formulating a life review booklet, was to achieve ego integrity among Chinese patients with advanced cancer. The aim of reviewing a life was to help patients recall, evaluate, and integrate their entire life experiences into a meaningful whole one. The aim of formulating a life review booklet was to help patients summarize and value their life again, and leave a personal legacy for their loved ones.

#### **3.2 Design of the life review program**

This section explains how to design a life review program for Chinese patients with advanced cancer in terms of its content, format, frequency, and duration, based on Erikson's theory, Confucian thoughts on human development, our previous study, and the literature.

### **3.2.1 Content of the life review program**

#### **3.2.1.1 Reviewing a life**

##### **A. Life review sections**

According to Erikson's theory, ego development goes through eight stages of life with each one building on previous stages. Life review, as an intervention to help individuals achieve ego integrity at the final life stage, should cover the whole life span from childhood to the present. Previous studies usually divided reviewing a life into four sections: childhood, adolescence, adulthood, and a summary and evaluation of the entire life (Lau, 1994; Haight et al., 1998; Erlen et al., 2001; Mastal-Smith et al., 2006; Ando & Tsuda, 2006; Ando et al., 2007a).

However, some writers suggest that ego development may be not necessarily fixed in chronological order by a linear fashion (Antonovsky & Sagy, 1990, Gross, 1996; Bee, 1998; Greene & Kropf, 2009). To address patients' current major concerns, reviewing a life in this study was designed to start with the present and working backwards. The reverse sequence helps patients to appreciate the program relevance for their present situations (Garland & Garland, 2001). In this present study, the process of reviewing a life was reorganized as three sections: the present, adulthood, and childhood and adolescence. The reverse sequence is because a review starting with the present and working backwards can help patients appreciate the relevance of the program to their present situation (Garland & Garland, 2001). At present, the patients are more concerned about their illness, and therefore are more willing to discuss it than other subjects. Meanwhile, discussing the illness also enables them to re-establish a sense of order, identify problems, solutions, and resources, as well as

to live fully within the shadows of “mortal time” (Pennebaker, 2000; Carlick & Builey, 2004). Thus, the section on the present focused on cancer experiences from diagnosis through survivorship to the present. Following the section on the present is the section on adulthood, in which many great life events usually happen, such as work, marriage, and family life. Contributions and achievements are also often made at this stage. Exploring life in adulthood is worthy of an independent section. The final section addresses adolescence and childhood. Given that childhood and adolescence are possibly a plain recollection due to the remoteness of time, they were combined into one section in this program.

## **B. Life review themes**

To structure a life review, major life themes at each stage need to be identified. The basic life themes were derived from Erikson’s theory.

### ***a. Life themes from Erikson’s theory***

Based on Erikson’s theory, Burnside and Haight (1994) identified nine life themes over an entire life span. They are death, grief, fear, religion, school, hardships, sex, work, and relationships. Among them, childhood and adolescence focus on grief, fear, school, religion, and relationship; while adulthood centers on sex, work, religion, hardships, and death. These life themes have been widely applied in life review programs for the elderly and palliative care patients, as described in Chapter 2. They were also employed in this program. Interestingly, despite the importance of raising and caring for children in achieving generativity in Erikson’s theory, Burnside and Haight did not include family as a life theme or family-related guiding questions (e.g., children) addressing adulthood.

### ***b. Cancer-related life themes***

As the life themes from Erikson's theory are not specific to cancer patients, cancer-related life themes were added to the program that was developed in this study. They were derived from our previous study, and include cancer, family, belief in heaven, and death.

The previous study was a descriptive qualitative study on the QOL concerns of advanced cancer patients (Xiao et al., 2008). The selection criteria for participants were: a diagnosis of advanced cancer; awareness of the diagnosis and prognosis of the disease; and no apparent cognitive and oral communication impairment. Nine patients receiving home-based palliative care from the Fujian Hospice were recruited. The semi-structured interviews were individually conducted at the patients' homes by the student researcher. The open-ended questions for exploring QOL concerns were modified from the Quality-of-Life Concerns in the End-of-Life Questionnaire (QOLC-E) (Appendix 4.4) (Pang et al., 2004, 2005). Each interview took 30 to 45 minutes. All interviews were tape-recorded and transcribed verbatim. A qualitative content analysis (Graneheim & Lundman, 2004) was adopted to analyze the qualitative data.

The participants' bio-socio-demographic characteristics are presented in Table 3.1. The mean age of the participants was 55 years. Most were male, married, lived with their family, had a secondary school education, and reported their spouse as their primary caregiver. The majority had suffered from the disease for more than six months and had received home-based palliative care for less than three months.

**Table 3.1 Characteristics of the participants**

	<b>n</b>	<b>%</b>	<b>Mean (SD)</b>	<b>Range</b>
<b>Age (years)</b>			55.00 (10.87)	33.00~68.00
<b>Months with the disease</b>			6.56 (2.00)	0.50~30.00
<b>Gender</b>				
Male	6	66.7		
Female	3	33.3		
<b>Education</b>				
Primary School	3	33.3		
Secondary School	6	66.6		
<b>Marital Status</b>				
Married	7	77.8		
Divorced	2	22.2		
<b>Living Condition</b>				
Live with family	8	88.9		
Live alone	1	11.1		
<b>Primary caregiver</b>				
Parents	1	11.1		
Spouse	6	66.7		
Sister	1	11.1		
No	1	11.1		
<b>Home-based palliative care</b>				
Less than 1 month	2	22.2		
1 to 3 months	5	55.5		
4 to 6 months	1	11.1		
7 to 12 months	1	11.1		

The qualitative data showed that the patients' QOL concerns were: (1) physical symptoms; (2) strong considerations for families; (3) achievements and contributions; (4) belief in heaven; and (5) a good death.

### ***Physical symptoms***

The participants often experienced physical symptoms, such as pain and cough, but they appeared not to show much concern about their physical discomfort.

“Cough. Cancer has spread to my lung, which makes it difficult for me to cough. Once there is a bit discomfort in the chest, I get worried. But I am very optimistic. I don't worry about the disease all the time. If you worry about the illness all the time, this would make your situation more serious. Take it easy.” (Patient D)



“The illness inevitably brings pain and suffering. It is impossible to avoid them. Patients need to face it and accept it. Acceptance allows me to feel peace.”  
(Patient B)

### ***Strong considerations for families***

The participants showed strong considerations for their families. Their major concerns were associated with their families, including perceiving oneself to be a burden on them, worrying about them, and expressing their hopes for them.

### **Self-perceived burden to families**

The participants felt themselves to be a burden on their families with regard to finances and caregiving, after they contracted the disease.

“I feel a burden on my family. About RMB 50,000 has been used for my treatment. There are no savings in my family now.” (Patient H)

“My parents used to attend various social activities. Now, they rarely do so since they have to take care of me in turn. If I experience pain at night, they accompany me all night without sleep. Obviously, I am a burden to them.”  
(Patient C)

### **Worries about families**

Faced with death, the participants did not care about their own future; however, they worried about the future life of their family members.

“Death is a natural end of life. It is inevitable for everyone. I do not worry it. However, I worry about my parents and son. My parents are old and my son is only seven years old. One day, I will die. Who will take care of them?”  
(Patient I)

“My major concern is my wife. She prefers to live in Fuzhou, her hometown. But my daughter works in Shanghai. She is too busy to take care of her mother. I worry that my wife cannot live well after I die.” (Patient F)

### Hopes for families

The participants mentioned that there was no hope in their own future but they hoped that their family would live well after they died.

“No hope for me. I am living day after day. I hope my family won’t be too sad about my death. I hope they have a happy life after my death. So I often tell my daughter to study hard and take care of my wife.” (Patient H)

“I know my illness is incurable. I will die in the near future. I do not fear death. Death is a natural part of life.... I wish my family will be healthy and happy forever.” (Patient C)

### ***Achievements and contributions***

The participants judged the goals that they had achieved and the value of their life according to their achievements within and contributions to their family.

### Achievements in family

The participants related the goals they had achieved in life to their children’s filial piety and career success, and to having completed their responsibilities to their family.

“I have attained my goals in life. My son and daughter are filial children. They do a great job. They are appreciated by their bosses. ” (Patient C)

“I raised my son by myself. Now, my son is grown up, has established his own , and has a four-year old child. So I have completed my obligations. And I have achieved my goal. ” (Patient H)

### Contributions to families

The participants valued their life since they had made contributions to their family, such as caring for their family and supporting their family financially.

“Family is most important for me. I devote my whole life to taking good care of my family. Due to my effort, they have a healthy and happy life. So what I have done is worthwhile. ” (Patient C)

“I had worked for about 40 years until I got the illness. All of my salary was used to support my family. In this sense, I am worthwhile.” (Patient F)

### ***Belief in heaven***

Some participants believed that Buddhism could do nothing to help them against their disease. However, they considered advanced cancer as their fate, which was predetermined by Heaven.

“I believe in Buddhism. However, if you suffer from cancer, it cannot bless you. Anyway, I think everything that happens in my life, including advanced cancer, is determined by Heaven. I have no choice but to accept.” (Patient C)

### ***A good death***

The participants acknowledged that death was inevitable in the near future, but they hoped to die without suffering.

“Due to the illness, my time is coming. Death is acceptable, but suffering accompanied with dying is horrible. I do expect I can pass away in peace and without suffering.” (Patient I)

“Advanced cancer is equal to impending death. I am now on this road. Everyone will die, won’t they? Anyway, it is okay if I die without suffering and pain.” (Patient F)

In brief, this study indicated that the major QOL concerns of Chinese patients with advanced cancer were strong considerations for their family, achievements and contributions, a belief in heaven, and a good death. This suggests that family, a belief in heaven, and death are most important issues in the patients’ present life. Therefore, a review of the present life among Chinese patients with advanced cancer should address cancer, family, belief in heaven, and death.

### *C. Chinese common life themes*

Apart from life themes from Erikson's theory and cancer-related life themes from our previous study, Chinese common life themes were included to raise the cultural sensitivity of the program that was developed. Chinese common life themes were identified based on cultural values and common experiences specific to Chinese people (Chong, 2000).

Confucianism is one of the three classical beliefs in Chinese culture. It has a tremendous impact on the lives of Chinese people. Reviewing his own life in later years, Confucius said, "At fifteen I set my heart upon learning. At thirty I was firmly established. At forty I had no more doubts. At fifty knew the Decree of Heaven. At sixty I was attuned to Heaven. At seventy I could follow my heart's desire without violating the regulations (Yao, 1993 p.18)." Although this is Confucius' own account of his development, it establishes a model of appropriate behavior for others to emulate.

Confucius' thoughts on human development indicate that life is a process of transformation in which people move through different developmental stages, with each stage having its own task. In adolescence, one should focus on learning. For Confucius, learning is more than the acquisition of empirical knowledge. It is a method of internalizing the proper manner of behaving in society. Through learning, at age thirty, one becomes an independent professional and has established his or her own family and career. At age forty, one should achieve a state of mental maturity, no longer struggling with confusion about how to conduct oneself in society. At age fifty, one should reach spiritual maturity, knowing the mission of heaven, such as one's responsibilities

to family and society. At sixty, one is ready to accept diversity and differences within the family or community. After the age of seventy, one can achieve the final fruits of a long process of maturation: harmony of man and heaven (Fu et al. 2005; Tu, 1978; Anonymous, 2010). Thus, in Confucius' view, study, dealings with people, family, and work are important life themes for Chinese people.

In addition, Chinese people's common experiences at a particular historical period also offer themes for reviewing a life. One major shared experience for many Chinese people is the hardship of the Cultural Revolution from 1966 to 1975. It was during such times of hunger, poverty, and suffering that people who are now above the age of 30 grew up. They commonly experienced inadequate food, dropped out of school, worked as children, or left home to work in the countryside. Thus, food and labor were specific life themes for many Chinese people in their childhood or adolescence. Generally, the identified Chinese common life themes included study, dealings with people, family, work, food and labor in childhood and adolescence. Here, "study" echoes Erikson's industry vs. inferiority, which means that a child is encouraged by parents and teachers to develop a feeling of competence and belief in skills. "Dealings with people" means how to treat others. It echoes Erikson's ego identity vs. role confusion and intimacy vs. isolation, which involve developing relationship with others. "Family" echoes Erikson's intimacy vs. isolation and generativity vs. stagnation, which involve marriage, early family life, and produce and raise children. "work" echoes Erikson's generativity vs. stagnation, which involves producing things. "Food and labor in childhood and adolescence" echoes Erikson's ego

identity vs. role confusion since no food and work as a children may cause children feel confused about themselves.

After integrating all identified life themes, the final life themes at each life review section for Chinese patients with advanced cancer are shown in Table 3.2.

**Table 3.2 Life themes for Chinese patients with advanced cancer**

Stage	Life theme	Source
The present (cancer experiences)	Illness, family, belief in heaven, death	Our previous study
Adulthood	Work, sex, hardship, religion, family, dealings with people,	Erikson's theory Confucian thoughts on human development
Childhood & Adolescence	School, religion, relationship, grief, fear, food, labor	Erikson's theory Chinese cohort experiences

### **C. Guiding questions for reviewing a life**

Based on the above life themes, guiding questions for reviewing a life were designed to stimulate Chinese patients with advanced cancer to recall their life experiences. Some guiding questions were adopted or modified from the LREF with the author's permission (Appendix 3.1). Other questions on cancer-related life themes and Chinese common life themes were designed by the student researcher. The development of guiding questions is shown in Table 3.3.

**Table 3.3 Development of guiding questions for reviewing a life**

Stages	Life themes	Guiding questions	Sources
The Present	Cancer Death	Please tell me about your disease. How does the disease affect you and your life? How do you deal with the disease? What have you learned from the disease? What do you think about birth, aging, illness, and death?	Developed by the student researcher
	Belief in heaven	How do you perceive destination in relation to your disease?	Developed by the student researcher
	Family	What are your concerns for your family in the current situation? If your disease becomes worse, what hopes, blessings, and advice do you have for your family?	Developed by the student researcher
Adulthood	General question	Tell me the most important events that happened in your adulthood.	Adopted from the LREF
	Dealing with people	How do you deal with people?	Developed by the student researcher
	Work	Please tell me about your work.	Adopted from the LREF
	Sex	Did you marry? (No) Why not? (Yes) What kind of person was your spouse? How was your marriage over time?	Adopted from the LREF
	Family	Please tell me about your family members? What have you done for your family?	Developed by the student researcher
	Hardship	What were the main difficulties you encountered during your adult years?	Adopted from the LREF
	Religion	What place did religion play in your life?	Adopted from the LREF

**LREF:** The life review and experiencing form (Haight & Bahr, 1984).

**Cont. Table 3.3 Development of guiding questions for reviewing a life**

Stages	Life themes	Guiding questions	Sources
Childhood & adolescence	General question	What are your impressions of your childhood and adolescence?	Modified from the LREF
	Relationship	How is your relationship with your family? Please tell me something about your friends.	Modified from the LREF
	School	How were your studies?	Modified from the LREF
	Labor	How did you work as child?	Developed by the student researcher
	Food	What do you feel about insufficient food in childhood or adolescence?	Developed by the student researcher
	Fear grief	What do you feel about being left alone, abandoned, and not being loved or cared as a child or adolescent?	Adopted from the LREF
	Religion	What place did religion play in your life?	Adopted from the LREF

**LREF:** The life review and experiencing form (Haight & Bahr, 1984).

### **3.2.1.2 Formulating a life review booklet**

Formulating a life review booklet was the other component of the life review program. This is because a document of storytelling interventions produces various positive effects. In their study, Willis and Day (2008) indicated that a life storybook enables older adults to value their stories through providing a holistic view of the past and present. Ando et al. (2007b) found that compiling an album from a life review offers terminally ill cancer patients the chance to appreciate their lives again and therefore enhances their spiritual well-being. Chochinov et al. (2005) reported that a generative document in dignity therapy serves as a



personal legacy for terminally ill patients, which helps patients be remembered after their death. More recently, Wise, Marchand, Aeschlimann, Causier, and Cleary (2009) reported that cancer patients perceive a well-honed life manuscript as the most appreciated component of an online narrative and life review education program. In China, a document has a specifically cultural value. Chinese people believe that a person's value in life is reflected in three aspects, namely "Li Gong" (meritorious service), "Li De" (high moral values), and "Li Yan" (great writings) (Zuo 2003). If the person achieves these aspects, his or her spirit is immortal. Therefore, a document of life experiences, a kind of "Li Yan," may help patients affirm value in their life and serve as a personal legacy for their loved ones.

In this study, the content and format of the life review booklet was determined by advanced cancer patients. Recorded in the booklet would be the patients' significant life experiences, views on life, and words to their family, including their advice, hopes and blessings. The booklet would be pasted with patients' favorite photos and pictures. The first person narrative was suggested to document the booklet. The patients own words were used as much as possible in the booklet to keep their unique style, which may easily bring back memories of them to family and friends when reading the booklet.

To sum up, the life review program for advanced cancer patients comprised reviewing a life and formulating a life review booklet. Reviewing a life was divided into three sessions, namely, the present, adulthood, and childhood and adolescence. Each session addressed major life themes corresponding to that

stage of life. A life review booklet was produced as a gift for patients based on their preference.

### **3.2.2 Duration and frequency of the life review program**

A literature search indicated that life review programs of various durations and frequencies were demonstrated to be effective in improving psycho-spiritual well-being among palliative care patients, as described in Chapter 2.

Regarding the duration, life review programs for palliative care patients varied from one to six weeks. Despite their effectiveness, some of the programs encountered a high drop-out rate. Steinhauser et al. (2008) found that approximately 50% of eligible hospice patients withdrew from a six-week “life preparation and completion” program due to functional decline or death. Ando et al. (2007a) revealed that above 30% of terminally ill cancer patients failed to complete a four-week life review program due to poor physical conditions. Ando et al. (2007b) also found that a one-week, two-session life review is feasible and effective in improving spiritual well-being among terminally ill cancer patients. Considering the drop-out rate and the effectiveness of conducting a life review among palliative care patients, three weeks was adopted as the duration of our life review program.

On the aspect of the frequency, life review programs for palliative care patients ranged from two to six sessions, with 30 minutes to one hour per session. These programs were carried out once a week, with the exception of Ando et al.’s (2007b) one-week life review, which featured two sessions a week. It is likely

that life review programs conducted twice a week were no more effective than those held once a week (Lappe, 1987). Therefore, our life review program used one session every week, with 30 minutes to one hour per session. In general, our program was a three-session weekly life review, addressing the present, adulthood, and childhood and adolescence, respectively.

### **3.2.3 Format of the life review program**

Life reviews can be conducted by groups and individuals. Considering the purpose and feasibility of the life review program for advanced cancer patients, in performing our life review program the individual approach was selected. The aim of our program was for the life review to produce therapeutic function, rather than to establish a new social network. Individuality is critical to ensuring the therapeutic effect of the life review (Haight & Dias, 1992; Haight & Haight, 2007). It offers privacy, confidentiality, and the chance for more feedback than would be possible under a group approach, so that patients are able to work over more painful life events (Hendricks, 1995). A great deal of research has consistently indicated that an individual life review program yields positive outcomes; while the effect of group life review programs is uncertain, as described in Chapter 2. In addition, compared to the group approach, the one-to-one approach is more feasible for advanced cancer patients, who may be facing physical challenges, transportation problems, or juggling medical schedules.

### **3.3 Validation of the life review program**

A panel consisting of a palliative care nurse specialist, a clinical psychologist, and a clinical oncology professor were invited to review the life review program

that was drafted. All of them had more than 10 years of work experience in their fields. They provided comments about the content, the format, the frequency and duration of the program, and guiding questions for reviewing a life based on their experience and knowledge. According to their comments, revisions were made until the experts came to an agreement. After the expert validation, three advanced cancer patients from the Fujian hospice were recruited to test whether the guiding questions for reviewing a life were understandable and acceptable.

The revisions on reviewing a life involved guiding questions and the duration of each life review session. First, the experts felt that the question, “What do you think about death?”, was too sensitive for patients, although if it could be handled well, this would be very beneficial to the patients. The test of guiding questions also found that two patients seemed reluctant to respond the death-related question. A significant observation in the test was that another patient naturally raised the topic of death by himself, using the phrase “birth, aging, illness, and death”. Thus, the two original questions, respectively addressing perceptions of the illness and death, were combined into one question—“What do you think about birth, aging, illness, and death?”. After the patients talked about birth, aging and illness, if they can not naturally move to talk about death after birth, aging and illness, the facilitator will further guide them to explore how they feel about death. Second, some specific questions addressing relationship were integrated into two open-ended questions in order not to add to the patients’ burden. Third, two questions, respectively addressing disappointments and unhappiness, were deleted since they could be explored under the life theme of hardship. The final version of guiding questions for

reviewing a life is shown in Appendix 3.2. Indeed, these questions are just guidelines. During the life review, the facilitator can ask further questions to help subjects to review their life experiences based on their stories and responses. Regarding the duration of each life review session, although 30 minutes to one hour per session was the preset period, it was suggested that our program should be flexible about duration, depending on a patient's health status and willingness to talk.

Other revisions related to the life review booklet. First, under the life review program advanced cancer patients would be invited to give the booklet a specific title, to reflect their unique life. Second, the information recorded in the booklet should depend on the patients' preferences, although suggestions about the contents of the booklet were made.

### **3.4 Characteristics of the life review program**

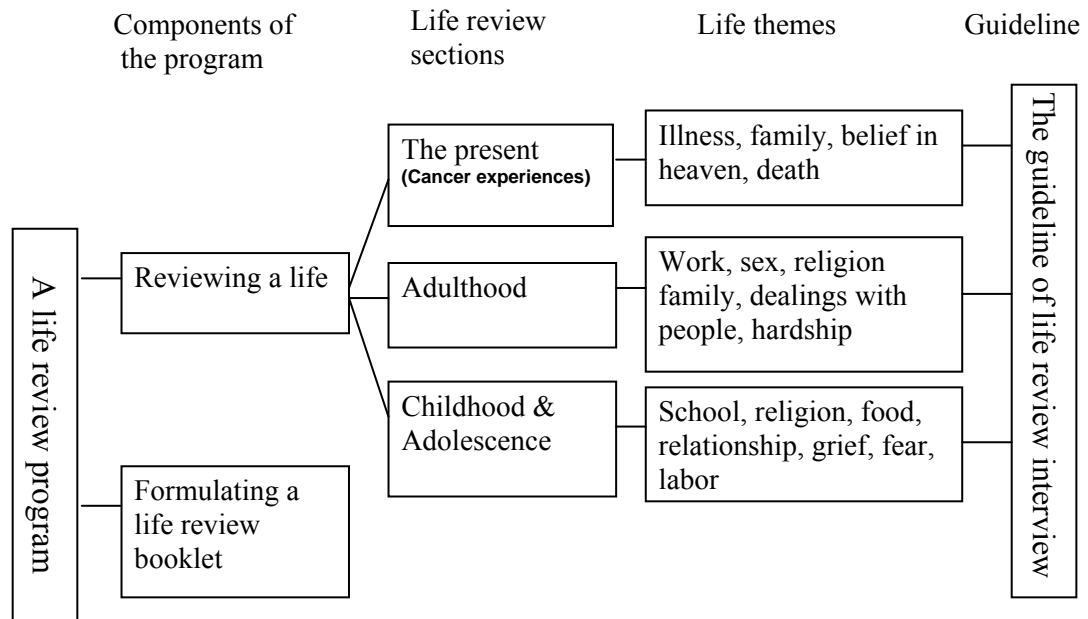
The program that we developed is a three-session life review program for Chinese patients with advanced cancer. There are some similarities between the program that we developed and previous life review programs. First, Erikson's theory is the theoretical framework guiding the design of the program. Life review programs are structured by having guiding questions for reviewing a life that address major life themes at each stage of life. Second, the programs are patient-centered in program design and delivery. Patients take a leading, dominant, or even controlling position in doing a life review, while the facilitator is simply responsible for guiding the patients to review their life. Third, an

individual approach is used to conduct a life review in order to enhance the therapeutic effect of the life review.

Despite the above similarities, the program that we developed has some unique characteristics compared to previous life review programs. First, this program addresses major life themes of Chinese people, including family, work, dealing with people, food, and labor. These themes were developed based on Confucian thoughts on human development as well as Chinese cohort experiences. They enhance the cultural sensitivity of the program. Second, the program addresses cancer-related life themes, including cancer, family, belief in heaven, and death. These life themes reflected the major concerns that arose after the Chinese patients with advanced cancer found that they were suffering from the disease. The integration of the patients' major concerns into the program contributes to the specificity of the program for advanced cancer patients. Third, this program combines reviewing a life with formulating a life review booklet, rather than simply focusing on the review. The booklet documents the patient's significant life experiences, views on life, and words (e.g., advice, blessings) for the bereaved. The booklet not only helps patients to value their entire life again, but also leaves a personal legacy for their loved ones. Finally, in this program, the life reviews begins with the present and works back to childhood. The reverse sequence used for reviewing a life fits well in addressing the current major concerns of advanced cancer patients. This design helps patients to appreciate that the program is relevant to their present situation, which encourages them to actively engage in reviewing their life.

### 3.5 Summary

This chapter describes the design of a three-session life review program combined with booklet, for Chinese patients with advanced cancer, see Figure 3.1. The similarities and differences of the program compared with previous life review programs were also discussed.



**Figure 3.1 The outline of the life review program**

## **CHAPTER 4**

### **CONCEPTUAL FRAMEWORK**

This chapter presents the conceptual framework of this study developed based on Erikson's theory, Butler's life review process, and the related literature. The operational definitions, research questions, and hypotheses of this study are also described.

#### **4.1 Development of the conceptual framework**

##### **4.1.1 Theoretical basis of the conceptual framework**

###### ***Life review and ego integrity***

Erikson's theory, Butler's life review process, and the related literature were adopted to construct the conceptual framework for this study. According to Erikson (1950), the ego develops through eight psychosocial stages, with each stage building on previous ones. The final stage associated with late adulthood is "ego integrity vs. despair." Integrating all of the preceding stages of life can help individuals to achieve ego integrity and avoid despair.

Butler's life review process has been considered to be a crucial extension of Erikson's theory (Kaminisky, 1984). Butler (1963) postulated that the integration of the previous stages of life involves a life review process, in which individuals recall, evaluate, and reintegrate their past experiences. During this process, the individuals express their feelings and thoughts on life experiences, reaffirm their contributions and achievements, reconcile their failures and disappointments, and finally integrate various life experiences of their entire life into a more



acceptable or meaningful whole. The successful integration of various life experiences helps individuals to achieve ego integrity.

### ***Ego integrity and quality of life***

During the process of achieving ego integrity, the integration of various life experiences enables individuals to create a positive and acceptable view of their life cycles (Stevens-Ratchford, 1993; Chiang et al., 2008). As a result, they can positively evaluate their life, thereby perceiving the quality of their life (Peck, 2001).

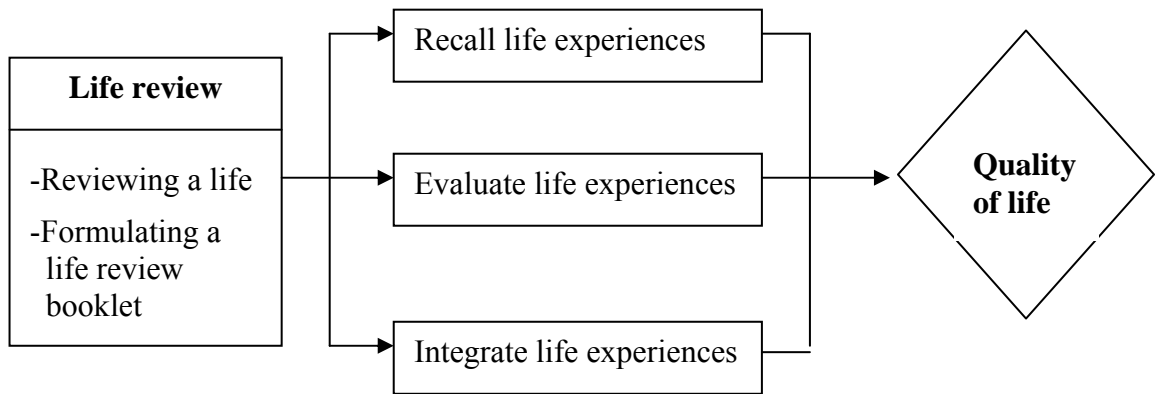
According to Meeberg's (1993) concept analysis of QOL, if the individuals perceive the quality of their life, they will be satisfied with their life, have a sense of self-esteem and pride regarding their life, feel happiness, and have a feeling of well-being. These outcomes of QOL are associated with ego integrity. First, satisfaction with life implies regarding life as meaningful and accepting resolutely that which life has been (Neugarten, Havighurst & Tobin, 1961). Acceptance of life is the core component of ego integrity (Santor & Zuroff, 1994; Rylands & Rickwood, 2001). Second, self-esteem is related to a person's perception of his real self-image and his ideal self-image (Cook, 1999). Higher self-esteem indicates more persistent sameness within one's self (Silber & Tippet, 1965). Both a persistent sameness within one's self and a persistent sharing of the same kind of essential character with others contribute to self identity (Erikson, 1956). Ego integrity is the culmination of a lifelong development of the self identity. Thus, enhancing self-esteem is essential to achieve ego integrity. In addition, Tesch's (1985) study has found that feelings of

happiness and well-being are associated with ego integrity. Therefore, QOL is able to reflect ego integrity.

QOL is particularly important in palliative care, where treatments result in limited gains in cure or prolonged survival. Improving QOL becomes the primary goal of palliative care (WHO, 2002). Accordingly, QOL has been considered to be the principal outcome measure of weighting the benefits and side effects of palliative care interventions (Richards & Ramirez, 1997). Previous studies have adopted QOL as an outcome to examine the effect of life review on palliative care patients, as described in Chapter 2. These studies have indicated that QOL is a sensitive indicator of life review (Erlen et al., 2001; Ando et al., 2007a). Given that QOL is able to reflect ego-integrity and is the ultimate goal of palliative care, QOL was selected to evaluate the effect of our life review program on advanced cancer patients.

#### **4.1.2 Conceptual framework of this study**

Based on Erikson's theory, Butler's life review process and the literature, the conceptual framework was developed for guiding this study, as shown in Figure 4.1. The life review program for Chinese patients with advanced cancer comprised reviewing a life and formulating a life review booklet, as described in Chapter 3. During the life review, patients would recall, evaluate, and integrate their life experiences from the present to childhood. The successful integration would help patients to improve their QOL.



**Figure 4.1 Conceptual framework of the study**

## **4.2 Operational definitions**

### ***Quality of life***

Quality of life was used to reflect ego integrity in this study. It was measured by the Single Item Scale (SIS) and the Quality of Life Concerns in the End of Life Questionnaire (QOLC-E). Details of the SIS and the QOLC-E are described in the instruments and measures section in Chapter 5.

## **4.3 Research questions**

This study addressed the following research questions:

Among advanced cancer patients in Fuzhou, China:

1. Will the life review program lead to an increase in QOL immediately after the life review program?
2. Will this effect of the life review program be sustained for three weeks after the program?
3. What are perceptions of the life review program among patients who participated and completed the program?

#### **4.4 Hypotheses**

Null hypotheses for this study are as follows:

Among advanced cancer patients in Fuzhou, China:

1. There is no difference between the control and the experimental groups in QOL after implementation of the life review program.
2. There is no difference within the experimental group in QOL between before the commencement of the program, immediately after the program, and three weeks after the program.
3. There is no difference within the control group in QOL between before the commencement of the program, immediately after the program, and three weeks after the program.

Research hypotheses for this study are as follows:

Among advanced cancer patients in Fuzhou, China:

1. The experimental group has a better QOL than the control group after implementation of the life review program.
2. The experimental group has a better QOL between before the commencement of the program, immediately after the program, and three weeks after the program.
3. The control group has a worse QOL between before the commencement of the program, immediately after the program, and three weeks after the program.

## **CHAPTER 5**

### **METHODOLOGY**

This chapter explains the randomized controlled trial for this study. Details of the sampling method are given; the life review intervention is described; the approaches used to collect and analyze data are presented; and ethical considerations are included.

#### **5.1 Research design**

A randomized controlled trial (RCT) was adopted to examine the effect of the life review program on advanced cancer patients because this approach is considered the scientific standard in clinical research for establishing a cause-and-effect relationship. This study involved the manipulation of an intervention, the randomized assignment of subjects, and a control group. However, this study was neither single-blinded nor double-blinded. The subjects were aware of what intervention they received. The student researcher, acting as the implementer of the intervention and the collector of qualitative data, knew the group assignment and the intervention.

#### **5.2 Study setting**

Subjects were recruited from the Fujian Hospice, which was sponsored by LKS foundation. The hospice had a home-based service department and an outpatient clinic. It only provided services for clients who are suffering from advanced cancer and have a low personal income (less than RMB 300 per month). About 40 new patients are admitted to the hospice every month. All services were free

of charge. The home visit team delivers holistic assessments, health education, medical consultations, and psychosocial support to patients when they are newly admitted to the hospice. Follow-up home visits are available but not regular, and are based on the patients' physical condition. Usually, after the first home visit, families go to the outpatient clinic every week to report the patients' situation and get professional advice, particularly a medical consultation on managing physical symptoms. Patients and their family can also seek general suggestions from the hospice by telephone at office hours. Furthermore, a nurse-led telephone follow-up consultation is provided for each patient once a week, to monitor the individual's physical condition and give emotional support. Generally, the psycho-spiritual support is unplanned and inadequate possibly because health providers lacked the time or ability, and patients did not seek out professional psycho-spiritual care.

### **5.3 Study sample**

#### **5.3.1 Criteria for subjects**

The inclusion criteria for subjects were patients:

- (1) Who were newly admitted to the study hospice;
- (2) Who were diagnosed with advanced cancer by a physician;
- (3) Who knew their diagnosis, prognosis, and therapy;
- (4) Who were adults ( $\geq 18$  years old).

The exclusion criteria for the subjects were patients:

- (1) Who were severely disabled and whose disease would be progressing rapidly (Karnofsky Performance Status, KPS $<40\%$ );

- (2) Who had cognitive impairments (more than two errors in the Short Portable Mental Status Questionnaire, SPMSQ);
- (3) Who had verbal communication impairments.

The reasons for the exclusion criteria are as follows:

- (1) The KPS is to measure palliative care patients' progressive decline in physical condition and exercise tolerance (Karnofsky, Abelmann, Graver & Burchenal, 1948). KPS grades a patient's general condition with an 11-point score system from 0 (death) to 100% (normal). A KPS of less than 40% means that the patient is severely disabled and that his/her disease will be progressing rapidly. According to the clinical experiences of physicians, patients with a KPS of less than 40% were considered too weak to participate in this six-week study.
- (2) To review a life, patients must have normal cognitive functioning for evaluating and integrating their life experiences. Patients with more than two errors in the SPMSQ are considered cognitively impaired, and were therefore excluded from this study.
- (3) Patients must be able to communicate with the facilitator so that the facilitator can guide them to recall memories, reaffirm positive experiences, reconcile negative experiences, and integrate various life experiences.

### **5.3.2 Randomized assignment**

The student researcher used Nquery Advisor 3.0 (Elashoff, 2000), a computer software, to randomly allocate subjects to the experimental and control groups. The Nquery Advisor generated a match of 40 sets of random numbers and 80

case numbers. Each set of random numbers included “1” and “2.” “1” represented “the experimental group”; and “2” represented “the control group.” According to the order of their recruitment, each subject was given a case number by the student researcher. Based on the case number, the matched random number was identified. The subjects with a random number of “1” were assigned to the experimental group, while those with a random number of “2” were assigned to the control group.

## **5.4 Intervention**

In this study, the subjects in the experimental and control groups received home-based palliative care services from the study hospice, as described in section 5.2 (Study setting). The study intervention was a three-week life review program, as described in Chapter 3. It was provided to the subjects in the experimental group. The following describes how the life review program was implemented, including reviewing a life and formulating a life review booklet.

### **5.4.1 Implementation of the life review program**

#### **5.4.1.1 Reviewing a life**

Reviewing a life was carried out individually once a week for three weeks by the student researcher acting as a facilitator at the subjects’ own homes. Before starting the life review a warm-up visit was paid. During this visit, the facilitator gave the subjects full disclosure of the life review program. She also shared the guiding questions for reviewing a life and discussed a calendar of future interviews with the subjects. Through this visit, the facilitator and the subjects



became familiar with each other, which laid the groundwork for the following sessions of the life review.

At the first life review session, the facilitator guided the subjects to reviewing the present, addressing the life themes of cancer, family, belief in heaven, and death. The subjects were asked to talk about their experiences with cancer by the facilitator, who used the guiding questions for reviewing a life. The facilitator listened attentively to their stories with empathy, understanding, and unconditional acceptance. The subjects were encouraged to express their feelings and views on their cancer experiences. Importantly, the subjects were facilitated to find the meaning of the illness and to reconcile themselves to the illness. When picking up the topic of death, the subjects were invited to leave words (e.g., hopes, blessings, advice) for their loved ones. At the end of the session, the facilitator summarized the subjects' experiences with cancer and restated the meaning of the illness, guiding the conversation towards a happy ending.

At the second life review session, the subjects were facilitated to work through their adulthood, involving such life themes as work, sex, family, dealings with people, hardship, and religion. Similar to the first session, the facilitator used the guiding questions for reviewing a life to evoke the subjects' memories and actively listened to their stories. More importantly, the facilitator guided them to evaluate and integrate their life experiences. For positive experiences, the facilitator helped the subjects relive happy moments and affirm their contributions and achievements. For negative experiences, the facilitator patiently assisted the subjects to let them go, accept them, or give new meaning

to them (Haight & Haight 2007). At the end of the session, the facilitator summarized the subjects' life in adulthood and highlighted the glorious aspects of their history.

At the third life review session, the subjects were guided to review their childhood and adolescence, addressing the life themes of school, religion, relationship, grief, fear, food, and labor. Similar to the first two sessions, the subjects were guided by the facilitator to recall, evaluate, and integrate their life experiences in childhood and adolescence. In addition, the facilitator told the subjects that this was the last session and that a finished life review booklet would be sent to them next day.

Of note, although the number of life review sessions was pre-set, flexibility in conducting the life review program was considered to be essential. The duration of each session largely depended on the subjects' willingness to talk and their physical condition.

#### **5.4.1.2 Formulating a life review booklet**

The facilitator compiled the life review booklet based on the three life review interviews. Specifically, at the warm-up visit, the facilitator had a brief discussion with the subjects about the name, the content, and the format of the booklet. She also suggested the subjects to collect their favorite photographs and pictures for making the booklet.

At the end of each life review session, the facilitator invited the subjects to identify the content of that session that would be documented in the booklet. After the completion of each session, the facilitator recorded the information as the subjects had requested, according to the tape-recorded interviews in the booklet. The subjects' favorite photographs and pictures were also pasted in appropriate places in the booklet. At the beginning of the next session, the subjects were invited to check what had been documented and pasted in the booklet. The subjects' suggestions were used to modify the booklet.

On the second day of the final life review session, the facilitator directly gave the subjects the finished life review booklet that documented their significant life experiences, views on life, and words for their loved ones. The subjects were asked to share the booklet with the facilitator and value their entire life again.

#### **5.4.2 Protocol of the life review program**

The protocol of the life review program (Appendix 4.1) was used to guide the facilitator in implementing the program and to assure consistency among the subjects. It was developed by the student researcher based on a review of the literature and on suggestions from experts. The expert panel reviewing the life review program were also invited to validate the protocol. Revisions were made based on their suggestions. The final protocol included the purpose of the program, the content of the program, guidelines for reviewing a life, and guidelines for formulating a life review booklet. The guidelines for reviewing a life involved attentive behavior, stimulating patients to recall memories, facilitating patients to affirm positive experiences and reconcile negative

experiences, managing patients' unpleasant emotions during reviewing a life. The guidelines for formulating the life review booklet included the format of the booklet, suggestions on content, and key points on the making of the booklet.

## **5.5 Instruments and measures**

### **5.5.1 The short portable mental status questionnaire (SPMSQ) (Chinese version)**

The Chinese version of the SPMSQ (Appendix 4.2) was chosen to screen the cognitive functioning of advanced cancer patients in this study. As with the original English version developed by Pfeiffer's (1975), the Chinese version of the SPMSQ is a 10-item simple questionnaire for measuring several intellectual functions, including orientation to surroundings and current events, short and long term memory, and calculation. A summary score is constructed by summing the total number of errors based on ten items. Zero to two errors are considered normal mental functioning; three to four errors mild cognitive impairment; five to seven errors moderate cognitive impairment; and eight or more errors severe cognitive impairment. The Chinese version of the SPMSQ has been demonstrated to have good discriminative power in differentiating the normal elderly from the elderly with depression, paranoid disorder, and dementia (Chi & Boey, 1993). Its Cronbach's alpha was 0.75 (Chou & Chi, 2000) and test-retest reliability was 0.70 to 0.84 (Chi & Boey, 1993; Li, 2005c).

### **5.5.2 Patient information form (PIF)**

A patient information form (Appendix 4.3) was used to collect the subjects' characteristics, including age, gender, education level, marital status, living conditions, family function, family financial status, participation in community

activities, diagnosis of disease, sites of metastasis, months of cancer, previous treatments, KPS, and use of other community health services. These variables were investigated in this study because they contributed to describing the subjects' profile and may also influence effect of the life review program. The items of the PIF, except for family function, were developed by the student researcher and validated by three experts in palliative care. The revisions were made to meet their agreement.

The Chinese version of the family APGAR index was adopted to measure the subjects' family function. As with the original English version proposed by Smilkstein (1978), the Chinese version of the family APGAR index is a self-reported, five-item questionnaire designed to detect dysfunction in family Adaptation, Partnership, Growth, Affection, and Resolve (the acronym APGAR). Each question is scored 2, 1, or 0, corresponding to answers of "almost always," "some of the time," and "hardly ever," respectively. In the score system, 7 to 10 suggests a well-functioning family; 4 to 6 indicates a moderately dysfunctional family; and 0 to 3 represents a severely dysfunctional family. The Chinese version of the family APGAR index had been demonstrated as able to distinguish different family functions, and its test-retest reliability of the whole scale and each component were 0.55 to 0.90 (Lu, Zeng, Liu, Zhong & Zhan, 1999).

### **5.5.3 Quality of life questionnaire**

#### **a. Single Item Scale (SIS)**

The SIS (Appendix 4.4) was used to measure the subjective view of overall QOL of advanced cancer patients in this study. The SIS is a numerical rating scale that

ranges from 0 as very bad to 10 as excellent (Cohen, Hassan, Lapointe & Mount, 1996). Before this present study, 10 Chinese patients with advanced cancer were interviewed twice by the student researcher to establish the test-retest reliability of the SIS. The Intra-class Correlation Coefficient (ICC) of the SIS was 0.73 among Chinese advanced cancer patients.

#### **b. Quality-Of-Life Concerns in the End-of-life Questionnaire (QOLC-E)**

The QOLC-E (Appendix 4.4) was selected to assess the QOL concerns of advanced cancer patients in this study, including physical discomfort, food-related concerns, health care concerns, support, negative emotions, sense of alienation, existential distress, and value of life. The QOLC-E was derived from a Chinese ethnographic study on eliciting primary determinants of QOL among 20 patients with advanced chronic obstructive pulmonary disease and 20 patients with metastatic cancer in their last months (Pang et al., 2004). A thematic analysis yielded 16 positive and 17 negative factors perceived by the patients as important factors. These were described as QOL concerns and compiled as the QOLC-E. Thus, the QOLC-E is culturally appropriate for Chinese patients with advanced cancer.

The QOLC-E is a 28-item multi-dimensional instrument involving eight subscales. The four positive subscales are support, value of life, food-related concerns, and health care concerns; the four negative subscales are physical discomfort, negative emotions, sense of alienation, and existential distress. The score system is an 11-point scale ranging from 0 (the least desirable) to 10 (the

most desirable). The scores of some items phrased negatively need to be reversed. After conversion, a higher score represents greater satisfaction with that facet.

The QOLC-E is a reliable and valid QOL assessment tool in palliative care patients (Pang et al., 2005). The Cronbach's alpha for the eight subscales and total QOLC-E among patients with advanced diseases were: 0.77 for the physical discomfort subscale; 0.57 for the food-related concerns subscale; 0.87 for the negative emotions and sense of alienation subscale; 0.64 for the support subscale; 0.83 for the value of life subscale; 0.79 for the existential distress subscale; 0.64 for the health care concerns subscale; and 0.87 for total QOLC-E. The construct validity of the subscales in the QOLC-E was established through comparing their correlations with the SIS, the Activities of Daily Living, Hospital Anxiety and Depression Scale. The SIS was significantly correlated with the eight subscales and total QOLC-E, with coefficients ranging from 0.27 to 0.60. Self-maintenance activities of daily living and instrumental activities of daily living were moderately correlated with the physical discomfort and food-related concerns subscales ( $r=0.51$  and  $0.46$ ,  $r=0.35$  and  $0.37$ , respectively), but weakly correlated with the other six subscales ( $r=-0.02\sim0.28$ ,  $P\leq0.01$ ). Contrarily, HADS indicated moderate to high correlations with these six subscales ( $r=-0.31\sim-0.63$ ).

The QOLC-E has been applied to patients with advanced diseases and the elderly in Hong Kong (Pang et al., 2005; Chan & Pang, 2007). It has been demonstrated to be a sensitive instrument for measuring changes in QOL concerns resulting from palliative care interventions, such as the "Let me talk advanced care

planning program” involving life stories, illness narratives, life review, and end-of-life care preferences (Chan, 2008).

Before the QOLC-E was used in this present study, its test-retest reliability was measured by the student researcher on 10 advanced cancer patients who met the selection criteria for this study. The patients were interviewed twice to establish the test-retest reliability of the scale. A two-day interval was chosen because this timespan was believed to minimize recall bias and to reduce the burden on patients, while accepting that there was a possibility that the condition of the patients might change during this interval (Lo et al., 2001). The ICC of eight scales and total QOLC-E were 0.76, 0.96, 0.89, 0.75, 0.96, 0.92, 0.87, 0.95, 0.95, and 0.92 respectively, as shown in Table 5.1. The internal consistency of the QOLC-E was calculated based on the baseline QOL data of this present study. The Cronbach’s alpha values for the eight scales and total QOLC-E were 0.58, 0.83, 0.60, 0.71, 0.62, 0.70, 0.72, 0.67 and 0.77 respectively, as shown in Table 5.1.

**Table 5.1 Test-retest reliability and internal consistency of the QOLC-E**

QOLC-E Subscales	Items	Test-retest reliability			Cronbach’s alpha
		ICC	95% CI	P value	
Physical discomfort	4	0.76	0.30~0.94	0.02*	0.58
Food-related concerns	2	0.96	0.84~0.99	0.00**	0.83
Health care concern	4	0.89	0.54~0.97	0.00**	0.60
Support	2	0.75	0.10~0.94	0.03*	0.71
Negative emotions	4	0.96	0.85~0.99	0.00**	0.62
Sense of alienation	3	0.92	0.69~0.98	0.00**	0.70
Existential distress	3	0.87	0.48~0.97	0.00**	0.72
Value of life	6	0.95	0.78~0.99	0.00**	0.67
Total QOLC-E	28	0.92	0.69~0.98	0.00**	0.77

ICC: Intra-class correlation coefficient; CI: Confidence Interval

\*  $p \leq 0.05$ ; \*\* $p \leq 0.01$ .



#### **5.5.4 A semi-structured questionnaire of the patients' perceptions of the life review program**

A semi-structured questionnaire (Appendix 4.5) was developed by the student researcher to guide interviews on the patients' perceptions of participation in the life review program. It consisted of five open-ended questions about their feelings about the program, the benefits of reviewing a life, the benefits of a life review booklet, the most appreciated component of the program, and suggestions for improving the program. The contents of the questionnaire were validated by two experts in palliative care as well as in the use of life review.

#### **5.6 Data collection**

Before the study commenced, ethical approval from the Human Ethics Committee of the Hong Kong Polytechnic University and permission from the Fujian Hospice were obtained. A brief meeting was arranged for the student researcher to introduce the study and explain the criteria for selecting the subjects to the physician, who was responsible for screening subjects for this study.

When patients were newly admitted to the study hospice, the physician screened potential eligible patients based on their medical records and his clinical judgment. He also briefly introduced the study to the patients and asked them whether they were willing to have their contact information given to the student researcher and to be contacted by the student researcher, who would explain to them details of the study. After gaining the patients' permission, the student researcher called them and arranged appointments within two days after being referred by the physician.

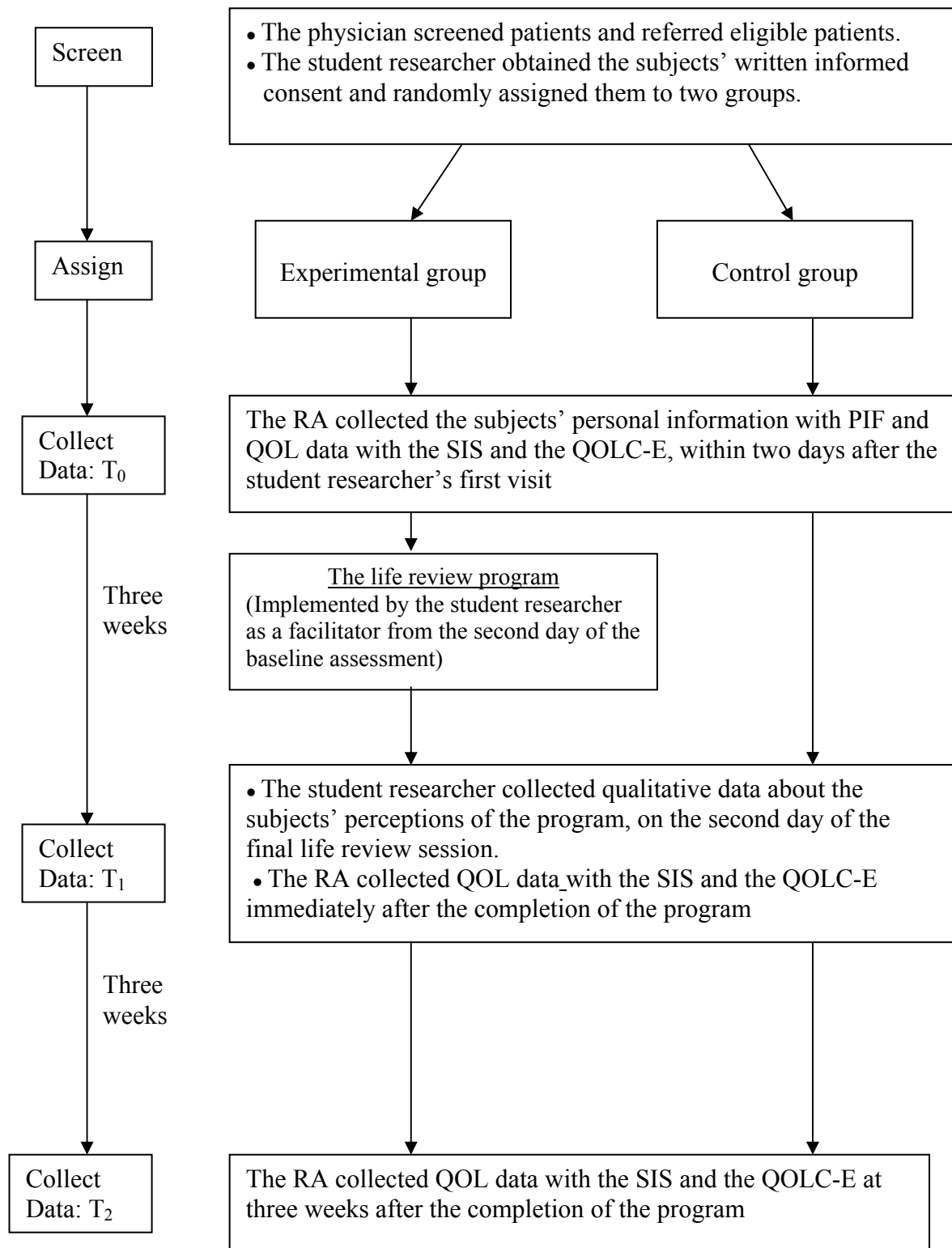
The student researcher visited individual patients in their homes and explained the screening for cognitive functioning and the study. Further to the physician's clinical judgment of the patients' cognitive functioning, the student researcher confirmed it using the SPMSQ. The patients who made less than two errors were invited to participate in the study. After obtaining their informed written consent, the student researcher randomly assigned the patients to the experimental group or the control group, as described in section 5.3.2.

Within two days after the student researcher's visit, the RA visited individual subjects of the experimental and control groups at their homes, and collected baseline QOL data ( $T_0$ ) with the SIS and the QOLC-E, and personal information with PIF. The RA read out each item of the questionnaires for them to respond to, and recorded their answers without making any judgments. The RA also reviewed their medical records in the study hospice, to collect their clinical information.

On the second day after the completion of the baseline assessment, the student researcher acted as a facilitator in conducting the life review program for the experimental group once a week for three weeks. All of the subjects in the experimental and control groups continued to receive the services of the study hospice during the study period. On the second day of the final life review session, the student researcher returned the life review booklets to the subjects in the experimental group. She also invited them to talk about their perceptions of participation in the program. These interviews were conducted in Chinese in a semi-structured format. The participants were first asked a broad question, 'What

do you think about the life review program?', to allow them to freely express their thoughts and feelings about the program. They were then asked four guiding questions designed to elicit their views on what, if anything, they had gained from reviewing their life and formulating the life review booklet, which parts in the program they liked or disliked the most and any suggestion they might have for improving the program. Then, based on their responses, subsequent probing questions were used to clarify points, gain insights and encourage more in-depth discussions. The interviewer collected whatever qualitative data could be collected. The qualitative data were collected until no new information can be gleaned by further data collection. All of the interviews were tape-recorded and transcribed.

Immediately after ( $T_1$ ) and three weeks ( $T_2$ ) after the completion of the program, the RA again collected the QOL data for all of the subjects of the experimental and control groups. Figure 5.1 shows the data collection procedure.



**Figure 5.1 Data collection for this study**

### **5.7 Training of a facilitator**

The student researcher, who had taken courses in Clinical Psychology and Psychology Measurement, was trained as a facilitator to conduct the life review program in this study. The main requirements of the facilitator involved asking probing questions from the guidelines on conducting a life review, then listening attentively and responding appropriately to the reviewers' stories. The skills for responding appropriately consisted of interview techniques and counselling skills, such as encouraging reviewers to talk, showing them unconditional positive regard and empathy, reframing negative experiences, and integrating their entire life experiences (Haight & Haight, 2007).

The training mainly involved three stages. First, the student researcher learned life review knowledge and skills from one symposium and one workshop held by The University of Hong Kong, and from watching tapes about life review interviews. Second, the student researcher was provided an opportunity to put such knowledge and skills into practice. She performed two life review interviews for two elderly people under the supervision of an experienced nurse, who specialized in life review and palliative care. Through listening to the audiotaped interviews, reading the transcript of the interviews, and responding to the life review expert's critical comments, she reflected on how to improve her facilitation skills. Third, the student researcher independently conducted three life review interviews for three volunteer advanced cancer patients from the study hospice to gain practice experience. All of the interviews were tape-recorded and transcribed verbatim. The nurse expert was again invited to criticize the student researcher's life review skills by reading the transcription.

Generally, the student researcher received the training to qualify as a life review facilitator before the study.

### **5.8 Training of a data collector**

Training a data collector prior to initiating fieldwork is required to ensure the quality of the data. Before this study, the student researcher was trained to be familiar with all of the instruments of this study, particularly the QOLC-E. She cleared up issues relating to the QOLC-E with its developer and observed a well-trained investigator use the QOLC-E for collecting QOL data. Then, through a workshop, she trained an RA to collect quantitative data for this study in an accurate and reliable manner. The RA was a register nurse with a Bachelor Degree in Nursing, some experiences in doing research and three-year working experience in care for cancer patients. In the workshop, the student researcher explained the purpose of the study, the procedure of data collection, and the items of the instruments to the RA. The student researcher also taught the RA how to ask questions from the instruments, record answers without any personal bias, and seek help if unexpected problems occur during the collecting of the data. The RA's uncertainties about the data collection procedure and instruments were clarified. A rehearsal by role playing was arranged to provide the RA with practical experience in data collection.

### **5.9 Data analysis**

#### **5.9.1 Quantitative data analysis**

The quantitative data that were collected were analyzed using the Statistical Package for Social Sciences (SPSS) 15.0 for Windows. The statistical tests were set as two-tailed and the level of significance was set at 0.05.

In this study, most of the socio-demographic and clinical variables, including gender, marital status, religion, living status, primary caregiver, participation in community activities, diagnosis of disease, sites of metastasis, previous treatments, and use of other community health services were treated as nominal data. Educational level, family function, and KPS were treated as ordinal data. Age and months with cancer were treated as ratio data. QOL data including overall QOL, physical discomfort, food-related concerns, health care concerns, support, negative emotions, sense of alienation, existential distress, and value of life were treated as interval data.

For interval and ratio data with normal distribution and insignificance on the homogeneity of variance test, parametric statistics were performed. Otherwise, nonparametric tests were applied. The following descriptive and inferential statistics were used in this study:

- (1) Frequency and percentage were used to describe the baseline socio-demographic and clinical data, except for age and months with cancer, which were described by mean and standard deviation.
- (2) Mean and standard deviation were used to describe QOL, including overall QOL, physical discomfort, food-related concerns, health care concerns, support, negative emotions, sense of alienation, existential distress, and value of life at  $T_0$ ,  $T_1$ , and  $T_2$ .
- (3) The Chi-square test was used to examine the equivalence in socio-demographic and clinical data at  $T_0$  between the experimental and control groups, except for age and months with cancer, which were compared using an independent sample t-test.

- (4) The independent sample t-test was used to examine the equivalence in QOL, including overall QOL, physical discomfort, food-related concerns, health care concerns, support, negative emotions, sense of alienation, existential distress, and value of life between the experimental and control groups.
- (5) The Chi-square test was used to examine the equivalence in socio-demographic and clinical data at T<sub>0</sub> between those who had completed the study and those had not, except for age and months with cancer, which were compared by the independent sample t-test.
- (6) The repeated measures ANOVA was used to evaluate the effect of the life review program on QOL, including overall QOL, physical discomfort, food-related concerns, health care concerns, support, negative emotions, sense of alienation, existential distress, and value of life between the experimental and control groups over time, including the between-group effect (intervention), within-group effect (time), and the interaction effect (time X group). In this analysis, when Mauchly's test of sphericity was met, the univariate test was applied; otherwise, an adjusted test, Greenhouse-Geisser with the Epsilon correction, was used (Munro, 2005).
- (7) A Post-hoc Pairwise Multiple Comparison with a Bonferroni adjustment ( $p < 0.025$  is considered significant) was used to examine the differences in QOL, including overall QOL, physical discomfort, food-related concerns, health care concerns, negative emotions, and value of life within the experimental group between T<sub>0</sub> and T<sub>1</sub>, T<sub>0</sub> and T<sub>2</sub>, and T<sub>1</sub> and T<sub>2</sub>.
- (8) A Post-hoc Pairwise Multiple Comparison with a Bonferroni adjustment ( $p < 0.025$  is considered significant) was used to examine the differences in QOL, including overall QOL, physical discomfort, food-related concerns,



- (9) The Independent Sample t-test was used to examine the differences in QOL, including overall QOL, support, negative emotions, sense of alienation, and value of life between the experimental and control groups at T<sub>0</sub>, T<sub>1</sub>, and T<sub>2</sub>.
- (10) The Mann-Whitney U test was used to examine the differences in existential distress between the experimental and control groups at T<sub>0</sub>, T<sub>1</sub>, and T<sub>2</sub>.

### **5.9.2 Qualitative data analysis**

A qualitative content analysis (Graneheim & Lundman, 2004) was employed to analyze the qualitative data collected from the semi-structured interviews. Based on the changes in overall QOL before and after the life review program, the participants were categorized into three groups for the analysis, including the improved group, unchanged group and decreased group. The student researcher and her chief supervisor separately analyzed the qualitative data. They read the transcribed interviews multiple times to obtain a sense of the whole. The various parts of the text about the subjects' perceptions were extracted and brought together into one text, which constituted the unit of analysis. Then, the text was divided into meaning units and condensed. The condensed meaning units were abstracted and labelled with a code. The codes were compared based on differences and similarities, and sorted into sub-categories and categories. A process of reflection and discussion between the student researcher and her supervisor was used to resolve discrepancies. The two co-supervisors were invited to do a member check after the data had been collected and fully

analyzed. An external reviewer conducted the inquiry audit for the qualitative data. The student researcher translated the meaning units, sub-categories, and categories into English. A local translator fluent in English and Chinese validated the student researcher's translation.

#### **5.10 Ethical considerations**

Before starting the study, ethical approval was obtained from the Human Subjects Ethics Sub-Committee (HSESC) of the Hong Kong Polytechnic University, and permission to conduct the study was obtained from the Fujian Hospice. The participants were provided with detailed information about the study, including the program, several data collection methods, a review of their medical records, and an explanation of the ethical issues involved (Appendix I). They were informed that they had the right to withdraw from the study or to refuse to participate in the study at any time without any penalty. They were assured that the services they were receiving from the study hospice would not be affected regardless of their participation. Written consent (Appendix II) was obtained from them before the study commenced. Since a life review may cause the participants to feel unpleasant emotions, the facilitator was aware of the need to be sensitive to their emotions. If they showed any unpleasant emotions during a review of their life, the facilitator dealt with this by following the guidelines for managing the unpleasant emotions of patients (Appendix 4.1).

The confidentiality of the subjects was ensured by several strategies. First, all questionnaires and qualitative data were coded without recording the names of the participants. Second, all completed questionnaires and tapes of the interviews

were kept in a secure place. Moreover, they were stored separately from personal identification sheets and written consent forms. Only the research team was allowed access to these documents. Finally, breaches of confidentiality were minimized when writing the report. Specific information that could be used to trace the subjects' personal identity was removed from the report.

### **5.11 Summary**

This chapter elaborated on the research design, study sample, study setting, intervention, data collection, data analysis, and ethical considerations of this study. The training of the data collector and the implementer of the life reviews were also introduced.

## **CHAPTER 6**

### **THE PILOT STUDY**

This chapter reports the pilot study, including its aims, procedure, results, and implications for the main study.

#### **6.1 Aims**

The pilot study served the following objectives.

1. To test the feasibility of the data collection procedure.
2. To test the feasibility of the developed life review program in Chinese patients with advanced cancer.
3. To estimate the sample size for the main study.

#### **6.2 Procedures**

A pilot study was carried out from February to April 2009, prior to the main study. The criteria for the subjects, the data collection procedure, the life review program, the facilitator, and the protocol of the life review program in the pilot study were the same as those in the main study.

Due to the small sample size, descriptive statistics were used to analyze the results of the pilot study. To estimate the sample size for the main study, the effect of the life review program on overall QOL was calculated, including the within-group effect (time), between-group effect (group), and interaction effect (time  $\times$  group). However, the statistical analysis could not be considered as having any relationship to the outcomes of the main study.

### **6.3 Results**

Ten patients were recruited in the pilot study. Five patients were allocated to the experimental group and five to the control group. In the experimental group, two participants dropped out after the first follow-up assessment ( $T_1$ ) because of loss of contact and death, respectively. In the control group, one participant dropped out after  $T_1$  due to death.

#### **6.3.1 Characteristics of the participants**

The participants' socio-demographic and clinical characteristics are shown in Table 6.1 and Table 6.2. Among the ten participants, four were male and six were female. The mean age was 55 years (Standard Deviation [SD] =10.42). Most were married, had received a primary or secondary school education, believed in a religion, lived with their family, and had a primary family caregiver. The majority did not have a sufficient family income, participate in community activities, or use other community health services. Half of them suffered from gastro-intestinal cancers or respiratory cancers. The mean number of months with cancer was 45 (SD=58.60). All of them had a metastasis. All of the participants had received at least one type of cancer treatment, either surgery, chemotherapy, radiotherapy, or Chinese traditional medicine, before being admitted to the study hospice. Their KPS ranged from 40% to 60%.

**Table 6.1 Socio-demographic characteristics of the participants**

<b>Variable</b>	<b>Total (n=10)</b>	<b>Control (n= 5)</b>	<b>Experimental (n=5)</b>
<b>Age (years)</b>			
Mean $\pm$ SD	55.00 $\pm$ 10.42	58.40 $\pm$ 11.70	51.62 $\pm$ 8.91
<b>Gender</b>			
Male	4	2	2
Female	6	3	3
<b>Educational level</b>			
No formal education	3	2	1
Primary School	3	2	1
Secondary School	4	1	3
<b>Marital status</b>			
Married	8	3	5
Widow	2	2	0
<b>Religion</b>			
Yes	7	3	4
No	3	2	1
<b>Living status</b>			
Live with family	10	5	5
Live alone	0	0	0
<b>Primary caregiver</b>			
Parents	1	1	0
Spouse	6	3	3
Children	2	0	2
Others	1	1	0
<b>Family function</b>			
No dysfunction	5	3	2
Moderate dysfunction	4	2	2
Severe dysfunction	1	0	1
<b>Family financial status</b>			
More than sufficient	1	0	1
Barely sufficient	2	2	0
Insufficient	1	0	1
Very insufficient	6	3	3
<b>Participation in community activities</b>			
Yes	0	0	0
No	10	5	5

**Table 6.2 Clinical characteristics of the participants**

<b>Variable</b>	<b>Total (n=10)</b>	<b>Control (n=5)</b>	<b>Experimental (n=5)</b>
<b>Months with cancer</b>			
Mean $\pm$ SD	45.00 $\pm$ 58.60	49.80 $\pm$ 68.20	40.20 $\pm$ 54.90
<b>Diagnosis</b>			
Gastro-intestinal cancer	3	1	2
Respiratory cancer	2	1	1
Gynecological cancer	1	1	0
Others	4	2	2
<b>Metastasis</b>			
Multiple sites	3	2	1
Bone	4	3	1
Internal organ	2	0	2
Lymph	1	0	1
<b>Types of previous treatments</b>			
One	8	5	3
Two	2	0	2
<b>KPS</b>			
40%	3	1	2
50%	5	3	2
60%	2	1	1
<b>Use of other community health services</b>			
Yes	2	0	2
No	8	5	3

### 6.3.2 Participants' perceptions of the life review program

Five patients in the experimental group participated in semi-structured interviews on perceptions of the life review program. None of them mentioned experiencing any negative effects from the program. In contrast, they gave a positive appraisal of the program. They considered the program to be useful in helping them to identify and appreciate their contributions and achievements. For example, Case A said, *“Through looking back on my life, I better understand my own life. I am glad to find that I did something meaningful for my family and society. I worked*

*hard to support my family so that they had a happy life. And, my work was often appreciated by colleagues and my boss.”*

Some participants stated that reviewing a life offered them an opportunity to get out of their mind and release themselves from terrible experiences. For example, Case D said, *“My son has suffered from obsessive-compulsive disorder for many years. I was tortured by his situation. But I felt too ashamed to share it with others. This program prompted me to talk about it. After revealing this terrible secret, I felt relieved.”*

In addition, the participants appreciated the life review booklets because, through the booklet, their families could learn experiences and lessons from them. Generally, all of the participants were satisfied with the life review program and had no further suggestions for refining the program.

### **6.3.3 Estimation of the sample size of the main study**

In a two-way analysis of variance, the effect size can be calculated based on both the main effects and the interaction effects (Portney & Watkins, 2000). The main effects included the effect of the life review program on overall QOL between the experimental and control groups (between-group effect) and the effect of the program on overall QOL over time (within-group effect). The interaction effects were the effect of the program between the experimental and control groups across three time points (group  $\times$  time). According to the equation of the effect size for the main effect (effect size =  $\sqrt{SSm / SSe}$  ; SSm: sum of square in the main effect; SSe: Sum of square in error) (Portney & Watkins, 2000), the effect



size was 0.38 for the within-group effect and 0.87 for the between-group effect. According to the equation of the effect size for the interaction effect (effect size =  $\sqrt{SS_I / SSe}$  ;  $SS_I$ : sum of square in the interaction effect;  $SSe$ : Sum of square in error), the effect size was 0.60. Table 6.3 shows the effect size of the life review program on overall QOL. It is usually more prudent to overestimate an effect size, so that a large enough sample can be recruited. Therefore, 0.38 was conceived as the expected effect size for the main study. According to the table of power of the F-test in the analysis of variance (Portney & Watkins, 2000) for  $\alpha$  0.05, df 1, power 80%, and effect size 0.38, 30 subjects for each group were needed. Taking into consideration a 30% withdrawal rate, the total sample size of the main study was 78.

**Table 6.3 The effect size of the life review program on overall QOL**

	df	Sum of Squares	Effect size
Within-group effect (Time)	2	4.44	0.38
Between-group effect (Group)	2	22.68	0.87
Interaction effect (Time X group)	2	11.01	0.60
Error	16	30.24	

**df:** degrees of freedom

## **6.4 Implications for the main study**

### **6.4.1 Feasibility of the data collection procedures**

The pilot study indicated that the instruments and measures for the main study were understandable and not offensive to advanced cancer patients. The RA was able to collect the data according to the data collection procedure. The student researcher, as the collector of the qualitative data, also successfully conducted the qualitative interviews. In addition, the procedures for screening the subjects,

randomly assigning them into groups, and implementing the intervention were smooth and effective. Thus, the pilot study confirmed the feasibility of the data collection procedure and no modification was adopted in the main study.

#### **6.4.2 Feasibility of the life review program**

The life review program was performed smoothly. Most patients were able to review a life once a week for three weeks under the guidance of the facilitator, except that one patient needed an additional session because sudden severe pain interrupted his life review interview. This finding confirmed that, as planned in this study, the pre-set life review sessions should be flexible, based on the patients' physical condition. The patients' perceptions of the program also provided evidence that the program is acceptable and feasible among Chinese patients with advanced cancer.

One significant observation was that some patients were humble about valuing their positive experiences. This may be due to the fact that, in Chinese culture, talking about one's achievements or strengths is considered boastful (Chong, 2000). Similar to the report of Holm, Lepp, and Ringsberg (2004), patients seldom shared negative experiences. This may be due to the constraint among Chinese people of saving face. It may also be the case that the patients did not adequately trust the facilitator. However, for a life review to be effective, patients should be encouraged to share their life experiences, whether positive or negative. Therefore, in the main study, the facilitator should pay more attention to developing a good rapport with patients and helping them to identify and appreciate positive experiences, as well as reveal negative experiences and reconcile themselves to them.

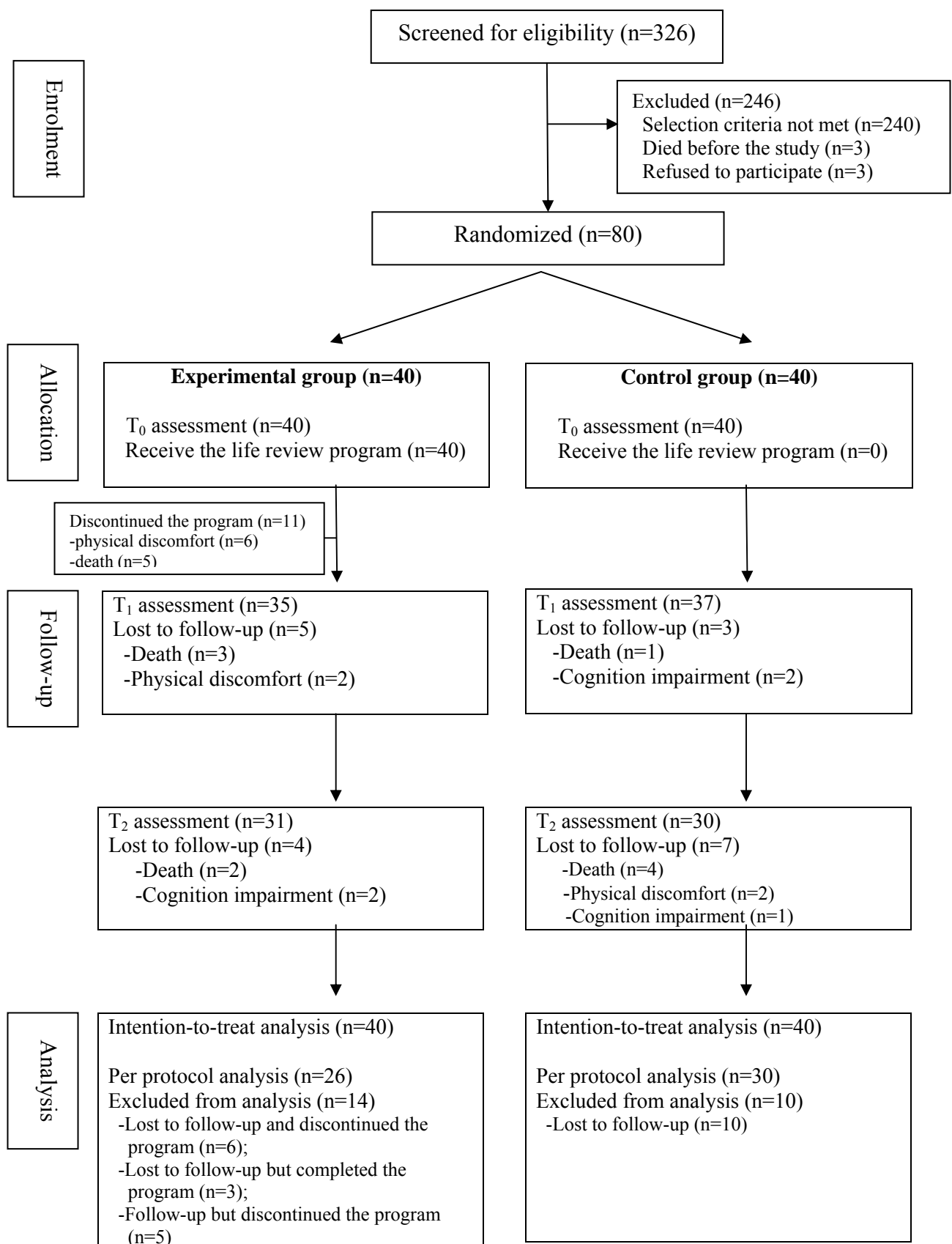
## **CHAPTER 7**

### **QUANTITATIVE RESULTS**

This chapter presents the results of the quantitative data. The first section reports the results from the intention-to-treat analysis, including the characteristics of the participants and the effects of the life review program. The second section reports those findings from the per-protocol analysis. Finally, a comparison of the results from these two analyses is described.

#### **7.1 Recruitment of subjects**

During April 2009 to January 2010, 326 patients were screened for the study. 246 were excluded from this study, as 240 of them did not meet the selection criteria, three died before the commencement of the study, and another three refused to participate in the study. Most of the 240 patients did not meet the criteria, “knowing their diagnosis, prognosis, and therapy” and/or “their functional performance less than KPS 40%”. In the end, 80 subjects participated in this study. They were randomly assigned to the experimental and control groups, with 40 subjects in each group. All of the subjects in the two groups finished the  $T_0$  assessment. In the experimental group, 29 subjects completed the life review program, 35 finished the  $T_1$  assessment, and 31 finished the  $T_2$  assessment, with a total of 26 subjects completing the life review program,  $T_1$  assessment, and  $T_2$  assessment. In the control group, 37 subjects finished the  $T_1$  assessment and 30 subjects finished the  $T_2$  assessment, with a total of 30 subjects in the control group completing the study. The reasons why those in the two groups did not complete the study included physical discomfort ( $n=9$ ), cognitive impairment ( $n=3$ ), and death ( $n=12$ ). Figure 7.1 shows the details of the subjects’ trial profile.



**Figure 7.1 Flow diagram of a trial of the life review program in patients with advanced cancer in Fuzhou, China**

## **7.2 Data entry and cleaning**

The student researcher established the database and entered the data that had been collected. To clean the data, frequency counts were conducted for the nominal and ordinal variables; and means, minimums, and maximums were run to check for interval and ratio variables. The identified errors were revised based on the raw data. To verify the accuracy of the data, the student researcher randomly selected 30% of the entered data and checked each individual variable value (field). An error rate of less than 0.5% errors was found.

## **7.3 Data analysis strategies**

The data collected were analyzed according to the intention to treat (ITT) principle. An ITT analysis includes all subjects in the groups for comparison, as they were originally randomized regardless of their compliance with the entry criteria, the treatment they subsequently received, and withdrawal from the study (Fisher *et al.*, 1990). An ITT analysis can preserve the strengths of randomization, closely capture what happens in real life, and provide practical information on the administration of a treatment. However, an ITT analysis dilutes the efficacy of the treatment (Sheiner & Rubin, 1995).

By contrast, a per protocol (PP) analysis excludes subjects who were not fully compliant with the study protocol and only focuses on fully compliant subjects. A PP analysis aims to detect the maximum potential effectiveness of a treatment. However, a PP analysis can lead to a biased comparison if the reasons for non-compliance are associated with the effectiveness of the treatment (Wang & Bakhai, 2006).

Considering the strengths and limitations of these two approaches, both were used to gain insights on the results of this study. While the main conclusions were drawn from the ITT analysis, supplemental results were shown by the PP analysis (Wang & Bakhai, 2006).

## 7.4 Missing data management

### 7.4.1 Percentages of missing data

In the ITT sample, the total number of data fields was equal to the number of subjects times the total number of variables: 80 (cases) x 22 (variables) =1,760 (data fields). The percentage of missing data was 0.06% in the socio-demographic variables, 1.65% in the SIS, and 1.97% in the QOLC-E. Generally, 3.30 % of the data in this dataset was missing (Table 7.1).

**Table 7.1 Missing data in the ITT sample**

Category	Missing items	Missing No of data fields in total	Percentage of missing data
Socio-demographics	Family financial status: 1	1/1760	0.06
SIS	T <sub>0</sub> SIS: 1 T <sub>1</sub> SIS: 8 T <sub>2</sub> SIS: 20	29/1760	1.65
QOLC-E	T <sub>0</sub> QOLC-E: 1 T <sub>1</sub> QOLC-E: 8 T <sub>2</sub> QOLC-E: 19	28/1760	1.59
Total		58/1760	3.30

Note: total number of data fields: 80 cases X 22 variables=1,760.

In the PP sample, the total number of data fields was 56 (cases) times 22 (variables), which was 1,232 data fields. The missing data for socio-demographic variables was 0.08%, that for the SIS was 0.16%, and that for the QOLC-E was 0.08%. The total percentage of missing data was 0.32% (Table 7.2).

**Table 7.2 Missing data in the PP sample**

Category	Missing items	Missing No. of data fields in total	Percentage of missing data
Socio-demographics	Family financial status: 1	1/1232	0.08
SIS	T <sub>0</sub> SIS: 1 T <sub>2</sub> SIS: 1	2/1232	0.16
QOLC-E	T <sub>0</sub> QOLC-E: 1	1/1232	0.08
Total		4/1232	0.32

Note: total number of data fields: 56 cases X 22 variables=1232.

#### **7.4.2 Management of missing data**

It is usually inevitable to have missing values on some variables for some subjects regardless of the vigilance of the data collector (Polit & Beck, 2004). The exclusion of the missing data may lead to bias in the clinical trial analysis. Since the total percentage of the missing data in this study was less than 5%, one approach to dealing with the possibility of bias was to assign a value to replace the missing data (Tabahnick, 2001). The missing data were replaced by a value produced by the SPSS 15.0 procedure, the mean value of the variables of the respective group for continuous variables, and the median of the variables of the respective group for nominal and ordinal variables.

#### **7.5 Power analysis**

A power analysis here was used to verify the likelihood of rejecting the null hypothesis. In a two-way analysis of variance, power can be determined for the main effects and interaction effects. In this study, the main effects included the effect of the life review program between the experimental and control groups (between-group effect) and the effect of the program over time (within-group effect); the interaction effect was the effect of the program between the

experimental and control groups across three time points (group  $\times$  time). Based on the repeated measures analysis of this study (which will be discussed below), the powers for those significant main effects and the interaction effect on overall QOL and QOL concerns ranged from 0.58 to 1.00 (Table 7.3). Except for health care concerns with a power of 0.58, the powers for QOL were all more than 0.80, which is generally viewed as an adequate level.

**Table 7.3 Powers for the within-group, between-group, and interaction effects of the life review program on QOL**

QOL	Power for within-group effect (time)	Power for between-group effect (group)	Power for interaction effect (group $\times$ time)
Overall QOL	1.00**	1.00**	1.00**
Physical discomfort	1.00**	0.13	0.32
Food-related concerns	1.00**	0.50	0.09
Health care concerns	0.85*	0.58*	0.28
Support	0.52	0.37	0.87**
Negative emotions	0.98**	0.83**	1.00**
Sense of alienation	0.16	0.85**	0.96**
Existential distress	1.00**	0.99**	0.96**
Value of life	0.97**	1.00**	1.00**

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ .

## 7.6 The intention-to-treat analysis

### 7.6.1 Characteristics of the participants in the ITT sample

Table 7.4 shows the socio-demographic characteristics of the participants. Among the 80 participants, 44 were female and 36 were male. The mean age was 59.2 years (SD=11.5), ranging from 39 to 84 years. Most of the participants had received either a primary school education (40.0%) or secondary school education (53.8%). A religious affiliation was professed by 73.5%. Those with spouses made up 72.5% of the sample, and those without spouses including the



divorced and the widowed, made up 27.5%. The overwhelming majority, 93.8%, lived with their family. The majority rated their spouse (51.3%) or children (35.0%) as their primary caregiver. A well-functioning family was reported by 56.3%. The family finances of most of the participants were either insufficient (48.8%) or very insufficient (42.5%). The majority did not participate in community activities.

Table 7.5 shows the clinical characteristics of the participants. Half of the participants suffered from gastro-intestinal cancer. Twenty percent had multiple metastases; 33.8% had a metastasis in the bone; 31.3% had a metastasis in an internal organ including the liver, lung, pancreas, and kidney; 15% had a metastasis in the lymph. The mean number of months with cancer was 20.8 (SD=18.5), ranging from 1 to 86 months. The majority had previously received one or two types of treatment, including surgery, chemotherapy, radiotherapy, and/or Chinese traditional medicine. The KPS of most of the participants was 40% or 50%. The majority did not receive other community health services.

**Table 7.4 Socio-demographic characteristics of the ITT sample**

<b>Variable</b>	<b>Total (n=80) n (%)</b>	<b>Control (n= 40) n (%)</b>	<b>Experimental (n=40) n (%)</b>	<b>t</b>	<b><math>\chi^2</math></b>	<b>p-value</b>
<b>Age (years)</b>				0.484		0.630 <sup>a</sup>
Mean $\pm$ SD	59.15 $\pm$ 11.50	59.78 $\pm$ 11.31	58.5 3 $\pm$ 11.80			
<b>Gender</b>					0.201	0.654 <sup>b</sup>
Male	44 (55.0)	22 (55.0)	20 (50.0)			
Female	36 (45.0)	18 (45.0)	20 (50.0)			
<b>Educational level</b>					5.457	0.140 <sup>b</sup>
No formal education	3 (3.8)	3 (7.5)	0 (0)			
Primary school	32 (40.0)	15 (37.5)	17 (42.5)			
Secondary school	43(53.8)	11(52.5)	22 (55.0)			
Tertiary education	2 (2.5)	1 (2.5)	1 (2.5)			
<b>Marital status</b>					0.251 <sup>1</sup>	0.617 <sup>b</sup>
With spouse	58 (72.5)	30 (75.0)	28 (70.0)			
Without spouse	12 (27.5)	10 (25.0)	12 (30.0)			
<b>Religion</b>					0.251	0.617 <sup>b</sup>
Yes	58(72.5)	28(70.0)	30(75.0)			
No	22 (27.5)	12 (30.0)	10 (25.0)			
<b>Living status</b>					1.920	0.359 <sup>c</sup>
Live with family	75 (93.8)	39 (97.5)	36 (90.0)			
Live alone	5 (6.3)	1 (2.5)	4 (10.0)			
<b>Primary caregiver</b>					2.396	0.494 <sup>b</sup>
Parents	6 (7.5)	3 (7.5)	3 (7.5)			
Spouse	41 (51.3)	20 (50.0)	21 (52.5)			
Children	28 (35.0)	16 (40.0)	12 (30.0)			
Others	5 (6.4)	1 (2.5)	4 (10.0)			
<b>Family function</b>					0.222	0.895 <sup>b</sup>
No dysfunction	45 (56.3)	23 (57.5)	22 (55.0)			
Moderate dysfunction	30 (37.5)	15 (37.5)	15 (37.5)			
Severe dysfunction	5 (6.3)	2 (5.0)	3 (7.5)			
<b>Family financial status</b>					0.844	0.656 <sup>b</sup>
Barely sufficient	7 (8.8)	3 (7.5)	4 (10.0)			
Insufficient	39 (48.8)	18 (45.0)	21 (52.5)			
Very insufficient	34 (42.5)	19 (47.5)	15 (37.5)			
<b>Participation in community activities</b>					0.346	1.000 <sup>c</sup>
Yes	3 (3.8)	1 (2.5)	2 (5.0)			
No	77 (96.3)	39 (97.5)	38 (95.0)			

a. Independent Sample t-test

b. Chi-Square Test

c. Fisher's Exact Test

**Table 7.5 Clinical characteristics of the ITT sample**

Variable	Total (n=80) n (%)	Control (n=40) n (%)	Experimental (n=40) n (%)	t	$\chi^2$	p-value
<b>Months with cancer</b>				-0.560		0.577 <sup>a</sup>
Mean $\pm$ SD	20.84 $\pm$ 18.50	19.68 $\pm$ 17.14	22.00 $\pm$ 19.91			
<b>Diagnosis</b>					1.125	0.771 <sup>b</sup>
Gastro-intestinal cancer	40 (50.0)	22(55.0)	18(45.0)			
Respiratory cancer	23 (28.8)	10(25.0)	13(32.5)			
Gynecological cancer	14(17.5)	7(17.5)	7(17.5)			
Others	3(3.8)	1(2.5)	2(5.0)			
<b>Site of metastasis</b>					0.410	0.938 <sup>b</sup>
Multiple sites	16 (20.0)	8 (20.0)	8 (20.0)			
Bone	27 (33.8)	13 (32.5)	14 (35.0)			
Internal organ	25(31.3)	12(30.0)	13(32.5)			
Lymph	12 (15.0)	7 (17.5)	5 (12.5)			
<b>Types of previous treatments</b>					0.658	0.720 <sup>b</sup>
One	45(56.3)	24(60.0)	21(52.5)			
Two	32(40.0)	15(37.5)	17(42.5)			
Three	3(3.8)	1(2.5)	2(5.0)			
<b>KPS</b>					0.892	0.640 <sup>b</sup>
40%	34 (42.5)	19 (47.5)	15 (37.5)			
50%	38 (47.5)	17 (42.5)	21 (52.5)			
60%	8 (10.0)	4 (10.0)	4 (10.0)			
<b>Use of other community health services</b>					0.721	0.675 <sup>c</sup>
Yes	6 (7.5)	4 (10.0)	2 (5.0)			
No	74 (92.5)	36 (90.0)	38 (95.0)			

a. Independent Sample t-test

b. Chi-Square Test

c. Fisher's Exact Test

### 7.6.2 Equivalence between the control and experimental groups in the ITT sample at the baseline assessment

Table 7.4 and Table 7.5 also compare the baseline differences between the experimental and control groups in socio-demographic and clinical characteristics using the independent t test and Chi-Square Test. The two groups were similar in the distribution of socio-demographic characteristics, including age, gender, educational level, marital status, religion, living status, primary caregiver, family finance, family function, and participation in community

activities. There were also no significant differences in clinical characteristics between the two groups in terms of the diagnosis of the disease, sites of metastasis, months with cancer, previous treatments, KPS, and the use of other community health services.

Table 7.6 shows the mean scores for QOL at the baseline assessment. Among the QOL measurements, advanced cancer patients attained the lowest scores in the food-related concerns subscale and the value of life subscale. There were no significant differences in overall QOL, physical discomfort, food-related concerns, health care concerns, support, negative emotions, sense of alienation, existential distress, and value of life between the experimental and control groups.

**Table 7.6 Mean scores for QOL at the baseline assessment in the ITT sample**

<b>QOL</b>	<b>Total (n=80) Mean ± SD</b>	<b>Control (n= 40) Mean ± SD</b>	<b>Experimental (n=40) Mean ± SD</b>	<b><i>t</i></b>	<b><i>p-value</i></b>
Overall QOL	4.96 ±1.10	5.15 ±1.12	4.83 ± 0.81	1.501	0.137
Physical discomfort	6.41 ± 1.15	6.16 ± 1.16	6.66 ± 1.09	-1.988	0.050
Food-related concerns	3.36 ± 2.10	3.03 ± 2.03	3.70 ± 2.14	-1.447	0.152
Health care concerns	7.74 ± 0.78	7.65 ± 0.68	7.83 ± 0.88	-1.033	0.305
Support	7.06 ± 1.28	7.15 ± 1.34	6.96 ± 1.22	0.654	0.515
Negative emotions	7.33 ± 1.40	7.43 ± 1.30	7.25 ± 1.50	0.556	0.580
Sense of alienation	6.87 ± 1.48	6.90 ± 1.45	6.84 ± 1.54	0.175	0.862
Existential distress	7.94 ± 2.15	7.98 ± 2.02	7.90 ± 2.29	0.162	0.872
Value of life	4.91 ± 1.00	5.08 ± 1.04	4.74 ± 0.95	1.537	0.128

### **7.6.3 Equivalence between the participants who had completed the study and those who had not at the baseline assessment**

As shown in Table 7.7, within the control group there were no significant differences in socio-demographic and clinical characteristics, with the exception of gender ( $\chi^2=6.599$ ,  $p=0.010$ ), between the participants who had completed the study and those who had not. There were no significant differences in the mean scores for QOL between the participants who had completed the study and those who had not.

As shown in Table 7.8, within the experimental group, there were no significant differences in socio-demographic and clinical characteristics between the participants who had completed the study and those who had not. There were no significant differences in the mean scores for QOL, with the exception of overall QOL ( $\chi^2=2.397$ ,  $p=0.022$ ) and health care concerns ( $\chi^2=2.582$ ,  $p=0.014$ ), between the participants who had completed the study and those who had not.

As shown in Table 7.9, in the ITT sample, there were no significant differences in socio-demographic and clinical characteristics, and QOL in terms of overall QOL, physical discomfort, food-related concerns, health care concerns, support, negative emotions, sense of alienation, existential distress, and value of life between the participants who had completed the study and those who had not.

**Table 7.7 Comparison between the participants who had completed the study and those who had not at the baseline assessment within the control group**

Variable	Completed (n=30) n (%)	Withdrew (n=10) n (%)	<i>t</i>	$\chi^2$	<i>p-value</i>
<b>Age (years)</b>			1.143		0.260 <sup>b</sup>
Mean ± SD	58.60 ± 10.55	63.30 ± 13.3			
<b>Gender</b>				6.599	0.010 <sup>a**</sup>
Male	13 (43.3)	9(90.0)			
Female	17 (56.7)	1(10.0)			
<b>Educational level</b>				1.905	0.592 <sup>a</sup>
No formal education	3 (10.0)	0(0.0)			
Primary school	10 (33.3)	5(50.0)			
Secondary school	16(43.3)	5(50.0)			
Tertiary education	1(13.3)	0(10.0)			
<b>Marital status</b>				0.178	0.673 <sup>a</sup>
With spouse	23 (76.7)	7(70.0)			
Without spouse	7(10.0)	3(30.0)			
<b>Religion</b>				0.635	0.426 <sup>a</sup>
Yes	20 (66.7)	8(80.0)			
No	10 (33.3)	2(20.0)			
<b>Living status</b>				0.342	1.000 <sup>c</sup>
Live with family	29 (96.7)	10(100.0)			
Live alone	1 (3.3)	0(0.0)			
<b>Primary caregiver</b>				0.444	0.931 <sup>a</sup>
Parents	2 (6.7)	1(10.0)			
Spouse	15 (50.0)	5(50.0)			
Children	12 (40.0)	4(40.0)			
Others	1 (3.3)	0(0.0)			
<b>Family function</b>				1.932	0.381 <sup>a</sup>
Not dysfunctional	19 (63.3)	4(40.0)			
Moderately dysfunctional	10 (33.3)	5(50.0)			
Severely dysfunctional	1 (3.3)	1(10.0)			
<b>Family financial status</b>				0.343	0.842 <sup>a</sup>
Barely sufficient	2 (6.7)	1(10.0)			
Insufficient	13 (43.3)	5(50.0)			
Very insufficient	15 (50.0)	4(40.0)			
<b>Participation in community activities</b>				0.342	1.000 <sup>c</sup>
Yes	1 (3.3)	0(0.0)			
No	29 (96.7)	10(100.0)			

\*\*  $p \leq 0.01$

a. Chi-Square Test

b. Independent Sample t-test

c. Fisher's Exact Test

**Cont. Table 7.7 Comparison between the participants who had completed the study and those who had not at the baseline assessment within the control group**

<b>Variable</b>	<b>Completed (n=30) n (%)</b>	<b>Withdrew (n=10) n (%)</b>	<b><i>t</i></b>	<b><math>\chi^2</math></b>	<b><i>p-value</i></b>
<b>Months with disease</b>			-0.522		0.604 <sup>b</sup>
Mean $\pm$ SD	20.50 $\pm$ 18.59	17.20 $\pm$ 12.28			
<b>Diagnosis</b>				6.061	0.109 <sup>a</sup>
Gastro-intestinal cancer	17 (56.7)	5(50.0)			
Respiratory cancer	5 (16.7)	5(50.0)			
Gynecological cancer	7 (23.3)	0(0.0)			
Others	1 (3.3)	0(0.0)			
<b>Site of metastasis</b>				1.121	0.772 <sup>a</sup>
Multiple sites	5 (16.7)	3(30.0)			
Bone	10 (33.3)	3(30.0)			
Internal organ	9 (16.1)	3(30.0)			
Lymph	6 (20.0)	1(10.0)			
<b>Types of previous treatments</b>				0.756	0.685 <sup>a</sup>
One	17 (56.7)	7(70.0)			
Two	12 (40.0)	3(30.0)			
Three	1 (3.3)	0(0.0)			
<b>KPS</b>				3.009	0.222 <sup>a</sup>
40%	12 (40.0)	7(70.0)			
50%	15 (50.0)	2(20.0)			
60%	3 (10.0)	1(10.0)			
<b>Use of other community health services</b>				1.481	0.224 <sup>a</sup>
Yes	2 (6.7)	2(20.0)			
No	28 (93.3)	8(80.0)			
<b>QOL</b>					
Overall QOL	5.27 $\pm$ 1.05	4.80 $\pm$ 1.32	1.157		0.255 <sup>b</sup>
Physical discomfort	6.22 $\pm$ 1.18	5.98 $\pm$ 1.14	0.566		0.575 <sup>b</sup>
Food-related concerns	3.30 $\pm$ 2.22	2.20 $\pm$ 1.01	1.504		0.141 <sup>b</sup>
Health care concerns	7.70 $\pm$ 0.65	7.50 $\pm$ 0.77	0.803		0.427 <sup>b</sup>
Support	7.23 $\pm$ 1.27	6.90 $\pm$ 1.58	0.676		0.503 <sup>b</sup>
Negative emotions	7.44 $\pm$ 1.38	7.38 $\pm$ 1.12	0.138		0.891 <sup>b</sup>
Sense of alienation	7.98 $\pm$ 2.12	6.40 $\pm$ 1.46	1.269		0.212 <sup>b</sup>
Existential distress	7.98 $\pm$ 2.12	8.00 $\pm$ 1.82	-0.030		0.976 <sup>b</sup>
Value of life	5.14 $\pm$ 1.07	4.92 $\pm$ 0.98	0.580		0.565 <sup>b</sup>

a. Chi-Square Test

b. Independent Sample t-test

c. Fisher's Exact Test

**Table 7.8 Comparison between the participants who had completed the study and those who had not at the baseline assessment within the experimental group**

<b>Variable</b>	<b>Completed (n=26) n (%)</b>	<b>Withdrawn (n=14) n (%)</b>	<b><i>t</i></b>	<b><math>\chi^2</math></b>	<b><i>p-value</i></b>
<b>Age (years)</b>			-0.121		0.905 <sup>b</sup>
Mean ± SD	58.69 ± 12.29	58.21 ± 11.26			
<b>Gender</b>				0.440	0.507 <sup>a</sup>
Male	14 (53.8)	6(33.3)			
Female	12 (46.2)	8(66.7)			
<b>Educational level</b>				2.203	0.332 <sup>a</sup>
Primary school	9 (34.6)	8(57.1)			
Secondary school	16 (62.6)	6(42.9)			
Tertiary education	1 (3.8)	0(0.0)			
<b>Marital status</b>				0.021	0.885 <sup>a</sup>
With spouse	18 (69.2)	10(71.4)			
Without spouse	8 (30.8)	4(28.6)			
<b>Religion</b>				0.147	1.000 <sup>c</sup>
Yes	19 (73.1)	11(83.3)			
No	7 (26.9)	3(16.7)			
<b>Living status</b>				0.195	1.000 <sup>c</sup>
Live with family	23 (88.5)	13(92.9)			
Live alone	3 (11.5)	1(7.1)			
<b>Primary caregiver</b>				2.114	0.549 <sup>a</sup>
Parents	3 (11.5)	0(0.0)			
Spouse	13 (50.0)	8(57.1)			
Children	8 (30.8)	4(28.6)			
Others	2 (7.7)	2(14.3)			
<b>Family function</b>				2.065	0.356 <sup>a</sup>
Not dysfunctional	16 (61.5)	6(42.9)			
Moderately dysfunctional	9 (34.6)	6(42.9)			
Severely dysfunctional	1 (3.8)	2(14.3)			
<b>Family financial status</b>				4.082	0.130 <sup>a</sup>
Barely sufficient	4 (15.4)	0(0.0)			
Insufficient	11 (42.3)	10(71.4)			
Very insufficient	11 (42.3)	4(28.6)			
<b>Participation in community activities</b>				1.134	0.533 <sup>c</sup>
Yes	2 (7.7)	0(0.0)			
No	24 (92.3)	14(100.0)			

a. Chi-Square Test

b. Independent Sample t-test

c. Fisher's Exact Test



**Cont. Table 7.8 Comparison between the participants who had completed the study and those who had not at the baseline assessment within the experimental group**

Variable	Completed (n=26) n (%)	Withdrew (n=14) n (%)	<i>t</i>	$\chi^2$	<i>p-value</i>
<b>Months with disease</b>			0.914		0.367 <sup>b</sup>
Mean ± SD	19.88 ± 20.0	25.93 ± 19.81			
<b>Diagnosis</b>				6.502	0.090 <sup>a</sup>
Gastro-intestinal cancer	12 (46.2)	6(42.9)			
Respiratory cancer	11 (42.3)	2(14.3)			
Gynecological cancer	2 (7.7)	5(35.7)			
Others	1 (3.8)	1(7.1)			
<b>Site of metastasis</b>				3.130	0.372 <sup>a</sup>
Multiple sites	4 (15.4)	4(28.6)			
Bone	11 (42.3)	3(21.4)			
Internal organ	7 (26.9)	6(42.9)			
Lymph	4 (15.4)	1(7.1)			
<b>Types of previous treatments</b>				2.440	0.295 <sup>a</sup>
One	16(61.5)	5(35.7)			
Two	9(34.6)	8(57.1)			
Three	1(3.8)	1(7.1)			
<b>KPS</b>				3.548	0.170 <sup>a</sup>
40%	7 (26.9)	8(57.1)			
50%	16 (61.5)	5(35.7)			
60%	3 (11.5)	1(7.1)			
<b>Use of other community health services</b>				0.208	1.000 <sup>c</sup>
Yes	1 (3.8)	1(7.1)			
No	25 (96.2)	13(92.9)			
<b>QOL</b>					
Overall QOL	5.04 ± 0.83	4.43 ± 0.65	2.397		0.022 <sup>b*</sup>
Physical discomfort	6.82 ±1.05	6.36 ±1.14	1.284		0.207 <sup>b</sup>
Food-related concerns	3.71 ±2.00	3.68 ±2.45	0.046		0.964 <sup>b</sup>
Health care concerns	8.08 ±0.69	7.38 ±1.03	2.582		0.014 <sup>b**</sup>
Support	7.21 ±1.17	6.50 ±1.22	1.808		0.079 <sup>b</sup>
Negative emotions	7.45 ±1.39	6.88 ±1.67	1.163		0.252 <sup>b</sup>
Sense of alienation	6.64 ±1.74	7.21 ±1.01	-1.130		0.266 <sup>b</sup>
Existential distress	8.26 ±1.69	7.25 ±3.09	1.333		0.196 <sup>b</sup>
Value of life	4.71 ±1.01	4.80 ±0.83	-0.271		0.787 <sup>b</sup>

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$

a. Chi-Square Test

b. Independent Sample t-test

c. Fisher's Exact Test

**Table 7.9 Comparison between the participants who had completed the study and those who had not at the baseline assessment in the ITT sample**

<b>Variable</b>	<b>Completed (n=56) n (%)</b>	<b>Withdrew (n=24) n (%)</b>	<b><i>t</i></b>	<b><math>\chi^2</math></b>	<b><i>p-value</i></b>
<b>Age (years)</b>			-0.600		0.550 <sup>a</sup>
Mean $\pm$ SD	58.64 $\pm$ 11.29	60.33 $\pm$ 12.14			
<b>Gender</b>				1.375	0.241 <sup>b</sup>
Male	27 (48.2)	15 (62.5)			
Female	29 (51.8)	9 (37.5)			
<b>Educational level</b>				4.263	0.234 <sup>b</sup>
No formal education	3 (5.4)	0 (0)			
Primary school	19 (33.9)	13 (54.2)			
Secondary school	32 (57.1)	11 (45.8)			
Tertiary education	2 (3.6)	0 (0.0)			
<b>Marital status</b>				0.048	0.827
With spouse	41 (73.2)	17 (70.8)			
Without spouse	15 (26.8)	7 (29.2)			
<b>Religion</b>				0.844	0.358 <sup>b</sup>
Yes	38 (69.6)	19 (79.2)			
No	17 (30.4)	5 (20.8)			
<b>Living status</b>				0.254	1.000 <sup>c</sup>
Live with family	52 (92.7)	23 (95.8)			
Live alone	4 (7.1)	1 (5.3)			
<b>Primary caregiver</b>				0.830	0.842 <sup>b</sup>
Parents	5 (8.9)	1 (4.2)			
Spouse	28 (50.0)	13 (54.2)			
Children	20 (35.7)	8 (33.3)			
Others	3 (5.4)	2 (8.4)			
<b>Family function</b>				4.074	0.130 <sup>b</sup>
No dysfunction	35 (62.5)	10 (41.7)			
Moderate dysfunction	19 (33.9)	11 (45.8)			
Severe dysfunction	2 (3.6)	3 (12.5)			
<b>Family financial status</b>				2.831	0.243 <sup>b</sup>
Barely sufficient	6 (10.7)	1 (4.2)			
Insufficient	24 (42.9)	15 (62.5)			
Very insufficient	26 (46.4)	8 (33.3)			
<b>Participation in community activities</b>				1.336	0.550 <sup>c</sup>
Yes	3 (5.4)	0 (0.0)			
No	53 (94.6)	24 (100.0)			

a. Independent Sample t-test

b. Chi-Square Test

c. Fisher's Exact Test

**Cont. Table 7.9 Comparison between the participants who had completed the study and those who had not at the baseline assessment in the ITT sample**

Variable	Completed (n=56) n (%)	Withdrew (n=24) n (%)	<i>t</i>	$\chi^2$	<i>p-value</i>
<b>Months with cancer</b>			-0.458		0.648 <sup>a</sup>
Mean ± SD	20.21 ± 19.09	22.29 ± 17.33			
<b>Diagnosis</b>				0.355	0.949 <sup>b</sup>
Gastro-intestinal cancer	29 (51.8)	11 (45.8)			
Respiratory cancer	16 (28.6)	7 (29.2)			
Gynecological cancer	9 (16.1)	5 (20.8)			
Others	2 (3.6)	1 (4.2)			
<b>Metastasis</b>				3.663	0.300 <sup>b</sup>
Multiple sites	9 (16.1)	7 (29.2)			
Bone	21 (37.5)	6 (25.0)			
Internal organ	16 (28.6)	9 (37.5)			
Lymph	10 (17.9)	2 (8.3)			
<b>Types of previous treatments</b>				0.546	0.761 <sup>b</sup>
One	33 (58.9)	12 (50.0)			
Two	21 (37.5)	11 (45.8)			
Three	2 (3.6)	1 (4.2)			
<b>KPS</b>				5.748	0.056 <sup>b</sup>
40%	19 (33.9)	15 (62.5)			
50%	31 (55.4)	7 (29.2)			
60%	6 (10.7)	2 (8.3)			
<b>Use of other community health services</b>				1.236	0.358 <sup>c</sup>
Yes	3 (5.4)	3 (12.5)			
No	53 (94.6)	21 (87.5)			
<b>QOL</b>					
Overall QOL	5.04 ± 0.99	4.58 ± 0.97	1.891		0.060
Physical discomfort	6.50 ± 1.15	6.20 ± 1.13	1.066		0.290
Food-related concerns	3.49 ± 2.11	3.06 ± 2.08	0.835		0.406
Health care concerns	7.88 ± 0.69	7.42 ± 0.91	1.860		0.072
Support	7.22 ± 1.21	6.67 ± 1.36	1.813		0.070
Negative emotions	7.45 ± 1.37	7.08 ± 1.46	1.063		0.291
Sense of alienation	6.87 ± 1.58	6.88 ± 1.25	-0.016		0.987
Existential distress	8.11 ± 1.92	7.56 ± 2.61	1.036		0.303
Value of life	4.94 ± 1.06	4.85 ± 0.88	0.379		0.706

a. Independent Sample t-test

b. Chi-Square Test

c. Fisher's Exact Test

#### **7.6.4 Effects of the life review program on the ITT sample**

This section presents the effects of the life review program on QOL in terms of overall QOL, physical discomfort, food-related concerns, health care concerns, support, negative emotions, sense of alienation, existential distress, and value of life.

##### ***Overall QOL***

Table 7.10 shows the overall QOL scores of the two groups across three time intervals. When comparing the effects of the program on the two groups over time, the repeated measures analysis indicated that there were significant differences in the within-group effect ( $F=32.881, p=0.000$ ), between-group effect ( $F=52.615, p=0.000$ ), and interaction effect ( $F=40.555, p=0.000$ ) (Table 7.11). Each group was examined for changes over time. The significant differences were identified in both the control group ( $F=49.535, p=0.000$ ) and the experimental group ( $F=21.764, p=0.000$ ). The Post-hoc tests of the control group showed significant differences in both  $T_0$  vs.  $T_1$  ( $p=0.000$ ),  $T_0$  vs.  $T_2$  ( $p=0.000$ ), and  $T_1$  vs.  $T_2$  ( $p=0.000$ ). The Post-hoc tests of the experimental group also showed significant differences in  $T_0$  vs.  $T_1$  ( $p=0.000$ ) and  $T_1$  vs.  $T_2$  ( $p=0.000$ ), but not in  $T_0$  vs.  $T_2$  ( $p=0.762$ ) (Table 7.12). The Independent Sample t-test was employed to examine overall QOL between the two groups at each time interval. There were significant changes at  $T_1$  ( $t=-7.560, p=0.000$ ) and  $T_2$  ( $t=-7.571, p=0.000$ ), but no significant differences at  $T_0$  ( $t=1.501, p=1.137$ ) (Table 7.13).

**Table 7.10 Mean scores for overall QOL at three time intervals in the ITT sample**

	Control group (n=40)			Experimental group (n=40)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Overall QOL	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	5.15 $\pm$ 1.12	4.05 $\pm$ 1.48	2.60 $\pm$ 1.31	4.83 $\pm$ 0.81	6.31 $\pm$ 1.17	5.13 $\pm$ 1.66

**Table 7.11 Comparison of overall QOL between the two groups across three time intervals in the ITT sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	32.881	0.000**
Between groups (Group)	1	52.615	0.000**
Time $\times$ Group	2	40.555	0.000**

\*\*  $p \leq 0.01$

**Table 7.12 Comparison of overall QOL within each group in the ITT sample**

	Within-group effect		
	df	F value	<i>p-value</i>
Control group	2	49.535	0.000**
Experimental group	2	21.764	0.000**
	Mean difference		<i>p-value</i>
Control group			
T <sub>0</sub> &T <sub>1</sub>	1.100		0.000**
T <sub>0</sub> &T <sub>2</sub>	2.554		0.000**
T <sub>1</sub> &T <sub>2</sub>	1.454		0.000**
Experimental group			
T <sub>0</sub> &T <sub>1</sub>	-1.489		0.000**
T <sub>0</sub> &T <sub>2</sub>	-0.308		0.762
T <sub>1</sub> &T <sub>2</sub>	1.181		0.000**

\*\*  $p \leq 0.01$

**Table 7.13 Comparison of overall QOL between the two groups at each time interval in the ITT sample**

	Time interval	Control (n=40) Mean $\pm$ SD	Experimental (n=40) Mean $\pm$ SD	t	<i>p-value</i>
Overall QOL	T <sub>0</sub>	5.15 $\pm$ 1.12	4.83 $\pm$ 0.81	1.501	0.137
	T <sub>1</sub>	4.05 $\pm$ 1.48	6.31 $\pm$ 1.17	-7.560	0.000**
	T <sub>2</sub>	2.60 $\pm$ 1.31	5.13 $\pm$ 1.66	-7.571	0.000**

\*\*  $p \leq 0.01$

### *Physical discomfort*

Table 7.14 shows the scores for physical discomfort in ITT among the groups across three time intervals. The repeated measures analysis indicated that the between-group effect ( $F=2.254$ ,  $p=0.137$ ) and the interaction effect ( $F=0.518$ ,  $p=0.596$ ) were not significant, but that the within-group effect was significant ( $F=35.185$ ,  $p=0.000$ ) (Table 7.15). Both the control group ( $F=15.824$ ,  $p=0.000$ ) and the experimental group ( $F=19.404$ ,  $p=0.000$ ) showed significant within-group effects. For the control group, significant differences were found in  $T_0$  vs.  $T_1$  ( $p=0.018$ ),  $T_0$  vs.  $T_2$  ( $p=0.000$ ), and  $T_1$  vs.  $T_2$  ( $p=0.031$ ). For the experimental group, significant differences were identified in  $T_0$  vs.  $T_1$  ( $p=0.010$ ),  $T_0$  vs.  $T_2$  ( $p=0.000$ ), and  $T_1$  vs.  $T_2$  ( $p=0.008$ ) (Table 7.16).

**Table 7.14 Mean scores for physical discomfort at three time intervals in the ITT sample**

	Control group (n=40)			Experimental group (n=40)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Physical discomfort	$T_0$	$T_1$	$T_2$	$T_0$	$T_1$	$T_2$
	$6.16 \pm 1.16$	$5.66 \pm 1.47$	$5.11 \pm 0.97$	$6.66 \pm 1.09$	$5.95 \pm 1.43$	$5.33 \pm 1.28$

**Table 7.15 Comparison of physical discomfort between the two groups across three time intervals in the ITT sample**

Effect	df	F	p-value
Within group (Time)	2	35.185	0.000**
Between groups (Group)	1	2.254	0.137
Time $\times$ Group	2	0.518	0.596

\*\*  $p \leq 0.01$

**Table 7.16 Comparison of physical discomfort within each group in the ITT sample**

		Within-group effect	
	df	F value	<i>p-value</i>
Control group	2	15.824	0.000**
Experimental group	2	19.404	0.000**
		Mean difference	<i>p-value</i>
Control group			
T <sub>0</sub> &T <sub>1</sub>		0.501	0.018*
T <sub>0</sub> &T <sub>2</sub>		1.048	0.000**
T <sub>1</sub> &T <sub>2</sub>		0.547	0.031*
Experimental group			
T <sub>0</sub> &T <sub>1</sub>		0.706	0.010**
T <sub>0</sub> &T <sub>2</sub>		1.326	0.000**
T <sub>1</sub> &T <sub>2</sub>		0.619	0.008**

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$

### ***Food-related concerns***

Table 7.17 shows the scores for food-related concerns among the groups across three time intervals. As shown in Table 7.18, the repeated measures analysis indicated that the between-group effect ( $F=3.936$ ,  $p=0.051$ ) and interaction effect ( $F=0.236$ ,  $p=0.790$ ) were not significant, but that the within-group effect was significant ( $F=22.650$ ,  $p=0.000$ ). As shown in Table 7.19, there were significant differences across three time intervals in the control group ( $F=19.910$ ,  $p=0.000$ ) and experimental group ( $F=7.274$ ,  $p=0.002$ ). The Post-hoc tests of the control group revealed significant differences in T<sub>0</sub> vs. T<sub>2</sub> ( $p=0.000$ ) and T<sub>1</sub> vs. T<sub>2</sub> ( $p=0.000$ ), but no significance in T<sub>0</sub> vs. T<sub>1</sub> ( $p=0.159$ ). The Post-hoc tests of the experimental group found significant differences in T<sub>0</sub> vs. T<sub>2</sub> ( $p=0.000$ ), but no significance in T<sub>0</sub> vs. T<sub>1</sub> ( $p=0.490$ ) and T<sub>1</sub> vs. T<sub>2</sub> ( $p=0.107$ ).

**Table 7.17 Mean scores for food-related concerns at three time intervals in the ITT sample**

	Control group (n=40)			Experimental group (n=40)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Food-related concerns	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	3.03 $\pm$ 2.03	2.46 $\pm$ 2.16	1.17 $\pm$ 1.57	3.70 $\pm$ 2.14	3.00 $\pm$ 2.55	2.06 $\pm$ 1.97

**Table 7.18 Comparison of food-related concerns between the two groups across three time intervals in the ITT sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	22.650	0.000**
Between groups (Group)	1	3.936	0.053
Time $\times$ Group	2	0.236	0.790

\*\*  $P \leq 0.01$

**Table 7.19 Comparison of food-related concerns within each group in the ITT sample**

	df	Within-group effect	
		F value	<i>p-value</i>
Control group	2	19.910	0.000**
Experimental group	2	7.274	0.002**
		Mean difference	<i>p-value</i>
Control group			
T <sub>0</sub> &T <sub>1</sub>		0.566	0.159
T <sub>0</sub> &T <sub>2</sub>		1.858	0.000**
T <sub>1</sub> &T <sub>2</sub>		1.293	0.000**
Experimental group			
T <sub>0</sub> &T <sub>1</sub>		0.700	0.490
T <sub>0</sub> &T <sub>2</sub>		1.635	0.000**
T <sub>1</sub> &T <sub>2</sub>		0.935	0.107

\*\*  $P \leq 0.01$



### ***Health care concerns***

Table 7.20 shows the scores for health care concerns among the groups at three time intervals. When comparing the effects between the experimental and control groups over time, the repeated measures analysis indicated significant differences in the within-group effect ( $F=5.561$ ,  $p=0.005$ ) and the between-group effect ( $F=4.766$ ,  $p=0.032$ ), but not in the interaction effect ( $F=1.305$ ,  $p=0.274$ ) (Table 7.21). When examining the effects on each group across three time intervals, no significant changes were observed in the control group ( $F=1.919$ ,  $p=0.154$ ); while there were significant differences in the experimental group ( $F=4.536$ ,  $p=0.014$ ). The Post-hoc test of the experimental group showed that a significance was found in  $T_0$  vs.  $T_2$  ( $p=0.028$ ), but not in  $T_0$  vs.  $T_1$  ( $p=0.091$ ) and  $T_1$  vs.  $T_2$  ( $p=1.000$ ) (Table 7.22).

**Table 7.20 Mean scores for health care concerns at three time intervals in the ITT sample**

	Control group (n=40)			Experimental group (n=40)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Health care concerns	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	7.65 $\pm$ 0.68	7.87 $\pm$ 0.78	7.74 $\pm$ 0.68	7.83 $\pm$ 0.88	8.15 $\pm$ 0.84	8.20 $\pm$ 0.76

**Table 7.21 Comparison of health care concerns between the two groups across three time intervals in the ITT sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	5.561	0.005*
Between groups (Group)	1	4.766	0.032*
Time $\times$ Group	2	1.305	0.274

\*  $P \leq 0.05$

**Table 7.22 Comparison of health care concerns within each group in the ITT sample**

	Within-group effect		
	df	F value	p-value
Control group	2	1.919	0.154
Experimental group	2	4.536	0.014**
Experimental group	Mean difference		p-value
T <sub>0</sub> &T <sub>1</sub>		-0.319	0.091
T <sub>0</sub> &T <sub>2</sub>		-0.370	0.028*
T <sub>1</sub> &T <sub>2</sub>		-0.052	1.000

\*  $P \leq 0.05$ ; \*\*  $P \leq 0.01$ .

### *Support*

Table 7.23 shows the scores for support among the two groups over time. As shown in Table 7.24, the repeated measures analysis showed significant differences in the interaction effect ( $F=6.330$ ,  $p=0.003$ ), but no significance in the within-group effect ( $F=2.850$ ,  $p=0.067$ ) and between-group effect ( $F=2.707$ ,  $p=0.104$ ). As shown in Table 7.25, the Independent Sample t-test found significant differences between the two groups at T<sub>1</sub> ( $t=-2.034$ ,  $p=0.045$ ) and T<sub>2</sub> ( $t=-3.056$ ,  $p=0.003$ ), but no significance in T<sub>0</sub> ( $t=0.654$ ,  $p=0.515$ ).

**Table 7.23 Mean scores for support at three time intervals in the ITT sample**

	Control group (n=40)			Experimental group (n=40)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Support	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	7.15 $\pm$ 1.34	7.04 $\pm$ 1.26	7.00 $\pm$ 0.97	6.96 $\pm$ 1.22	7.57 $\pm$ 1.06	7.69 $\pm$ 1.05

**Table 7.24 Comparison of support between the two groups across three time intervals in the ITT sample**

Effect	df	F	p-value
Within group (Time)	1.80	2.850	0.067
Between groups (Group)	1	2.707	0.104
Time $\times$ Group	1.80	6.330	0.003**

\*\*  $P \leq 0.01$

**Table 7.25 Comparison of support between the two groups at each time interval in the ITT sample**

	Time interval	Control (n=30)	Experimental (n=26)	t	p-value
		Mean $\pm$ SD	Mean $\pm$ SD		
Support	T <sub>0</sub>	7.15 $\pm$ 1.34	6.96 $\pm$ 1.22	0.654	0.515
	T <sub>1</sub>	7.04 $\pm$ 1.26	7.57 $\pm$ 1.06	-2.034	0.045*
	T <sub>2</sub>	7.00 $\pm$ 0.97	7.69 $\pm$ 1.05	-3.056	0.003**

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ .

### *Negative emotions*

Table 7.26 shows the scores for negative emotions among the two groups at three time intervals. When comparing the effects of the program between the two groups across three time intervals, the repeated measures analysis showed that there were significant differences in the within-group effect ( $F=9.987$ ,  $p=0.000$ ), between-group effect ( $F=8.683$ ,  $p=0.004$ ) and interaction effect ( $F=20.033$ ,  $P=0.000$ ) (Table 7.27). There were significant within-group effects in both the experimental group ( $F=23.147$ ,  $p=0.000$ ) and the control group ( $F=3.586$ ,  $p=0.032$ ) (Table 6.28). The Post-hoc tests for each group indicated no significant differences in the control group including T<sub>0</sub> vs. T<sub>1</sub> ( $p=0.276$ ), T<sub>0</sub> vs. T<sub>2</sub> ( $p=0.065$ ), and T<sub>1</sub> vs. T<sub>2</sub> ( $P=0.641$ ), but significant differences in the experimental group including T<sub>0</sub> vs. T<sub>1</sub> ( $p=0.000$ ), T<sub>0</sub> vs. T<sub>2</sub> ( $p=0.002$ ), and T<sub>1</sub> vs. T<sub>2</sub> ( $p=0.004$ ). The Independent Sample t-test revealed that no significant differences at T<sub>0</sub> ( $t=0.556$ ,  $p=0.580$ ), but significant differences at T<sub>1</sub> ( $t=-4.261$ ,  $p=0.000$ ) and T<sub>2</sub> ( $t=-3.826$ ,  $p=0.000$ ) (Table 7.29).

**Table 7.26 Mean scores for negative emotions at three time intervals in the ITT sample**

	Control group (n=40)			Experimental group (n=40)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Negative emotions	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	7.43 $\pm$ 1.30	7.19 $\pm$ 1.59	6.94 $\pm$ 1.16	7.25 $\pm$ 1.50	8.70 $\pm$ 1.58	8.08 $\pm$ 1.48

**Table 7.27 Comparison of negative emotions between the two groups across three time intervals in the ITT sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	9.987	0.000**
Between groups (Group)	1	8.683	0.004**
Time × Group	2	20.033	0.000**

\*\*  $P \leq 0.01$

**Table 7.28 Comparison of negative emotions within each group in the ITT sample**

Within-group effect			
	df	F value	<i>p-value</i>
Control group	1.69	3.586 <sup>a</sup>	0.032*
Experimental group	2	23.147	0.000**
Mean difference			
<i>p-value</i>			
Control group			
T <sub>0</sub> &T <sub>1</sub>		0.236	0.276
T <sub>0</sub> &T <sub>2</sub>		0.483	0.065
T <sub>1</sub> &T <sub>2</sub>		0.248	0.641
Experimental group			
T <sub>0</sub> &T <sub>1</sub>		-1.450	0.000**
T <sub>0</sub> &T <sub>2</sub>		-0.831	0.002**
T <sub>1</sub> &T <sub>2</sub>		0.619	0.004**

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (Epsilon), since Mauchly's test of Sphericity is not assumed.

**Table 7.29 Comparison of negative emotions between the two groups at each time interval in the ITT sample**

	Time interval	Control (n=40) Mean ± SD	Experimental (n=40) Mean ± SD	t	<i>p-value</i>
Negative emotions	T <sub>0</sub>	7.43±1.30	7.25±1.50	0.556	0.580
	T <sub>1</sub>	7.19±1.59	8.70±1.58	-4.261	0.000**
	T <sub>2</sub>	6.94±1.16	8.08±1.48	-3.826	0.000**

\*\*  $p \leq 0.01$

### *Sense of alienation*

Table 7.30 shows the scores of sense of alienation among the groups. As shown in Table 7.31, the repeated measures analysis revealed that there were significant differences in the between-group effect ( $F=9.191$ ,  $p=0.003$ ) and the interaction effect ( $F=9.118$ ,  $p=0.000$ ) between the experimental and control groups across three time intervals, but no significance in the within-group effect ( $F=0.704$ ,  $p=0.484$ ). The Independent Sample t-test was employed to examine the effects of the program between the two groups at each time interval. There were no significant differences between the two groups at  $T_0$  ( $t=0.175$ ,  $p=0.862$ ), but significant changes at  $T_1$  ( $t=-3.952$ ,  $p=0.000$ ) and  $T_2$  ( $t=-4.465$ ,  $p=0.000$ ) (Table 7.32).

**Table 7.30 Mean scores for sense of alienation at three time intervals in the ITT sample**

	Control group (n=40)			Experimental group (n=40)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Sense of alienation	$T_0$	$T_1$	$T_2$	$T_0$	$T_1$	$T_2$
	6.90 $\pm$ 1.45	6.45 $\pm$ 1.32	6.39 $\pm$ 1.02	6.84 $\pm$ 1.54	7.59 $\pm$ 1.26	7.33 $\pm$ 0.87

**Table 7.31 Comparison of sense of alienation between the two groups across three time intervals in the ITT sample**

Effect	df	F	P-value
Within group (Time)	1.82	0.704 <sup>a</sup>	0.484
Between groups (Group)	1	9.191	0.003**
Time $\times$ Group	1.82	9.118 <sup>a</sup>	0.000**

\*\*  $p \leq 0.01$

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (Epsilon), since Mauchly's test of Sphericity is not assumed.

**Table 7.32 Comparison of sense of alienation between the two groups at each time interval in the ITT sample**

	Time interval	Control (n=40)	Experimental (n=40)	t	p-value
		Mean $\pm$ SD	Mean $\pm$ SD		
Sense of alienation	T <sub>0</sub>	6.90 $\pm$ 1.45	6.84 $\pm$ 1.54	0.175	0.862
	T <sub>1</sub>	6.45 $\pm$ 1.32	7.59 $\pm$ 1.26	-3.952	0.000**
	T <sub>2</sub>	6.39 $\pm$ 1.02	7.33 $\pm$ 0.87	-4.465	0.000**

\*\*  $p \leq 0.01$

### ***Existential distress***

Table 7.33 shows the scores for existential distress among the groups at three time intervals. The repeated measures analysis revealed that there were significant differences in the within-group effect ( $F=21.243$ ,  $p=0.000$ ), the between-group effect ( $F=14.301$ ,  $p=0.000$ ), and the interaction effect ( $F=17.447$ ,  $p=0.000$ ) between the experimental and control groups over time (Table 7.34).

When examining the effects on each group over time, significant differences were found in the control group ( $F=31.852$ ,  $p=0.000$ ) but not in the experimental group ( $F=2.628$ ,  $p=0.079$ ). Within the control group, significant differences were observed at T<sub>0</sub> vs. T<sub>1</sub> ( $p=0.000$ ), T<sub>0</sub> vs. T<sub>2</sub> ( $p=0.000$ ), and T<sub>1</sub> vs. T<sub>2</sub> ( $p=0.015$ ) (Table 7.35). The Mann-Whitney U test indicated that there were no significant differences between the two groups at T<sub>0</sub> ( $z=0.034$ ,  $p=0.973$ ), but significant differences at T<sub>1</sub> ( $z=-4.265$ ,  $p=0.000$ ) and T<sub>2</sub> ( $z=-4.442$ ,  $p=0.000$ ) (Table 7.36).

**Table 7.33 Mean scores for existential distress at three time intervals in the ITT sample**

	Control group (n=40)			Experimental group (n=40)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Existential distress	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	7.98 $\pm$ 2.02	6.17 $\pm$ 2.49	5.04 $\pm$ 2.41	7.90 $\pm$ 2.29	8.38 $\pm$ 1.89	7.66 $\pm$ 2.39

**Table 7.34 Comparison of existential distress between the two groups across three time intervals in the ITT sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	21.243	0.000**
Between groups (Group)	1	14.301	0.000**
Time × Group	2	17.447	0.000**

\*\*  $p \leq 0.01$

**Table 7.35 Comparison of existential distress within each group in the ITT sample**

	df	Within-group effect	
		F value	<i>p-value</i>
Control group	2	31.852	0.000**
Experimental group	2	2.628	0.079
		Mean difference	<i>p-value</i>
Control group			
T <sub>0</sub> &T <sub>1</sub>		1.812	0.000**
T <sub>0</sub> &T <sub>2</sub>		2.939	0.000**
T <sub>1</sub> &T <sub>2</sub>		1.127	0.015*

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ .

**Table 7.36 Comparison of existential distress between the two groups at each time interval in the ITT sample**

	Time interval	Control (n=40)	Experimental (n=40)	z	<i>p-value</i>
		Mean ± SD	Mean ± SD		
Existential distress	T <sub>0</sub>	7.98± 2.02	7.90±2.29	-0.034	0.973
	T <sub>1</sub>	6.17±2.49	8.38±1.89	-4.265	0.000**
	T <sub>2</sub>	5.04±2.41	7.66±2.39	-4.442	0.000**

\*\*  $p \leq 0.01$

### *Value of life*

Table 7.37 shows the scores for value of life among the groups at three time intervals. The repeated measures analysis revealed that there were significant differences in the within-group effect ( $F=9.344$ ,  $p=0.000$ ), the between-group effect ( $F=68.218$ ,  $p=0.000$ ), and the interaction effect ( $F=117.227$ ,  $p=0.000$ ) between the experimental and control groups over time (Table 7.38). Each group was examined for changes over time. As shown in Table 7.39, the significant differences were observed in both the control group ( $F=80.989$ ,  $p=0.000$ ) and the experimental group ( $F=54.924$ ,  $p=0.000$ ). The Post-hoc tests of the control group showed significant differences in  $T_0$  vs.  $T_1$  ( $p=0.000$ ),  $T_0$  vs.  $T_2$  ( $p=0.000$ ), and  $T_1$  vs.  $T_2$  ( $p=0.001$ ). The Post-hoc tests of the experimental group indicated significant differences in  $T_0$  vs.  $T_1$  ( $p=0.000$ ) and  $T_0$  vs.  $T_2$  ( $p=0.000$ ), but not in  $T_1$  vs.  $T_2$  ( $p=0.101$ ). The effects of the program between the two groups at each time interval were examined, as shown in Table 7.40. There were no significant differences at  $T_0$  ( $t=1.537$ ,  $p=0.128$ ), but significant changes were observed at  $T_1$  ( $t=-10.441$ ,  $p=0.000$ ) and  $T_2$  ( $t=-11.080$ ,  $p=0.000$ ).

**Table 7.37 Mean scores for value of life at three time intervals in the ITT sample**

Value of life	Control group (n=40)			Experimental group (n=40)		
	Mean $\pm$ SD			Mean $\pm$ SD		
	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	5.08 $\pm$ 1.04	4.06 $\pm$ 1.15	3.48 $\pm$ 0.91	4.74 $\pm$ 0.94	6.56 $\pm$ 0.98	6.24 $\pm$ 1.29



**Table 7.38 Comparison of value of life between the two groups across three time intervals in the ITT sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	1.83	9.344 <sup>a</sup>	0.000**
Between groups (Group)	1	68.218	0.000**
Time × Group	1.83	117.227 <sup>a</sup>	0.000**

\*\*  $p \leq 0.01$

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (Epsilon), since Mauchly's test of Sphericity is not assumed.

**Table 7.39 Comparison of value of life within each group in the ITT sample**

Within-group effect			
	df	F value	<i>p-value</i>
Control group	2	80.989	0.000**
Experimental group	1.52	54.924 <sup>a</sup>	0.000**
Mean difference			<i>p-value</i>
Control group			
T <sub>0</sub> &T <sub>1</sub>		1.025	0.000**
T <sub>0</sub> &T <sub>2</sub>		1.600	0.000**
T <sub>1</sub> &T <sub>2</sub>		0.575	0.000**
Experimental group			
T <sub>0</sub> &T <sub>1</sub>		-1.815	0.000**
T <sub>0</sub> &T <sub>2</sub>		-1.506	0.000**
T <sub>1</sub> &T <sub>2</sub>		0.310	0.101

\*\*  $p \leq 0.01$

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (Epsilon), since Mauchly's test of Sphericity is not assumed.

**Table 7.40 Comparison of the value of life between the two groups at each time interval in the ITT sample**

	Time interval	Control (n=40) Mean ± SD	Experimental (n=40) Mean ± SD	t	<i>p-value</i>
Value of life	T <sub>0</sub>	5.08±1.04	4.74±0.94	1.537	0.128
	T <sub>1</sub>	4.06±1.15	6.56±0.98	-10.441	0.000**
	T <sub>2</sub>	3.48±0.91	6.24±1.29	-11.080	0.000**

\*\*  $P \leq 0.01$

## **7.7 The per-protocol analysis**

### **7.7.1 Characteristics of the participants in the PP sample**

Fifty-six patients fully completed the study (PP sample). Table 7.41 shows the socio-demographic characteristics of the PP sample. Table 7.42 shows the clinical characteristics of the PP sample.

### **7.7.2 Equivalence between the control and experimental groups at the baseline assessment in the PP sample**

Table 7.41 and Table 7.42 also show that no significant differences in socio-demographic and clinical characteristics were observed between the experimental group and the control group.

Table 7.43 shows the mean scores of QOL of the PP sample at the baseline assessment. There were no significant differences in QOL, except for health care concerns ( $t=-2.104$ ,  $p=0.040$ ).

**Table 7.41 Socio-demographic characteristics of the PP sample**

<b>Variable</b>	<b>Total (n=56) n (%)</b>	<b>Control (n= 30) n (%)</b>	<b>Experimental (n=26) n (%)</b>	<b>t</b>	<b><math>\chi^2</math></b>	<b>p-value</b>
<b>Age (years)</b>				-0.030		0.976 <sup>a</sup>
Mean $\pm$ SD	58.6 $\pm$ 11.29	58.60 $\pm$ 10.55	58.69 $\pm$ 12.30			
<b>Gender</b>					0.617	0.432 <sup>b</sup>
Male	27 (48.2)	13 (43.3)	14 (53.8)			
Female	29 (51.8)	17 (56.7)	12 (46.2)			
<b>Educational level</b>					2.781	0.427 <sup>b</sup>
No formal education	3 (5.4)	3 (10.0)	0 (0.0)			
Primary school	19 (33.9)	10 (33.3)	9 (34.6)			
Secondary school	32 (57.1)	16 (53.3)	16 (61.5)			
Tertiary education	2 (3.6)	1 (3.3)	1 (3.8)			
<b>Marital status</b>					0.393	0.531 <sup>b</sup>
With spouse	41 (73.2)	23 (76.7)	18 (69.2)			
Without spouse	15 (26.8)	7 (23.3)	8 (30.8)			
<b>Religion</b>					0.271	0.603 <sup>b</sup>
Yes	38 (69.6)	20 (66.7)	19 (73.1)			
No	17 (30.4)	10 (33.3)	7 (26.9)			
<b>Living status</b>					1.414	0.328 <sup>c</sup>
Live with family	52 (92.7)	29 (96.7)	23 (88.5)			
Live alone	4 (7.1)	1 (3.3)	3 (11.5)			
<b>Primary caregiver</b>					1.197	0.754 <sup>b</sup>
Parents	5 (8.9)	2 (6.7)	3 (11.5)			
Spouse	28 (50.0)	15 (50.0)	13 (50.0)			
Children	20 (35.7)	12 (40.0)	8 (30.8)			
Others	3 (5.4)	1 (3.3)	2 (7.7)			
<b>Family function</b>					0.024	0.988 <sup>b</sup>
No dysfunction	35 (62.5)	19 (63.3)	16 (61.5)			
Moderate dysfunction	19 (33.9)	10 (33.3)	9 (34.6)			
Severe dysfunction	2 (3.6)	1 (3.3)	1 (3.8)			
<b>Family financial status</b>					1.169	0.557 <sup>b</sup>
Barely sufficient	6 (10.7)	2 (6.7)	4 (15.4)			
Not sufficient	24 (42.9)	13 (43.3)	11 (42.3)			
Very insufficient	26 (46.4)	15 (50.0)	11 (42.3)			
<b>Participation in community activities</b>					0.522	0.592 <sup>c</sup>
Yes	3 (5.4)	1 (3.3)	2 (7.7)			
No	53 (94.6)	29 (96.7)	24 (92.3)			

a. Independent Sample t-test

b. Chi-Square Test

c. Fisher's Exact Test

**Table 7.42 Clinical characteristics of the PP sample**

<b>Variable</b>	<b>Total (n=56) n (%)</b>	<b>Control (n= 30) n (%)</b>	<b>Experimental (n=26) n (%)</b>	<b>t</b>	<b><math>\chi^2</math></b>	<b>p-value</b>
<b>Months with cancer</b>				0.119		0.906 <sup>a</sup>
Mean $\pm$ SD	20.21 $\pm$ 19.09	20.50 $\pm$ 18.59	19.88 $\pm$ 20.03			
<b>Diagnosis</b>					5.633	0.131 <sup>b</sup>
Gastro-intestinal cancer	29 (51.8)	17 (56.7)	12 (46.2)			
Respiratory cancer	16 (28.6)	5 (16.7)	11 (42.3)			
Gynecological cancer	9 (16.1)	7 (23.3)	2 (7.7)			
Others	2 (3.6)	1 (3.3)	1 (3.8)			
<b>Metastasis</b>					0.526	0.913 <sup>b</sup>
Multiple sites	9 (16.1)	5 (16.7)	4 (15.4)			
Bone	21 (37.5)	10 (33.3)	11 (42.3)			
Internal organ	16 (28.6)	9 (16.1)	7 (26.9)			
Lymph	10 (17.9)	6 (20.0)	4 (15.4)			
<b>Types of previous treatments</b>					0.174	0.917 <sup>b</sup>
One	33(58.9)	17(56.7)	16(61.5)			
Two	21(37.5)	12(40.0)	9(34.6)			
Three	2(3.6)	1(3.3)	1(3.8)			
<b>KPS</b>					1.068	0.586 <sup>b</sup>
40%	19 (33.9)	12 (40.0)	7 (26.9)			
50%	31 (55.4)	15 (50.0)	16 (61.5)			
60%	6 (10.7)	3 (10.0)	3 (11.5)			
<b>Use of other community health services</b>					0.219	1.000 <sup>c</sup>
Yes	3 (5.4)	2 (6.7)	1 (3.8)			
No	53 (94.6)	28 (93.3)	25 (96.2)			

a. Independent Sample t-test

b. Chi-Square Test

c. Fisher's Exact Test

**Table 7.43 Mean scores for QOL at the baseline assessment in the PP sample**

QOL	Total (n=56) Mean $\pm$ SD	Control (n= 30) Mean $\pm$ SD	Experimental (n=26) Mean $\pm$ SD	<i>t</i>	<i>p-value</i>
Overall QOL	5.04 $\pm$ 0.99	5.27 $\pm$ 1.05	5.04 $\pm$ 0.82	0.916	0.364
Physical discomfort	6.50 $\pm$ 1.15	6.22 $\pm$ 1.18	6.82 $\pm$ 1.05	-2.001	0.051
Food-related concerns	3.49 $\pm$ 2.11	3.30 $\pm$ 2.22	3.71 $\pm$ 2.00	-0.723	0.473
Health care concerns	7.88 $\pm$ 0.69	7.70 $\pm$ 0.65	8.08 $\pm$ 0.69	-2.104	0.040*
Support	7.22 $\pm$ 1.21	7.23 $\pm$ 1.27	7.21 $\pm$ 1.17	0.066	0.947
Negative emotions	7.45 $\pm$ 1.37	7.44 $\pm$ 1.38	7.45 $\pm$ 1.39	-0.028	0.978
Sense of alienation	6.87 $\pm$ 1.58	7.07 $\pm$ 1.43	6.64 $\pm$ 1.74	1.003	0.320
Existential distress	8.11 $\pm$ 1.92	7.98 $\pm$ 2.12	8.26 $\pm$ 1.70	0.538	0.593
Value of life	4.94 $\pm$ 1.06	5.14 $\pm$ 1.07	4.71 $\pm$ 1.02	1.526	0.133

\*  $p \leq 0.05$

### 7.7.3 Effects of the life review program on the PP sample

#### *Overall QOL*

Tables 7.44, 7.45, 7.46, and 7.47 show the scores for the perspective on the overall QOL of the two groups. The repeated measures analysis revealed that there were significant differences in the within-group effect ( $F=20.963$ ,  $p=0.000$ ), the between-group effect ( $F=56.534$ ,  $p=0.000$ ), and the interaction effect ( $F=28.984$ ,  $p=0.000$ ). The significant within-group effect was observed in both the control group ( $F=36.961$ ,  $p=0.000$ ) and experimental group ( $F=13.103$ ,  $p=0.000$ ). For the control group, there were significant differences in  $T_0$  vs.  $T_1$  ( $p=0.002$ ),  $T_0$  vs.  $T_2$  ( $p=0.000$ ), and  $T_1$  vs.  $T_2$  ( $p=0.000$ ). For the experimental group, there were significant differences in  $T_0$  vs.  $T_1$  ( $p=0.000$ ) and  $T_1$  vs.  $T_2$  ( $p=0.010$ ), but no significance in  $T_0$  vs.  $T_2$  ( $p=0.426$ ). When examining overall QOL between the two groups at each time interval, the findings indicated that there was no significant difference at  $T_0$  ( $t=0.916$ ,  $p=0.364$ ), but significant changes at  $T_1$  ( $t=-7.074$ ,  $p=0.000$ ) and  $T_2$  ( $t=-7.093$ ,  $p=0.000$ ).

**Table 7.44 Mean scores for overall QOL at three time intervals in the PP sample**

	Control group (n=30)			Experimental group (n=26)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Overall QOL	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	5.27 $\pm$ 1.05	4.27 $\pm$ 1.41	2.60 $\pm$ 1.52	5.04 $\pm$ 0.82	6.58 $\pm$ 0.95	5.54 $\pm$ 1.58

**Table 7.45 Comparison of overall QOL between the two groups across three time intervals in the PP sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	20.963	0.000**
Between groups (Group)	1	56.534	0.000**
Time $\times$ Group	2	28.984	0.000**

\*\*  $p \leq 0.01$

**Table 7.46 Comparison of overall QOL within each group in the PP sample**

	Within-group effect		
	df	F value	<i>p-value</i>
Control group	2	36.961	0.000**
Experimental group	2	13.103	0.000**
	Mean difference		<i>p-value</i>
Control group			
T <sub>0</sub> &T <sub>1</sub>	1.005		0.002**
T <sub>0</sub> &T <sub>2</sub>	2.672		0.000**
T <sub>1</sub> &T <sub>2</sub>	1.667		0.000**
Experimental group			
T <sub>0</sub> &T <sub>1</sub>	-1.538		0.000**
T <sub>0</sub> &T <sub>2</sub>	-0.505		0.426
T <sub>1</sub> &T <sub>2</sub>	1.033		0.010**

\*\*  $p \leq 0.01$

**Table 7.47 Comparison of overall QOL between the two groups at each time interval in the PP sample**

	Time interval	Control (n=30) Mean $\pm$ SD	Experimental (n=26) Mean $\pm$ SD	t	<i>p-value</i>
Overall QOL	T <sub>0</sub>	5.27 $\pm$ 1.05	5.04 $\pm$ 0.82	0.916	0.364
	T <sub>1</sub>	4.27 $\pm$ 1.41	6.58 $\pm$ 0.95	-7.074	0.000**
	T <sub>2</sub>	2.60 $\pm$ 1.52	5.54 $\pm$ 1.58	-7.093	0.000**

\*\*  $p \leq 0.01$

### ***Physical discomfort***

Tables 7.48, 7.49, and 7.50 show the scores for the perspective on physical discomfort among the groups. The repeated measures analysis indicated that there were significant differences in the within-group effect ( $F=20.347$ ,  $p=0.000$ ) and the between-group effect ( $F=5.178$ ,  $p=0.027$ ), but no significance in the interaction effect ( $F=0.145$ ,  $p=0.865$ ). Both the control and experimental group showed significant differences in physical discomfort over time ( $F=14.234$ ,  $p=0.000$ ;  $F=7.388$ ,  $p=0.002$ ). For the control group, there were no significant differences in  $T_0$  vs.  $T_1$  ( $p=0.271$ ), but significant differences in  $T_0$  vs.  $T_2$  ( $p=0.000$ ) and  $T_1$  vs.  $T_2$  ( $p=0.006$ ). For the experimental group, no significant differences were observed in  $T_0$  vs.  $T_1$  ( $p=0.339$ ) and  $T_1$  vs.  $T_2$  ( $p=0.096$ ), but a significant effect in  $T_0$  vs.  $T_2$  ( $p=0.003$ ).

**Table 7.48 Mean scores for physical discomfort at three time intervals in the PP sample**

Physical discomfort	Control group (n=30)			Experimental group (n=26)		
	Mean $\pm$ SD			Mean $\pm$ SD		
	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	6.22 $\pm$ 1.18	5.87 $\pm$ 1.47	5.11 $\pm$ 1.12	6.82 $\pm$ 1.05	6.36 $\pm$ 1.28	5.78 $\pm$ 1.08

**Table 7.49 Comparison of physical discomfort between the two groups across three time intervals in the PP sample**

Effect	df	F	p-value
Within group (Time)	2	20.347	0.000**
Between groups (Group)	1	5.178	0.027*
Time $\times$ Group	2	0.145	0.865

\*\*  $p \leq 0.01$

**Table 7.50 Comparison of physical discomfort within each group in the PP sample**

	df	Within-group effect	
		F value	p-value
Control group	2	14.234	0.000**
Experimental group	2	7.388	0.002**
		Mean difference	p-value
Control group			
T <sub>0</sub> &T <sub>1</sub>		0.350	0.271
T <sub>0</sub> &T <sub>2</sub>		1.108	0.000**
T <sub>1</sub> &T <sub>2</sub>		0.758	0.006**
Experimental group			
T <sub>0</sub> &T <sub>1</sub>		0.462	0.339
T <sub>0</sub> &T <sub>2</sub>		1.038	0.003**
T <sub>1</sub> &T <sub>2</sub>		0.577	0.096

\*\*  $P \leq 0.01$

#### *Food-related concerns*

Tables 7.51, 7.52, and 7.53 show the scores for the perspective on food-related concerns among the groups. The repeated measures analysis indicated the between-group effect ( $F=3.465$ ,  $p=0.068$ ) and interaction effect ( $F=0.854$ ,  $p=0.429$ ) were not significant between the two groups over time, but the within-group effect was significant ( $F=15.020$ ,  $p=0.000$ ). Each group was also examined for changes across three time intervals. There were significant differences found in the control group ( $F=18.372$ ,  $p=0.000$ ), but not in the experimental group ( $F=3.066$ ,  $p=0.055$ ). For the control group, the Post-hoc tests revealed significant differences in T<sub>0</sub> vs. T<sub>1</sub> ( $p=0.000$ ), T<sub>1</sub> vs. T<sub>2</sub> ( $p=0.000$ ), and T<sub>0</sub> vs. T<sub>2</sub> ( $p=0.035$ ).

**Table 7.51 Mean scores for food-related concerns at three time intervals in the PP sample**

	Control group (n=30)			Experimental group (n=26)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Food-related concerns	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	3.30 $\pm$ 2.22	2.47 $\pm$ 2.23	1.17 $\pm$ 1.82	3.71 $\pm$ 2.00	3.40 $\pm$ 2.66	2.40 $\pm$ 2.29



**Table 7.52 Comparison of food-related concerns between the two groups across three time intervals in the PP sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	15.020	0.000**
Between groups (Group)	1	3.465	0.068
Time × Group	2	0.854	0.429

\*\*  $p \leq 0.01$

**Table 7.53 Comparison of food-related concerns within each group in the PP sample**

Within-group effect			
	df	F value	<i>p-value</i>
Control group	1.57	18.372 <sup>a</sup>	0.000**
Experimental group	2	3.066	0.055
Mean difference			
Control group			
T <sub>0</sub> &T <sub>1</sub>		0.833	0.035*
T <sub>0</sub> &T <sub>2</sub>		2.133	0.000**
T <sub>1</sub> &T <sub>2</sub>		1.300	0.000**

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ .

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (Epsilon), since Mauchly's test of Sphericity is not assumed.

### ***Health care concerns***

Tables 7.54, 7.55, and 7.56 indicate the scores for the perspective on health care concerns among the groups. Using the repeated measures to analyze the scores between the two groups over time, the findings indicated significance in the within-group effect ( $F=3.503$ ,  $p=0.034$ ) and the between-group effect ( $F=13.240$ ,  $p=0.001$ ), but not in the interaction effect ( $F=0.875$ ,  $p=0.420$ ). Each group was examined for changes across three time intervals. No significant change was observed in either the experimental group ( $F=1.813$ ,  $p=0.172$ ) or the control group ( $F=2.271$ ,  $p=0.114$ ).

**Table 7.54 Mean scores for health care concerns at three time intervals in the PP sample**

	Control group (n=30)			Experimental group (n=26)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Health care concerns	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	7.70 $\pm$ 0.65	7.93 $\pm$ 0.77	7.74 $\pm$ 0.79	8.08 $\pm$ 0.69	8.41 $\pm$ 0.68	8.40 $\pm$ 0.58

**Table 7.55 Comparison of health care concerns between the two groups across three time intervals in the PP sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	3.503	0.034*
Between groups (Group)	1	13.240	0.001**
Time $\times$ Group	2	0.875	0.420

\*  $P \leq 0.05$ ; \*\*  $P \leq 0.01$ .

**Table 7.56 Comparison of health care concerns within each group in the PP sample**

	Within-group effect		
	df	F value	<i>p-value</i>
Control group	2	1.813	0.172
Experimental group	2	2.271	0.114

### **Support**

Tables 7.57, 7.58, and 7.59 show the scores for the perspective on support among the groups. The repeated measures analysis showed a significant difference in the interaction effect ( $F=3.830$ ,  $p=0.025$ ), but no significant differences in the within-group effect ( $F=1.739$ ,  $p=0.181$ ) and the between-group effect ( $F=3.486$ ,  $p=0.067$ ). The Independent Sample t-test was used to examine changes between the experimental and control groups at each time interval. There were significant differences in T<sub>1</sub> ( $t=-2.261$ ,  $p=0.028$ ) and T<sub>2</sub> ( $t=-2.479$ ,  $p=0.016$ ), but not at T<sub>0</sub> ( $t=0.066$ ,  $p=0.947$ ).

**Table 7.57 Mean scores for support at three time intervals in the PP sample**

	Control group (n=30)			Experimental group (n=26)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Support	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	7.23 $\pm$ 1.27	7.18 $\pm$ 1.09	7.00 $\pm$ 1.13	7.21 $\pm$ 1.17	7.85 $\pm$ 1.10	7.79 $\pm$ 1.25

**Table 7.58 Comparison of support between the two groups across three time intervals in the PP sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	1.739	0.181
Between groups (Group)	1	3.486	0.067
Time $\times$ Group	2	3.830	0.025*

\*  $p \leq 0.05$ **Table 7.59 Comparison of support between the two groups at each time interval in the PP sample**

	Time interval	Control (n=30) Mean $\pm$ SD	Experimental (n=26) Mean $\pm$ SD	t	<i>p-value</i>
Support	T <sub>0</sub>	7.23 $\pm$ 1.27	7.21 $\pm$ 1.17	0.066	0.947
	T <sub>1</sub>	7.18 $\pm$ 1.09	7.85 $\pm$ 1.10	-2.261	0.028*
	T <sub>2</sub>	7.00 $\pm$ 1.13	7.79 $\pm$ 1.25	-2.479	0.016*

\*  $p \leq 0.05$

### *Negative emotions*

Tables 7.60, 7.61, 7.62, and 7.63 show the scores for the perspective on negative emotions among the groups. The repeated measures analysis showed that there were significant differences in the within-group effect ( $F=6.529$ ,  $p=0.002$ ), the between-group effect ( $F=9.222$ ,  $p=0.004$ ), and the interaction effect ( $F=16.617$ ,  $p=0.000$ ). There were significant differences in the experimental group over time ( $F=18.844$ ,  $p=0.000$ ), but no significance was found in the control group over time ( $F=2.736$ ,  $p=0.084$ ). Within the experimental group, there were significant differences in  $T_0$  vs.  $T_1$  ( $p=0.000$ ) and  $T_0$  vs.  $T_2$  ( $p=0.004$ ), but not in  $T_1$  vs.  $T_2$  ( $p=0.098$ ). Regarding the interaction effect, there were significant differences at  $T_1$  ( $t=-4.224$ ,  $p=0.000$ ) and  $T_2$  ( $t=-3.569$ ,  $p=0.001$ ), but not at  $T_0$  ( $t=-0.028$ ,  $p=0.978$ ).

**Table 7.60 Mean scores for negative emotions at three time intervals in the PP sample**

	Control group (n=30)			Experimental group (n=26)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Negative emotion	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	7.44 $\pm$ 1.38	7.13 $\pm$ 1.72	6.94 $\pm$ 1.35	7.45 $\pm$ 1.39	8.89 $\pm$ 1.33	8.33 $\pm$ 1.56

**Table 7.61 Comparison of negative emotions between the two groups across three time intervals in the PP sample**

Effect	df	F	<i>p</i> -value
Within group (Time)	2	6.529	0.002**
Between groups (Group)	1	9.222	0.004**
Time $\times$ Group	2	16.617	0.000**

\*\*  $p \leq 0.01$

**Table 7.62 Comparison of negative emotions of each group at three time intervals in the PP sample**

	df	Within-group effect	
		F value	<i>p-value</i>
Control group	1.65	2.736 <sup>a</sup>	0.084
Experimental group	2	18.844	0.000**
		Mean difference	<i>p-value</i>
Experimental group			
T <sub>0</sub> &T <sub>1</sub>		-1.442	0.000**
T <sub>0</sub> &T <sub>2</sub>		-0.875	0.004**
T <sub>1</sub> &T <sub>2</sub>		0.567	0.098

\*\*  $p \leq 0.01$

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (Epsilon), since Mauchly's test of Sphericity is not assumed.

**Table 7.63 Comparison of negative emotions between the two groups at each time interval in the PP sample**

	Time interval	Control (n=30)	Experimental (n=26)	t	<i>p-value</i>
		Mean $\pm$ SD	Mean $\pm$ SD		
Negative emotions	T <sub>0</sub>	7.44 $\pm$ 1.38	7.45 $\pm$ 1.39	-0.028	0.978
	T <sub>1</sub>	7.13 $\pm$ 1.72	8.89 $\pm$ 1.33	-4.224	0.000**
	T <sub>2</sub>	6.94 $\pm$ 1.35	8.33 $\pm$ 1.56	-3.569	0.001**

\*\*  $p \leq 0.01$

### *Sense of alienation*

Tables 7.64, 7.65, and 7.66 show the scores for the perspective on the sense of alienation among the groups. The repeated measures analysis showed that there were no significant differences in the within-group effect ( $F=0.645$ ,  $p=0.527$ ), but a borderline significance in the between-group effect ( $F=4.072$ ,  $p=0.049$ ), and a significance in the interaction effect ( $F=11.376$ ,  $p=0.000$ ). The Independent Sample t-test indicated that there were significant differences in sense of alienation between the two groups at T<sub>1</sub> ( $t=-3.123$ ,  $p=0.003$ ) and T<sub>2</sub> ( $t=-3.622$ ,  $p=0.001$ ), but not at T<sub>0</sub> ( $t=1.003$ ,  $p=0.320$ ).

**Table 7.64 Mean scores for sense of alienation at three time intervals in the PP sample**

	Control group (n=30)			Experimental group (n=26)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Sense of alienation	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	7.07 $\pm$ 1.43	6.47 $\pm$ 1.45	6.39 $\pm$ 1.18	6.64 $\pm$ 1.74	7.65 $\pm$ 1.38	7.44 $\pm$ 0.95

**Table 7.65 Comparison of sense of alienation between the two groups across three time intervals in the PP sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	0.645	0.527
Between groups (Group)	1	4.072	0.049*
Time $\times$ Group	2	11.376	0.000**

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$

**Table 7.66 Comparison of sense of alienation between the two groups at each time interval in the PP sample**

	Time interval	Control (n=30) Mean $\pm$ SD	Experimental (n=26) Mean $\pm$ SD	t	<i>p-value</i>
Sense of alienation	T <sub>0</sub>	7.07 $\pm$ 1.43	6.64 $\pm$ 1.74	1.003	0.320
	T <sub>1</sub>	6.47 $\pm$ 1.45	7.65 $\pm$ 1.38	-3.123	0.003**
	T <sub>2</sub>	6.39 $\pm$ 1.18	7.44 $\pm$ 0.95	-3.622	0.001**

\*\*  $p \leq 0.01$

### ***Existential distress***

Tables 7.67, 7.68, 7.69, and 7.70 show the scores for the perspective on existential distress among the groups. The repeated measures analysis revealed that there were significant differences in the within-group effect ( $F=13.616$ ,  $p=0.000$ ), the between-group effect ( $F=18.230$ ,  $p=0.000$ ), and the interaction effect ( $F=13.740$ ,  $p=0.000$ ). The significant within-group effect was found in the control group ( $F=21.837$ ,  $p=0.000$ ) and a borderline effect was observed in the experimental group ( $F=3.132$ ,  $p=0.052$ ). The Post-hoc tests of the control group showed significant differences at  $T_0$  vs.  $T_1$  ( $P=0.000$ ),  $T_0$  vs.  $T_2$  ( $p=0.000$ ), and  $T_1$  vs.  $T_2$  ( $p=0.038$ ). When examining the differences in existential distress between the two groups at each time interval, the Mann-Whitney U test indicated that there were significant differences at  $T_1$  ( $z = -4.145$ ,  $p = 0.000$ ) and  $T_2$  ( $z = -4.060$ ,  $p=0.000$ ), but not at  $T_0$  ( $z=-0.286$ ,  $p=0.775$ ).

**Table 7.67 Mean scores for existential distress at three time intervals in the PP sample**

	Control group (n=30)			Experimental group (n=26)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Existential distress	$T_0$	$T_1$	$T_2$	$T_0$	$T_1$	$T_2$
	7.98 $\pm$ 2.12	6.24 $\pm$ 2.60	5.04 $\pm$ 2.79	8.26 $\pm$ 1.70	9.01 $\pm$ 1.16	8.17 $\pm$ 2.27

**Table 7.68 Comparison of existential distress between the two groups across three time intervals in the PP sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	2	13.616	0.000**
Between groups (Group)	1	18.230	0.000**
Time $\times$ Group	2	13.740	0.000**

\*\*  $P \leq 0.01$

**Table 7.69 Comparison of existential distress within each group in the PP sample**

	Within-group effect		
	df	F value	p-value
Control group	2	21.837	0.000**
Experimental group	2	3.132	0.052
Mean difference			p-value
Control group			
T <sub>0</sub> &T <sub>1</sub>		1.733	0.000**
T <sub>0</sub> &T <sub>2</sub>		2.933	0.000**
T <sub>1</sub> &T <sub>2</sub>		1.200	0.038*

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ .

**Table 7.70 Comparison of existential distress between the two groups at each time interval in the PP sample**

	Time interval	Control (n=30)	Experimental (n=26)	z	p-value
		Mean $\pm$ SD	Mean $\pm$ SD		
Existential distress	T <sub>0</sub>	7.98 $\pm$ 2.12	7.88 $\pm$ 2.24	-0.286	0.775
	T <sub>1</sub>	6.24 $\pm$ 2.60	8.49 $\pm$ 2.01	-4.145	0.000**
	T <sub>2</sub>	5.04 $\pm$ 2.79	7.66 $\pm$ 2.73	-4.062	0.000**

\*\*  $p \leq 0.01$

### *Value of life*

Tables 7.71, 7.72, 7.73, and 7.74 display the scores for the perspective on the value of life among the groups. The repeated measures analysis revealed that there were significant differences in the within-group effect ( $F=11.404$ ,  $p=0.000$ ), the between-group effect ( $F=40.662$ ,  $p=0.000$ ), and the interaction effect ( $F=102.613$ ,  $p=0.000$ ). The significant within-group effects were observed in both the control group ( $F=85.991$ ,  $p=0.000$ ) and the experimental group ( $F=43.331$ ,  $p=0.000$ ). The Post-hoc tests indicated that the control group showed significant differences in T<sub>0</sub> vs. T<sub>1</sub> ( $p=0.000$ ), T<sub>0</sub> vs. T<sub>2</sub> ( $p=0.000$ ), and T<sub>1</sub> vs. T<sub>2</sub> ( $p=0.000$ ); the experimental group showed significant differences in T<sub>0</sub> vs. T<sub>1</sub> ( $p=0.000$ ) and T<sub>0</sub> vs. T<sub>2</sub> ( $p=0.000$ ), but not in T<sub>1</sub> vs. T<sub>2</sub> ( $p=0.896$ ). The Independent Sample t-test indicated significant differences between the two groups at T<sub>1</sub> ( $t=-8.510$ ,  $p=0.000$ ) and T<sub>2</sub> ( $t=-9.057$ ,  $p=0.000$ ), but not at T<sub>0</sub> ( $t=1.526$ ,  $p=0.133$ ).



**Table 7.71 Mean scores for value of life at three time intervals in the PP sample**

	Control group (n=30)			Experimental group (n=26)		
	Mean $\pm$ SD			Mean $\pm$ SD		
Value of life	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>	T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	5.14 $\pm$ 1.07	4.27 $\pm$ 1.12	3.48 $\pm$ 1.06	4.71 $\pm$ 1.02	6.68 $\pm$ 0.97	6.47 $\pm$ 1.40

**Table 7.72 Comparison of value of life between the two groups across three time intervals in the PP sample**

Effect	df	F	<i>p-value</i>
Within group (Time)	1.76	11.404 <sup>a</sup>	0.000**
Between groups (Group)	1	40.662	0.000**
Time $\times$ Group	1.76	102.613 <sup>a</sup>	0.000**

\*\*  $p \leq 0.01$

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (Epsilon), since Mauchly's test of Sphericity is not assumed.

**Table 7.73 Comparison of value of life within each group in the PP sample**

	Within-group effect		
	df	F value	<i>p-value</i>
Control group	2	85.991	0.000**
Experimental group	1.45	43.331 <sup>a</sup>	0.000**
Mean difference			<i>p-value</i>
<b>Control group</b>			
T <sub>0</sub> &T <sub>1</sub>		0.867	0.000**
T <sub>0</sub> &T <sub>2</sub>		1.656	0.000**
T <sub>1</sub> &T <sub>2</sub>		0.789	0.000**
<b>Experimental group</b>			
T <sub>0</sub> &T <sub>1</sub>		-1.968	0.000**
T <sub>0</sub> &T <sub>2</sub>		-1.756	0.000**
T <sub>1</sub> &T <sub>2</sub>		0.212	0.896

\*\*  $p \leq 0.01$

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (Epsilon), since Mauchly's test of Sphericity is not assumed.

**Table 7.74 Comparison of value of life between the two groups at each time interval in the PP sample**

	Time interval	Control (n=30)	Experimental (n=26)	t	p-value
		Mean $\pm$ SD	Mean $\pm$ SD		
Value of life	T <sub>0</sub>	5.14 $\pm$ 1.07	4.71 $\pm$ 1.02	1.526	0.133
	T <sub>1</sub>	4.27 $\pm$ 1.12	6.68 $\pm$ 0.97	-8.510	0.000**
	T <sub>2</sub>	3.48 $\pm$ 1.06	6.47 $\pm$ 1.40	-9.057	0.000**

\*\*  $p \leq 0.01$

### 7.8 Comparison of results from the ITT analysis and PP analysis

In the ITT analysis (Table 7.75), there were significant within-group effects on overall QOL, physical discomfort, food-related concerns, health care concerns, negative emotions, existential distress, and value of life. There were significant between-group effects on overall QOL, health care concerns, negative emotions, sense of alienation, existential distress, and value of life. There were significant interaction effects on overall QOL, support, negative emotions, sense of alienation, existential distress, and value of life.

In the PP analysis (Table 7.75), significant within-group effects were observed on overall QOL, physical discomfort, food-related concerns, health care concerns, negative emotions, existential distress, and value of life. Significant between-group effects were identified on overall, physical discomfort, health care concerns, negative emotions, sense of alienation, existential distress, and value of life. Significant interaction effects were detected on overall QOL, support, negative emotions, sense of alienation, existential distress, and value of life.

**Table 7.75 The results from the ITT analysis and PP analysis**

	ITT analysis								PP analysis							
	WE	WE <sub>E</sub>	WE <sub>C</sub>	BE	IE	IE <sub>T1</sub>	IE <sub>T2</sub>		WE	WE <sub>E</sub>	WE <sub>C</sub>	BE	IE	IE <sub>T1</sub>	IE <sub>T2</sub>	
Overall QOL	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
Physical discomfort	*	*	*	NS	NS	NS	NS	*	*	*	*	*	NS	NS	NS	NS
Food-related concerns	*	*	*	NS	NS	NS	NS	*	NS	*	NS	NS	NS	NS	NS	NS
Health care concerns	*	*	NS	*	NS	NS	NS	*	NS	NS	NS	*	NS	NS	NS	NS
Support	NS	NS	NS	NS	*	*	*	NS	NS	NS	NS	NS	*	*	*	*
Negative emotions	*	*	*	*	*	*	*	*	*	*	NS	*	*	*	*	*
Sense of alienation	NS	NS	NS	*	*	*	*	NS	NS	NS	NS	*	*	*	*	*
Existential distress	*	NS	*	*	*	*	*	*	NS	*	*	*	*	*	*	*
Value of life	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*

WE: Within-group effect (time) in two groups;

WE<sub>E</sub>: Within-group effect (time) in the experimental group

WE<sub>C</sub>: Within-group effect (time) in the control group

BE: Between-group effect (group)

IE : Interaction effect (time×group) at three time intervals

IE<sub>T1</sub>: Interaction effect (time×group) at T<sub>1</sub>

IE<sub>T2</sub>: Interaction effect (time×group) at T<sub>2</sub>

“\*”: a significant difference

“NS”: no significant difference

The comparison of the significant results of these two strategies of analysis indicated three situations: (1) significant results in both the ITT analysis and the PP analysis; (2) significant results in the PP analysis but not in the ITT analysis; and (3) significant results in the ITT analysis but not in the PP analysis. First, in this study most ITT results were similar to the PP results. This suggests that although some subjects were noncompliant, they might be equally distributed between the experimental and control groups. This is supported by the results of the study indicating that, at the baseline assessment there were no significant

differences in socio-demographic, clinical characteristics, and QOL between the participants who had completed the study and those who had not, except for gender, overall QOL, and health care concerns.

Second, the significant differences in food-related concerns, health care concerns, and negative emotions within the experimental group were observed in the ITT analysis but not in the PP analysis. This reveals that there might be a confounding reason for such differences (Wang & Bakhai, 2006). Thus, when interpreting these significant results, some other possible reasons apart from the intervention need to be taken into consideration.

Third, a significant between-group effect on physical discomfort was found in the PP analysis but not in the ITT. It is possible that the reasons for the high rate of non-compliance in this study are related to the effectiveness of the life review on physical discomfort. Given that the ITT analysis can preserve the strengths of randomization, the main conclusions of the study would be drawn from the results of the ITT analysis.

## **CHAPTER 8**

### **QUALITATIVE RESULTS**

This chapter reports the qualitative results of the study. The qualitative data were divided into three groups according to the changes of their overall QOL before and after the life review program. Each group's perceptions of participation in the program are described.

#### **8.1 Characteristics of the participants**

##### **8.1.1 Categorization of the participants**

Twenty-six patients who completed the life review program participated in the semi-structured interviews on perceptions of the program. To separately analyze the perceptions of participants with different QOL scores, the participants were categorized based on the changes in overall QOL scores before and after the program.

To identify the changes in overall QOL across three time intervals, the scores for overall QOL were defined as three levels by the student researcher. A score of 1 to 3 represented poor overall QOL; a score of 4 to 6 represented moderate overall QOL; and a score of 7 to 10 represented good overall QOL. As shown in Table 8.1, at the baseline assessment ( $T_0$ ), two of the participants indicated that their overall QOL was poor, 23 that it was moderate, and one that it was good. Immediately after the program ( $T_1$ ), 10 indicated that their overall QOL was moderate and 16 that it was good. Three weeks after the program ( $T_2$ ), four said that it was poor, eight that it was moderate, and 14 that it was good. The changes in overall QOL fell into four patterns: (a) QOL level:  $T_0 < T_1 \leq T_2$ ; (b) QOL level:

$T_0 < T_1 > T_2$  and  $T_0 < T_2$ ; (c) QOL level:  $T_0 = T_1 = T_2$ ; and (d) QOL level:  $T_0 = T_1 > T_2$ . The participants in the first two patterns were regarded as the improved group, those in the third pattern as the unchanged group, and those in the fourth pattern as the decreased group. Among the 26 participants, 17 were in the improved group; six were in the unchanged group; and three were in the decreased group.

**Table 8.1 Three types of overall QOL of the participants**

Time	Type of overall QOL		
	Poor n (%)	Moderate n (%)	Good n (%)
$T_0$	2(7.7)	23(88.5)	1(3.8)
$T_1$	0(0.0)	10(38.5)	16(61.5)
$T_2$	4(15.4)	8(30.8)	14(53.9)

### 8.1.2 Characteristics of the three identified groups

In the improved group ( $n=17$ ), ten (58.8%) were male and seven (41.2%) were female. The mean age was 60.29 ( $SD=13.07$ ). The majority had a spouse (70.6%), a secondary school education (70.5%), a religion (64.7%), and a well-functioning family (58.5%). All of the participants lived with their family.

In the unchanged group ( $n=6$ ), four were male and two were female. The mean age was 57.33 ( $SD=9.77$ ). Four participants had received a secondary school education, lived with their family, and had a spouse, a religion, and a well-functioning family.

In the decreased group ( $n=3$ ), one was male and two were female. The mean age was 68.00 ( $SD=9.54$ ). Two of the participants had a secondary school education, a spouse, a religion, and a moderately dysfunctional family. All of them lived with their family. Table 8.2 shows the characteristics of the three identified groups.

**Table 8.2 Characteristics of the three identified groups**

<b>Variable</b>	<b>Total (n=26) n (%)</b>	<b>Improved group(n=17) n (%)</b>	<b>Unchanged group (n=6) n (%)</b>	<b>Decreased Group (n=3) n (%)</b>
<b>Age (years)</b>				
Mean $\pm$ SD	59.12 $\pm$ 12.67	60.29 $\pm$ 13.07	57.33 $\pm$ 9.77	68.00 $\pm$ 9.54
<b>Gender</b>				
Male	15(57.7)	10(58.8)	4(66.7)	1(33.3)
Female	11(42.3)	7(41.2)	2(33.3)	2(66.7)
<b>Educational level</b>				
Primary school	8(30.8)	5(29.4)	1(16.7)	2(66.7)
Secondary school	17(65.4)	12(70.5)	4(66.7)	1(33.3)
Tertiary education	1(3.8)	0(0.0)	1(16.7)	0(0.0)
<b>Marital status</b>				
With spouse	18(69.2)	12(70.6)	4(66.7)	2(66.7)
Without spouse	8(30.8)	5(29.4)	2(33.3)	1(33.3)
<b>Religion</b>				
Yes	17(65.4)	11(64.7)	4(66.7)	2(66.7)
No	9(34.6)	6(35.3)	2(33.3)	1(33.3)
<b>Living status</b>				
Live with family	24(92.3)	17(100.0)	4(66.7)	3(100.0)
Live alone	2(7.7)	0(0.0)	2(33.3)	0(0.0)
<b>Primary caregiver</b>				
Parents	3(11.5)	3(18.8)	0(0.0)	0(0.0)
Spouse	13(50.0)	9(50.0)	3(50.0)	1(33.3)
Children	8(30.8)	5(31.3)	2(33.3)	1(33.3)
Others	2(7.7)	0(0.0)	1(16.7)	1(33.3)
<b>Family function</b>				
No dysfunction	15(57.7)	10(58.8)	4(66.7)	1(33.3)
Moderate dysfunction	10(38.5)	6(35.3)	2(33.3)	2(66.7)
Severe dysfunction	1(3.8)	1(5.9)	0(0.0)	0(0.0)
<b>Family financial status</b>				
Barely sufficient	4(15.4)	4(23.5)	2(28.6)	0(0.0)
Insufficient	12(46.2)	7(41.2)	3(42.9)	2(66.7)
Very insufficient	10(38.5)	6(35.3)	2(28.6)	1(33.3)
<b>Participation in community activities</b>				
Yes	1(3.8)	0(0.0)	0(0.0)	1(33.3)
No	25(96.2)	17(100.0)	6(100.0)	2(66.7)

Cont. Table 8.2 Characteristics of the three identified groups

Variable	Total (n=26) n (%)	Improved group(n=17) n (%)	Unchanged group (n=6) n (%)	Decreased Group (n=3) n (%)
<b>Months with disease</b>				
Mean ± SD	19.50±19.55	21.24±14.24	22.67±22.25	3.33±0.58
<b>Diagnosis</b>				
Gastro-intestinal cancer	12(46.2)	7(41.2)	2(33.3)	3(100.0)
Respiratory cancer	10(38.5)	7(41.2)	3(50.0)	0(0.0)
Gynecological cancer	2(7.7)	1(5.9)	1(16.7)	0(0.0)
Others	2(7.7)	2(11.8)	0(0.0)	0(0.0)
<b>Sites of metastasis</b>				
Multiple sites	5(19.2)	3(17.6)	2(33.3)	0(0.0)
Bone	10(38.5)	8(47.1)	2(33.3)	0(0.0)
Internal organ	6(23.1)	3(17.6)	1(16.7)	2(66.7)
Lymph	5(19.2)	3(17.6)	1(16.7)	1(33.3)
<b>Types of previous treatments</b>				
One	16(61.5)	10(58.8)	3(50.0)	3(100.0)
Two	9(34.6)	6(35.3)	3(50.0)	0(0.0)
Three	1(3.8)	1(5.9)	0(0.0)	0(0.0)
<b>KPS</b>				
40%	7(26.9)	5(29.4)	2(33.3)	0(0.0)
50%	16(61.5)	11(64.7)	3(50.0)	2(66.7)
60%	3(11.5)	1(5.9)	1(16.7)	1(33.3)
<b>Use of other community health services</b>				
Yes	1(3.8)	0(0.0)	0(0.0)	1(33.3)
No	25(96.2)	17(100.0)	6(100.0)	2(66.7)



## **8.2 Perceptions of the life review program in the improved group**

The participants in the improved group perceived that the life review program helped them to (a) accept their unique life; (b) have feelings of emotional relief; (c) achieve a sense of meaning in life; (d) leave a personal legacy; and (e) make future orientation.

### **8.2.1 Accepting one's unique life**

The participants in the improved group stated that through the life review program, they were able to integrate various life experiences and move towards acceptance.

“The program stimulated me to examine my whole life. I appreciated my successes and achievements. I also acknowledged that the negative was a part of my life. Generally, my whole life is okay. I can accept it.” (Case 1)

“Through the life review, I better understood my life. Life is full of ups and downs, no exception for me. I achieved some successes and also encountered some failures. I experienced happy moments and also tough times. Anyway, I have done my best in my life. I have no regrets.” (Case 10)

“I was preoccupied by the illness before. I was very sad since I was just waiting for death. This program prompted me to reconsider my life. I realized that the illness was not my whole life, but merely one of many difficulties in my life. I also experienced something meaningful in my life, such as my work and family. I can say that I have a great life, although it was a little shorter compared to some of my peers.” (Case 15)

“The life review gave me an overall picture of my life. While reviewing my life, the contributions and value of life were identified; and the difficulties and disappointments were also

examined. I know what I did well and what I did not do well in my life. This is my life. It is okay for me.” (Case 16)

### **8.2.2 Having feelings of emotional relief**

The participants in the improved group experienced relief from negative emotions after participating in the life review program. This was because the program offered them a chance to express their feelings and views on their experiences in life, reconcile themselves to the negative aspects of their life, and relive happy moments.

#### **8.2.2.1 Expressing feelings and views on life experiences**

Some participants pointed out that expressing their feelings and thoughts on their experiences in life helped them to ease their mind and achieve a sense of relief.

“During the interviews, I gave full expression to my feelings and what I thought about my past life experiences. I relieved myself of my blue mood.” (Case 1)

“Many things happen in one’s life. It is good to collect them for patients. I even broke into tears when talking about the sad ones. And, I could not help laughing when talking about the happy moments. Anyway, it made me feel relaxed and better.” (Case 10)

#### **8.2.2.2 Reconciling the negative**

Some participants mentioned that they experienced relief from negative feelings through letting go, accepting, and giving positive meaning to their negative experiences.

“After examining the unpleasant experiences, I found that I had no better choice at those moments. It is no use bearing a grudge and blaming others. Let bygones be bygones. Letting go of grudges tended to take away my anger.” (Case 23)

“A series of losses occurred in my life. After discussing them, I learned to put them in their appropriate places. I think that whatever happened in my life was predestined by Heaven. I accepted my fate. This acceptance gives me a peaceful mind. I am not as upset as before.” (Case 16)

“Some people did hurt me a lot in the past. This often makes me feel resentful. But when you asked me whether I had learned something from the events, I realized that the lessons helped me to cope better with my later life. So, my bad feelings went away.” (Case 13)

### **8.2.2.3 Reliving happy moments**

Reliving happy moments was another way in which patients alleviated their negative emotions. This was demonstrated by several cases.

“I am so glad to recall my past life, particularly my childhood. At that time, I lived in the village with beautiful scenery, refresh air, and nice people. I had a very happy life there.... Talking about these memories really cheered me up and alleviated some unpleasant emotions.” (Case 19)

“Reviewing my life helped me recall happy moments in the past, such as my interesting military training, my successful career in the Ya Xi Ya Company, and gatherings with good friends. This alleviated the suffering associated with the illness.” (Case 17)

### **8.2.3 Achieving a sense of meaning in life**

The participants in the improved group felt a sense of meaning in life since, through the life review program, they appreciated their contributions, achievements, and good moral qualities.

### 8.2.3.1 Appreciating contributions and achievements

Some participants expressed the opinion that the life review program had enabled them to perceive meaning in life through identifying and appreciating their contributions and accomplishments, including raising offspring, establishing homes, and having a successful career.

“As a housewife, I was not able to make great contributions to the society, but I did something for my family. I brought up two grandsons, who are now excellent high school students and filial boys. This is the most meaningful thing in my life!” (Case 4)

“For the family, I built this house and helped my son establish his own family. For society, I worked on the village committee to ensure the security of the village. I received some official awards and decorations. These things make me feel that my life is worthwhile. I am satisfied with what I have done.” (Case 15)

“After I got the illness, I felt that I was suffering and that life was meaningless. Reviewing my life helped me to find something meaningful in my life. I, as a professor of Fujian Teachers Training College, had cultivated many students in my career. Some of them have achieved great success in their fields.” (Case 8)

“I have done the best in my life as a daughter-in-law, a wife, a mother, and a clerk. All I have done were beneficial to my family and the society. In this sense, my life is meaningful.” (Case 19)

### 8.2.3.2 Affirming personal moral qualities

Some of the participants mentioned that the life review program helped them to affirm their good personal qualities, particularly those of *Ren* (benevolence 仁), and *Yi* (righteousness 义). These moral qualities gave meaning to their lives.

“After reviewing my life, I understand myself better. In my whole life, I have taken care of my parents and children, loved my

brothers and sisters, and been loyal to my friends. I have never done harm to people or to society. That is why people always say that I am a good person.” (Case 10)

“I used to regard myself as the devil. After re-examining my life, I found that, actually, I also did good things for others. For example, I generously gave 10 or 50 Yuan to disabled beggars. I tried my best to help friends when they were in trouble. To some extent, I am a benevolent person.” (Case 6)

#### **8.2.4 Leaving a personal legacy**

The participants in the improved group valued the life review booklet documenting their significant life experiences, views on life, and words for their loved ones. They regarded the booklet as a personal legacy that would transmit their values in life and help them to be remembered by their loved ones.

“I am so glad to have this booklet. It is invaluable! It will be transferred from one generation to another. My offspring will have an opportunity to know me and learn lessons from my successes and failures.” (Case 21)

“Previously, I worried that my son may not remember me after I die since he is only one and a half years old. Now, I have this wonderful booklet with words and pictures left for him. I believe he will know me and remember me through this booklet.” (Case 9)

“Oh, what a beautiful and meaningful booklet! I like it very much. It will be left for my mother and older sister after I pass away. With this booklet, they can still remember me after I die. Otherwise, I will probably disappear just as I die.” (Case 5)

#### **8.2.5 Making future orientations**

The participants in the improved group indicated that the life review program had helped them to make future orientation, including arranging their funeral and

their money and properties, and leaving words (e.g., advice, blessings) for the bereaved.

“After reviewing my life, I summarized my life and look forward to the future. I am now at the end of my life. I know what to do in my final days. I will arrange some family issues. I will also tell my family to arrange for Buddhist music to be played at my funeral.” (Case 11)

“Through these interviews, I looked back on my life. I went through each stage of life from birth to the present. Now, I have arrived at the final stage of my life. I think it is time to leave my words for the family. And thanks for writing down my instructions and blessings for my family in the life review booklet.” (Case 15)

“Reviewing my life pointed out a direction for me.... When death is inevitable, the most important thing is to make good arrangements for approaching the end of life and not to leave regrets. So, I decide to transfer my money to my wife’s bank account and the ownership of this flat to my son this week.” (Case 10)

### **8.3 Perceptions of the life review program in the unchanged group**

The participants in the unchanged group struggled between accomplished tasks and unresolved conflicts. They indicated that uncontrolled physical discomfort influenced their life review. However, they believed that the life review program helped them by improving their mood and leaving a personal legacy.

#### **8.3.1 Struggling between accomplished tasks and unresolved conflicts**

The participants in the unchanged group recalled life experiences but felt difficulty in integrating positive and negative experiences into a meaningful whole. On the one hand, they confirmed that they had completed responsibilities

to family and society. On the other hand, they were disturbed by unresolved conflicts, such as illness, unemployment, and divorce.

“The life review helped me look back on my life. I have no regrets about the past, since I had accomplished my life tasks. Unfortunately, my later adulthood was accompanied by cancer. Now, I am losing myself. I live just like a monk, who goes on tolling the bell. My life before the illness was meaningful, but it has become meaningless after the illness.” (Case 7)

“During the life review, I recalled the happy times and identified what I have done for my family. I also got a chance to complain about the unpleasant experiences, such as unemployment. It is difficult for me to pretend that they did not happen in my life.” (Case 9)

“The program evoked my memories. I am proud of my good work. But I am frustrated with my family life. What I had done brought irreparable harm for my ex-wife and daughter. I never forgive myself.” (Case 18)

### **8.3.2 Enhancing mood**

The participants in the unchanged group mentioned that sharing life experiences with the facilitator had improved their mood.

“The program gave me a better mood. You were very kind to visit me and patiently listen to my stories. It was the first time for me to share my experiences with others. I even told you some events that my family did not know.” (Case 26)

“At the first interview, I didn’t think I would talk much with you. With the progress of the program, I preferred to share my feelings and thoughts with you. I felt better after our talks.” (Case 9)

“I liked to share my stories with you very much. Our conversations were just like talks between brother and sister. I felt relaxed and happy.” (Case 3)

### **8.3.3 Leaving a generativity booklet**

Similar to the improved group, the unchanged group also expressed the view that the life review booklet served as a personal legacy for their loved ones.

“Actually, the booklet was made for the families rather than for patients themselves. Through this booklet, my offspring have a chance to know me. Furthermore, I hope it can help my family to remember me.” (Case 3)

“The booklet is useful. It will be left behind me for my son. I believe that he can learn something from the booklet. It is helpful for his growth.” (Case 7)

### **8.3.4 Feeling difficulty in reviewing a life due to uncontrolled physical discomfort**

The participants in the unchanged group expressed difficulties in reviewing their life. This was frequently due to uncontrolled physical discomfort, such as pain, breathlessness, and fatigue.

“Although I take pain killers on my physician’s orders, I still suffer from pain sooner or later. When I was encountering pain, I was not able to review my life in detail.” (Case 18)

“The breathlessness prevented me from sharing more stories with you. If I did not suffer from it, I would have done better.” (Case 3)

“Due to the illness, I often felt fatigue during the interviews. I could not afford to analyze my life experiences.” (Case 20)



#### **8.4 Perceptions of the life review program in the decreased group**

Unlike the improved and unchanged groups, the decreased group showed negative perceptions of their participation in the life review program. They were:

(1) being overwhelmed with negative feelings triggered by painful life experiences; and (2) failing to freely share life experiences due to the presence of family members during the interviews.

##### **8.4.1 Being overwhelmed with negative feelings of encountering a painful life**

The participants in the decreased group stated that the life review program evoked painful experiences in their life. Unfortunately, they failed to reconcile these memories into more acceptable or meaningful ones. Instead, these memories triggered negative emotions in them.

“My life was tough. It was full of failures, such as my unhappy marriage and my unsuccessful career. Talking about my past tended to reopen old wounds. It brought out unpleasant emotions.”  
(Case 22)

“Recalling my life reminded me of sad memories. I lost my father in childhood, lost my husband in middle age, and got an incurable disease in old age. These experiences really made me feel sad and in pain.” (Case 2)

##### **8.4.2 Failing to freely share life experiences due to the presence of family members during the interviews**

The participants in the decreased group showed that presence of family members in during the interviews prevented them from freely sharing some experiences that might spoil family relationships or impose a burden on their family.

“It is good to conduct the program using an individual approach. I can freely express my internal thoughts. Honestly, when my

husband was there, it was not good to tell you how he had treated me over the years. Otherwise, he would be angry with me after you left.” (Case 24)

“My daughter’s presence influenced our talks to a degree. I didn’t want to talk about the difficulties of my life in front of her. These experiences would make her feel sorry for me. I didn’t want to add to her burdens.” (Case 22)

## **8.5 Summary**

This chapter described the perceptions of the three identified groups of their participation in the life review program. The improved group perceived that the life review program helped them to: (1) accept their unique life; (2) have feelings of emotional relief; (3) achieve a sense of meaning in life; (4) leave a personal legacy; (5) make future orientation. The perceptions of the unchanged group were of: (1) struggling between accomplished tasks and unresolved conflicts; (2) enhancing mood; (3) leaving a generativity booklet; and (4) feeling difficulty in reviewing a life due to uncontrolled physical discomfort. The perceptions of the experimental patients with decreased QOL involved: (1) being overwhelmed with negative feelings of encountering a painful life; and (2) failing to freely share life experiences due to presence of family members in the interviews.

## **CHAPTER 9**

### **DISCUSSION**

This chapter discusses the quantitative and qualitative results of the study, as described in Chapter 7 and Chapter 8, respectively. The first section discusses the characteristics of the advanced cancer patients who withdrew from this study. The second section focuses on the effect of the life review program on advanced cancer patients. Finally, some reasons for failing to improve QOL are examined.

#### **9.1 Characteristics of the participants who withdrew from this study**

A total of 24 participants withdrew from this study. The proportion of participants in the experimental group who did not complete the study (n=14; 35%) was similar to that of the control group (n=10; 25%). Given the nature of advanced cancer, it probably should not come as a surprise that those did not complete the study did so due to physical discomfort (n=9; 11.3%), cognitive impairment (n=3; 3.7%), and death (n=12; 15.0%).

In this study, 8/80 (10%) participants withdrew immediately after the three-week life review program and 16/80 (20%) three weeks after the program. Compared with Ando et al.'s (2007a) four-week life review, which had a drop-out rate of over 30%, and Steihauser et al.'s (2008) six-week 'life completion and preparation' program, which had a 50% drop-out rate, this study had a lower withdrawal rate. It is likely that patients receiving palliative care at home are less ill than those in palliative care units and hospices.

## **9.2 Effect of the life review program on quality of life**

### **9.2.1 Overall QOL**

The study indicated that the patients in the experimental group demonstrated a significant improvement in overall QOL immediately after the program and three weeks after the program. The reasons for such a significant improvement might initially be due to the methodological advantages of the life review program. First, reviewing a life in the program started with the present and worked back to childhood. This helps patients to appreciate that the program is relevant to their present situation (Garland & Garland, 2001). Once the patients reconciled themselves to their experience with cancer, they were able to move on to reviewing other great life experiences. Second, an individual approach was used in the program to ensure that the patients felt free to reveal their life experiences. As a result, the patients may reconcile themselves to more negative experiences and affirm more positive experiences (Hendricks, 1995). Third, structure, a critical characteristic of a successful life review (Haight & Haight, 2007), is also addressed in this program. The guiding questions for reviewing a life among Chinese patients with advanced cancer were specifically designed to ensure that the patients' reviews cover each stage of their entire life. In addition, different from other studies on life review that are limited to reviewing a life (Ando & Tsuda, 2006; Ando et al., 2007a), the life review program in this study combined reviewing a life and formulating a life review booklet. Similar to other products of storytelling interventions, such as a life review album and a generativity document, a life review booklet can serve as a personal legacy, which may further enhance the effect of the life review (Oleson, 1989). These advantages of the program should help patients to recall, evaluate, and integrate various life

experiences. The qualitative results of this study provide evidence that after participating in the life review program, patients were able to integrate their life experiences and accept their unique life. This acceptance of life implies that patients have a sense of satisfaction with their life and feel the quality of their life (Neugarten, Haighurst & Tobin, 1961)

Another possible reason for the significant increase in overall QOL is that the life review program enabled patients to achieve a positive and accepting view of the cycles of their life. According to the qualitative results of this study, patients affirmed and appreciated their contributions, achievements, and moral qualities, as well as reconciled themselves with negative experiences through letting go, accepting, and giving a positive meaning to these experiences during the program. Finally, they integrated their life experiences into a more acceptable or meaningful whole. The integration enabled patients to form a positive outlook towards their life (Stevens-Ratchford, 1993; Chiang et al., 2008). Thus, they were able to positively evaluate their life, thereby perceiving a better overall QOL (Peck, 2001).

Another significant finding on overall QOL was that the experimental group showed a significant increase immediately after the program but no significant difference at three weeks after the program, compared to the baseline assessment. However, compared with the situation immediately after the program, the mean scores for overall QOL saw a decrease at three weeks after the program. The findings indicate that the life review program is able to improve patients' overall QOL, but that the positive effect deteriorates after the program is discontinued.

This suggests that there is a need to employ the life review as part of the usual arrangements for care, in order to maintain its effect on patients' QOL.

Some other studies shared a similar result with that of this study (Ando et al., 2007a; Steinhauser et al., 2008). Ando et al. (2007a) found that terminal cancer patients in the life review program group had a better overall QOL compared with the control group. Steinhauser et al. (2008) also reported that those eligible hospice patients who participated in a program related to the life review showed an improvement in QOL. Unlike this present study, the above two studies did not examine the extended effect of the life review program. Rather, they adopted a comparison study design or pre-post design. Nevertheless, the above two studies reinforced the findings of this study.

Apart from overall QOL, the effects of the life review program on QOL concerns were also revealed in this study, including physical discomfort, food-related concerns, support, health care concerns, negative emotions, sense of alienation, existential distress, and value of life.

### **9.2.2 Physical discomfort**

Regarding physical discomfort, a significant decline was found in both the control group and the experimental group across three time intervals. This indicated that the physical comfort of patients in both groups worsened over the study period. This is possibly associated with the deterioration resulting from advanced cancer, in which physical symptoms often become serious and even difficult to control.

The insignificance of the difference in physical discomfort between the experimental and control groups may be attributed to the nature of the life review program, which is a psycho-spiritual intervention and therefore has less impact on physical discomfort. However, physical discomfort is associated with psychosocial and spiritual concerns. Thus, symptom management and life review can be integrated to enhance the effect of the life review program.

The findings of this study on physical discomfort are consistent with the results of several other life review studies (Ando et al., 2007a; Steinhauser et al., 2008). Ando et al. (2007a) reported an insignificant change in physical well-being among terminally ill cancer patients who participated in a four-week life review program. Similarly, Steinhauser et al. (2008) found an insignificant pre-post comparison in physical function. The above researchers attributed this result to a small sample size, since the significance may be obscured by the lower statistical power of a small sample. Although the above two studies did not evaluate physical discomfort, their findings on physical well-being or physical functions are similar as the finding of this study.

### **9.2.3 Food-related concerns**

Similar to physical discomfort, a significant within-group effect in food-related concerns was found in both the control and experimental groups. The finding indicated that patients in the two groups had a continuous increase in food-related concerns across three time intervals. One possible reason for this is the loss of appetite resulting from deterioration due to the advancement of the cancer and the management of symptoms (Souter, 2005). Another possible reason is that

the patients were not satisfied with the food, due to the limited choices (Bell, Lee & Ristovski-Slijepcevic, 2009). In addition, patients faced with the fact that they will probably die in the near future often struggle with negative emotions, which would reduce their enjoyment of food. Generally, a vicious cycle of food-related concerns starts when the patients lose their appetite, fail to eat food that they like, and experience unpleasant emotions.

It is worth mentioning that advanced cancer patients attained the lowest score in food-related concerns among eight QOL concerns over the study period. This finding indicated that food-related concerns are the major QOL concern among Chinese patients with advanced cancer. Apart from the possible reasons discussed above, it is also possible that food plays an important role in Chinese people's life. This suggests that other interventions for improving the QOL of Chinese patients with advanced cancer should take food into consideration.

#### **9.2.4 Health care concerns**

Health care concerns are an indicator of how patients evaluate the health care services that are available to them. The greater the concern for health care, the greater the satisfaction with the services. In this study, a significant improvement was found in health care concerns in the experiment group but not in the control group. This finding reveals that patients are more satisfied with the services after participating in the program.

According to Wagner and Bear (2008), effective support, health information, participation in decision-making, and professional/technical competencies can



contribute to patient satisfaction with health care. In this study, the life review program is an individualized and patient-centered intervention. During the program, the facilitator was caring, supportive, respectful, concerned, and empathic. Such an attitude gives patients effective support (Kuosmanen, Hatonen, Jyrykinen, Katajisto & Valimaki, 2006; Liu & Wang, 2007). Although the facilitator did not provide any health information for patients, she did deliver information about affirming positive life experiences and reconciling negative experiences to them. Regarding participation in decision-making, the patients in the life review program group were encouraged to express the future arrangements they would make, and to undertake preparations for death in accordance with their desires. In addition, the higher level of satisfaction with the services may also be due to the facilitator's competence in carrying out the life review, which was to offer to meet the psycho-spiritual needs of the patients.

#### **9.2.5 Support**

In relation to support, a significant change was observed in the interaction effect. Compared with the patients in the control group, patients in the experimental group perceived a higher level of support immediately after the program and three weeks after the program.

The significant improvement in support might be related to the life review program, which offers emotional, appraisal, informational, and instrumental support. First, the facilitator's caring attitude, empathy, and presence in listening to the patients' stories with genuine interest and complete attention may give patients emotional support (Finfgeld-Connett, 2005; Finfgeld-Connett, 2007;

Ando et al., 2007a). Second, the facilitator provided appraisal support for the patients by affirming their positive experiences and unconditionally accepting all of their stories (Langford, Bowsher, Maloney & Lillis, 1997). Third, the facilitator's words of reassurance and skills at reflection may render information support to the patients. Last, but not least, the facilitator provided a tangible service by compiling a life review book for the patients.

The finding of this study is congruent with the result of Ando et al.'s (2007a) study. They reported that terminal cancer patients participating in their four-week life review program achieved a higher level of social support immediately after the program.

#### **9.2.6 Negative emotions**

In this study, patients in the experimental group demonstrated a significant reduction in negative emotions immediately after the program and three weeks after the program, compared with patients in the control group.

The finding is supported by the qualitative results of this study, indicating that the life review program helped patients gain relief from their negative feelings or positively enhanced their moods. Some participants stated that the program provided them with an opportunity to express feelings and thoughts about their life experiences, and therefore resulted in a relief from negative emotions, consistent with the findings of Butler (2009). Some participants stated that reliving past happy moments helped to alleviate their negative emotions. This is echoed by Jones et al. (2003), who explained that positive experiences rekindle

positive thoughts and balance against negativity, making a person feel better. Some participants expressed the view that reconciling themselves to negative experiences contributed to a relief from negative feelings, because the reconciliation enabled them to let go, accept and/or give new meanings to the negative experiences. Other participants stated that sharing life experiences improved their mood. This is confirmed by the findings of Symes et al.'s (2007) study. They reported that a life review enhances mood through alleviating loneliness, talking about one's life, having a therapeutic listener, and following a chronological frame. In some ways, the life review is a way of gaining psychological purification (Ando et al., 2007).

This study also indicated that patients in the experimental group demonstrated a significant increase in the mean scores for negative emotions immediately after the life review program and three weeks after the program, compared to the baseline assessment. However, when compared with the situation immediately after the program, the mean scores for negative emotions showed a significant decrease at three weeks after the program. The results indicated that the life review program could reduce the patients' negative emotions but that such an effect deteriorated after the discontinuation of the program. This suggests a need to use the life review as part of the usual arrangements for care, in order to sustain the effect of the life review program with regard to negative emotions.

The findings of this study on negative emotions are similar to the results of some other studies. Although other studies did not evaluate changes in negative emotions, participants in their life review programs demonstrated a significant

decrease in depression (Haight et al., 1998; Watt & Cappeliez, 2000; Jones, 2003; Hanaoka & Okamura, 2004; Ando & Tsuda, 2006; Mastel-Smith et al., 2007) and anxiety (Ando et al., 2007b), as well as a significant improvement in psychological well-being (Haight, 1988; Haight et al., 1998).

#### **9.2.7 Sense of alienation**

Alienation is an experience of disconnectedness with one's self, with others, and with one's god, nature, or a transcendent realm of being (Younger, 1995). In this study, patients in the experimental group demonstrated a significant reduction in sense of alienation immediately after the program and three weeks after the program, compared with patients in the control group.

One possible reason for the significant reduction in sense of alienation is that the life review program helps patients to connect with their self (Younger, 1995). This is supported by the qualitative results of this study. After participation in the life review program, participants were able to integrate previous stages of their life, accept their unique life, achieve a sense of meaning in life, and make future orientations, leading to ego integrity, which will be discussed in detail in section 9.4.

Another possible reason for a reduced sense of alienation is that the life review program helps patients to connect with others. During the program, the facilitator established a connection with patients by visiting them, supporting them, and sharing their life experiences. More importantly, the facilitator guided patients to reconcile old conflicts, for example past estrangements from other people,

through forgiving, accepting, and letting go. After the reconciliation of the estrangements, the patients moved to amend broken relationships and reconnect with cut-off relatives, friends, and family (Zerwekh, 2006).

Finally, the significant reduction in sense of alienation may be due to the fact that the life review program helps patients to connect with God, nature, or a transcendent realm of being (Younger, 1995). In the life review program, patients were asked to discuss the role played by religion and/or belief in heaven in each stage of life. This provides patients with an opportunity to reunite with God or their faith, thereby reducing their sense of alienation.

#### **9.2.8 Existential distress**

Existential distress is a form of internal distress, when a person is unable to see meaning in his or her existence (Frankl, 1985). In this study, patients in the experimental group demonstrated a significant mitigation in existential distress immediately after the program and three weeks after the life review program. The sense of existential distress was mitigated after the program, possibly because the program enabled patients to find meaning in life (Butler, 1974). This is supported by the qualitative results of this study, indicating that participants **achieved a sense of meaning in life** after the program. Some participants showed that they found meaning in life from their contributions to and achievements in family and/or society. Other participants found meaning in life from their moral qualities, such as Ren (benevolence) and Yi (righteousness). Once meaning in life is identified, existential distress will be alleviated.

The mitigation of existential distress may also relate to the fostering of hope after the life review program. Herth (1990) and Johnson (2007) have reported that life review is a hope-fostering strategy. During the life review program, patients relived their positive and happy moments, and acknowledged their interesting and fulfilling lives. These memories can serve to enrich the present moment and renew the process of hope. Furthermore, patients were invited to express their hopes for their loved ones in the program, which was documented in the life review booklets.

The reduction of existential distress could also be explained by the fact that the life review program alleviates a sense of powerlessness among advanced cancer patients. Powerlessness means that a person notes the loss of certainty and feels that life is subject to unknown conditions that s/he can not control (Sharoff, 2004). A sense of powerlessness over an uncertain future is not uncommon in patients approaching death. The life review program encouraged them to clarify their future arrangements and prepare for death. This is supported by the qualitative results of this study, indicating that through a life review patients were able to make future orientations, such as arranging funerals, money, and properties, as well as leaving words for the bereaved. These plans contributed to reducing their sense of powerlessness.

No study has reported the effect of life review on existential distress among patients with cancer or other life-threatening diseases. But several other studies concerning the elderly share a similar result with this study (Hanaoka & Okamura 2004; Haight et al., 1998; Serrano et al., 2004; Liao & Lin, 2008).

While these studies did not examine the effect of the life review program on existential distress, they evaluated hopelessness and powerlessness. The studies of Hanaoka and Okamura (2004), Haight et al. (1998), and Serrano et al. (2004) indicated that the elderly in the life review program demonstrated a significant decrease in hopelessness immediately after the program and/or three months or one year after the program. Liao and Lin (2008) reported that one elderly stroke patient experienced a reduction in feelings of powerlessness after participating in a life review. Their findings reinforced the finding of this study on existential distress.

#### **9.2.9 Value of life**

In this study, patients in the experimental group demonstrated a significant improvement in value of life immediately after the program and three weeks after the program compared with the control group. Such an effect can be explained by Confucian views on the value of life. The Confucian belief is that people relate the value of life to “Li Gong” (立功), “Li De” (立德) and “Li Yan” (立言), which are called the “Three Eternities in Life” (人生三不朽) (Zuo 2003). The qualitative results of this study support the assertion that the life review program help patients to value their life by affirming their “Li Gong,” “Li De,” and “Li Yan.”

“Li Gong” refers to making great contributions to and achievements in family and society (Liu, 1996). In this study, the patients with improved overall QOL pointed out that the life review program enabled them to identify and appreciate their contributions and accomplishments, such as raising offspring, establishing

homes, and having a successful career. This affirmation of their contributions and accomplishments in family and society enhanced their self-esteem (Garland & Garland, 2001).

“Li De” refers to developing and practising the virtues and personal qualities that Confucius had highlighted as being particularly important (Liu, 1996). Ren (benevolence) and Yi (righteousness) are basic virtues in Confucianism. Ren indicates the relationship between two people. In practice, Ren means loving people. Yi means doing what is morally right and proper in any situation with regard to the Five cardinal Relations, namely between the emperor (government) and people, parent and child, spouses, siblings, and friends (Lian, Wang & Wang, 2005). Thus, practising Ren and Yi indicates “Li De.” In this study, participants with improved overall QOL stated that the life review program facilitated them to affirm their personal qualities, particularly Ren and Yi. Therefore, the program improves the value of life among Chinese patients with advanced cancer.

“Li Yan” means that people leave behind their great writings as an immortal legacy to all posterity (Liu, 1996). The life review booklet produced in this study served as a kind of “Li Yan.” Most participants considered the life review booklet to be a personal legacy. The booklet documented the patients’ significant experiences, views on life, and words for loved ones. It not only transmitted the patients’ life values, but also helped them to be remembered by their offspring.

In addition, patients in the experimental group demonstrated a significant increase in value of life immediately after the program and three weeks after the



program, compared with the baseline assessment. However, no significant difference in value of life was found between immediately after the program and three weeks after the program within the experimental group. This indicated that the life review program could improve the patients' feelings about value of life, but that the effect deteriorated after the discontinuation of the program. This suggests that there is a need to use life review as part of the usual arrangements for care, in order to maintain the effect of the program on the value of life.

The findings of this study are similar to the results of other studies (Ando & Tsuda, 2006; Ando et al., 2007a, 2007b). Ando and Tsuda (2006) reported that cancer patients receiving the life review program demonstrated a significant improvement in self-esteem immediately after the program. Ando et al. (2007a, 2007b) found that terminal cancer patients in the life review group demonstrated a significant improvement in spiritual well-being immediately after the program.

It should be noted that this study indicated that value of life was the second major QOL concern of Chinese patients with advanced cancer. Through the life review program, the patients demonstrated the greatest improvement in value of life among the eight QOL concerns. This suggests that patients benefit most from the life review program in the area of improving value of life.

## **Summary**

In response to research questions One and Two about the effect of the life review program on QOL, this study was able to demonstrate its therapeutic effects on overall QOL, health care concerns, support, negative emotions, sense of

alienation, existential distress, and value of life. However, this study failed to find it effective in alleviating physical discomfort and food-related concerns. Thus, the null hypothesis, which stated that there was no difference in QOL within and between the control and experimental groups, cannot be fully rejected. The results of this study also revealed that the life review program may benefit advanced cancer patients most in the aspect of improving value of life.

In response to research question Three about the patients' perceptions of their participation in the life review program, this study indicated that the program helped participants to undertake preparations for death and achieve ego integrity.

### **9.3 Impact of the life review program on preparations for death**

Preparations for death, making arrangements for approaching the end of one's lifespan, are a particularly important aspect in palliative care. Western literature has reported that preparing for death involves thinking about the past, talking to other persons about death, naming a decision maker, putting one's affairs in order, planning one's estate and/or signing a will, and making preparations for one's funeral (Steinhauser et al., 2000; Pinquart & Sorensen 2002). In the Chinese context, people make personal preparations for death by organizing their material affairs, leaving instructions and a will, giving gifts, and arranging their funeral (Mak, 2007).

The qualitative results of this study indicated that the life review program enabled patients with improved overall QOL to make future orientations. During the program, patients were encouraged to review their entire life. The reviews

helped them to value their life experiences, reconcile old conflicts, and complete unfinished business. Chan and Yau (2009-2010) claimed that a re-examination of values in one's life and the completion of unfinished tasks are equated with early preparations for death. More than an examination of the past, the reviews also increased the patients' awareness of their current situation, with death being in the forefront. This motivates the patients to think about what they will do with the time they have left and what things they want to give, and legacy they want to leave, to their loved ones. As a result, the patients moved to make plans for the future. They started to make arrangements on the disposal of their money and property, and planning their funeral. They also left words (e.g., advice and blessings) for the bereaved, which were recorded in the life review booklet. Thus, the life review program enables patients to prepare for death. This view was supported by Pickrel (1989), who reported that life review is a means of resolving conflicts and help individuals to prepare for death.

It is worth mentioning that the life review program is a challenge to customary beliefs about death. Usually, in Chinese society death is thought of as a social taboo. People believe that talking about death will attract evil spirits, bring bad luck, or even increase the likelihood of its occurrence (Ding, 2000). They attempt to avoid the word "death" in daily life; instead they replace it with the phrase "he is not here now" (Zheng, 1994). This avoidance of death leads to a lack of open communication and active preparation for death-related issues (Chan & Chow, 2006). However, our life review program included death as a life theme for reviewing a life. It encouraged patients to openly discuss death-related issues. It also helped patients to undertake preparations by making plans for the

future, such as funeral arrangements, arrangements for their property and money, and leaving words for the bereaved.

#### **9.4 Impact of the life review program on ego integrity**

Ego integrity is a sense of wholeness and coherence. According to Erikson (1950), major constituents of ego integrity involve accepting one's one and only life cycle, giving order and meaning to one's life, and having no fear of death.

The qualitative results of this study found that patients with improved overall QOL were able to accept their unique life after participating in the life review program. During the life review, the facilitator guided patients to reaffirm positive experiences, particularly their contributions to family and society and their moral qualities (e.g., benevolence, filial piety, and righteousness). The facilitator also helped the patients to reconcile their failures and disappointments by letting them go, accepting them, and giving new significance to these experiences based on their stories and beliefs. The facilitator encouraged those with a belief in Taoist philosophy to pardon their own mistakes or those of others, and set negative experiences aside since doing nothing (*Wu Wei* 无为) and letting nature take its course are considered to be important approaches to self-cultivation in Taoist philosophy (Zhu, 2000). For patients with a belief in heaven, the facilitator guided them to accept negative experiences because heaven determines all things, such as the time of birth, the hour of death, the manner of death, and the experiences between birth and death (Li, 2005a; Lian, Wang & Wang, 2005). Furthermore, since the meaning of old stories depends on personal interpretations of life experiences (Drewery, Winslade & Monk, 2000), the

patients were also facilitated to optimistically interpret the negative experiences in their own way, so as to give positive meaning to life's difficulties and disappointments. In short, from different perspectives, those unpleasant stories were reconstructed to bring about desired changes in the patients' views of themselves and their world. Finally, various life experiences were integrated into an acceptable whole, and the patients moved towards acceptance.

The patients with improved overall QOL also stated that the life review program enabled them to achieve a sense of meaning in life. When reviewing a life through evaluating the past, the patients affirmed their contributions, achievements, and good moral qualities. They further found meaning in life from these positive experiences. This finding was supported by Frankl (2006), who proposed that meaning in life can be discovered by three ways: by creating a work or doing a deed; by experiencing goodness, truth, and beauty; and by taking positive attitudes towards unavoidable suffering. The contributions, achievements, and good moral qualities fall into the first way of man's search for meaning. This finding can also be explained by Confucian views on value of life, wherein "Li Gong" (contributions and achievements 立功) and "Li De" (high moral qualities 立德) are two aspects for achieving immortality of the spirit, as described in section 9.2.

In addition, transcending their fear of death, after participating in the life review program patients with improved overall QOL were able to undertake preparations for death, as described in section 9.3.

In general, the life review program helped patients accept their unique life, achieve a sense of meaning in life, and make future orientations. This suggests that the life review program may facilitate the achievement of ego integrity, as reported by Erikson (1986) and Butler (1963). Indeed, accepting one's unique life and achieving a sense of meaning in life also contribute to a better QOL. Neugarten, Haighurst, and Tobin (1961) proposed that acceptance of life can improve life satisfaction. A higher level of life satisfaction equals the perception of a better QOL. In addition, meaning in life is spiritual/existential in aspect, which has been demonstrated to be a major determinant of QOL among patients approaching death (Cella, 1991; Lo et al., 2002). Achieving a sense of meaning in life implies a better QOL.

## **9.5 Reasons for failing to improve quality of life**

The reasons for failing to improve QOL among patients receiving the life review program were uncontrolled physical discomfort, painful life experiences, and the presence of family members during the interviews.

### **9.5.1 Uncontrolled physical discomfort**

Some patients whose overall QOL was unchanged expressed the view that uncontrolled physical discomforts, such as pain, breathlessness, and fatigue, hindered them in reviewing their life in depth. The quantitative results of this study also indicated that nine patients withdrew from the study due to physical discomfort. These results suggest that the priority in caring for patients should be symptom control. Otherwise, it would be meaningless for them to participate in a life review program. This was echoed by Jenko et al. (2007), who found that it

impossible to conduct a life review when the patients' physical symptoms were not well controlled. Therefore, there is a great need to control physical discomfort before starting a psycho-spiritual intervention.

### **9.5.2 Painful life experiences**

Patients with decreased overall QOL stated that they experienced negative feelings since the life review program evoked painful experiences in their life. Although the life review program aims to help patients integrate their entire life, including positive and negative experiences, into an acceptable or meaningful whole, these patients were preoccupied by the painful experiences, thereby triggering their negative emotions. This finding is consistent with previous reports (Lashley, 1993; Korte, Bohlmeijer & Smit, 2009), indicating that a life review may cause emotional distress and even despair to patients. This suggests that the life review program may not be applicable to those with painful life experiences. This kind of patient should be referred to a professional psychologist.

### **9.5.3 Presence of family members during the interviews**

Although our life review program was designed for Chinese patients with advanced cancer, the families of two patients with decreased overall QOL participated in the life review interviews. The study found that the presence of family members prevented patients from freely sharing their life experiences during the life review. Possibly, most Chinese prefer not to burden their families. Once family members are present in the life review interviews, the patients will first be concerned about the feelings of their family. Some experiences,

particularly negative experiences, may be evoked but not shared. Therefore, the presence of family members interferes with the effect of the life review program on QOL. However, western literature suggests that a life review with family members present will provide patients and families with a means of sharing their thoughts and engaging in mutual discussions about end-of-life problems (Haight & Bahr, 1984; Ufema, 2002). Further studies are needed to explore the role of family members in a life review.

Apart from the above three reasons, certain characteristics of the patients may also influence the changes in the overall QOL of advanced cancer patients participating in a life review program. This study found that patients with decreased overall QOL tended to have a more dysfunctional family, tighter family finances, and to have been ill with cancer for fewer months, as compared with the patients with improved and unchanged overall QOL. The findings indicated that family function, family finances, and duration on cancer may be associated with the decreased overall QOL, as found in previous studies (Jia et al., 2000; Yang, Qiu, Lu & Pang, 2005; Zheng et al., 2007; He, 2009). Thus, family function, family finances, and duration on cancer may have contributed to a decrease in the QOL of the patients who participated in the life review program.

## **9.6 Summary**

This chapter has critically discussed the quantitative and qualitative results of this study, see table 9.1.



**Table 9.1 Factors and positive outcomes in life review**

<b>Factors</b>	<b>Positive outcome in life review</b>
<ul style="list-style-type: none"> <li>★ Methodological advantages of the life review program <ul style="list-style-type: none"> <li>- <i>Starting with the present and worked back to childhood in a life review</i></li> <li>- <i>Using an individual approach</i></li> <li>- <i>Designing specific guiding questions for reviewing a life among Chinese patients with advanced cancer</i></li> <li>- <i>Combining reviewing a life and formulating a life review booklet in the program</i></li> </ul> </li> <li>★ Forming a positive outlook towards life</li> </ul>	Overall QOL
<ul style="list-style-type: none"> <li>★ Effective support from the facilitator</li> <li>★ Information about review a life from the facilitator</li> <li>★ Participation in decision-making</li> <li>★ Facilitator's professional/technical competencies</li> </ul>	Health care concerns
<ul style="list-style-type: none"> <li>★ Facilitator's caring attitude, empathy, and presence</li> <li>★ Affirming participants' positive experiences and unconditionally accepting all of their stories</li> <li>★ Facilitator's words of reassurance and skills at reflection</li> <li>★ Compiling a life review book for participants</li> </ul>	Support
<ul style="list-style-type: none"> <li>★ Expressing feelings and thoughts</li> <li>★ Reliving past happy moments</li> <li>★ Reconciling themselves to negative experiences</li> </ul>	Negative emotions
<ul style="list-style-type: none"> <li>★ Connecting with their self</li> <li>★ Connecting with others</li> <li>★ Connecting with God, nature, or a transcendent realm of being</li> </ul>	Sense of alienation
<ul style="list-style-type: none"> <li>★ Achieving a sense of meaning in life</li> <li>★ Fostering of hope</li> <li>★ Alleviating a sense of powerlessness</li> </ul>	Existential distress
<ul style="list-style-type: none"> <li>★ Appreciating contributions and accomplishments</li> <li>★ Affirming personal qualities</li> <li>★ Leaving a personal legacy</li> </ul>	Value of life
<ul style="list-style-type: none"> <li>★ Making arrangements on the disposal of money and property</li> <li>★ Planning their funerals</li> <li>★ Leaving words (e.g., advice and blessings) for the bereaved</li> </ul>	Preparation for death
<ul style="list-style-type: none"> <li>★ Encouraging patients to openly discuss death-related issues</li> <li>★ Helping patients to undertake preparations</li> </ul>	Challenge to customary beliefs about death
<ul style="list-style-type: none"> <li>★ Accepting unique life</li> <li>★ Achieving a sense of meaning in life</li> <li>★ Making future orientations</li> </ul>	Ego integrity

This study has been able to demonstrate that the life review program, including reviewing a life and formulating a life review booklet, has a significant effect on improving QOL in terms of overall QOL, health care concerns, support, negative emotions, sense of alienation, existential distress, and value of life. The effectiveness of the program on health care concerns may mainly be attributed to the facilitator's visits. However, the effectiveness of the program on overall QOL, negative emotions, sense of alienation, existential distress, and value of life may largely be due to the life review program.

The qualitative results indicated that the life review program can encourage patients to undertake preparations for death by making future orientations, such as making arrangements for the disposition of money and property, and funeral arrangements, and leaving words for the bereaved in the life review booklet. This is a challenge to customary beliefs about death. The qualitative results also showed that the life review program can help patients to achieve ego integrity through accepting their unique life, achieving a sense of meaning in life, and making future orientations. In addition, this study revealed some reasons for failing to improve overall QOL, including uncontrolled physical discomfort, painful life experiences, and the presence of family members during the interviews. This provides directions for future life review programs in Chinese communities.

## **CHAPTER 10**

### **IMPLICATIONS, LIMITATIONS, AND RECOMMENDATIONS**

This final chapter begins with a summary of the key findings and contributions. Then, the implications for practice, the limitations of this study, and recommendations for further study are presented. The thesis ends with the conclusions of this study.

#### **10.1 Key findings and contributions**

The purpose of this study was to develop a life review program and evaluate its effects with a sample of Chinese patients with advanced cancer in Fuzhou. First, the life review program for Chinese patients with advanced cancer was designed and validated. Then, an RCT was adopted to examine the effect of the developed program on the QOL of Chinese patients with advanced cancer. Semi-structured interviews were employed to elicit the patients' perceptions of their participation in the program.

##### **10.1.1 Develop a life review program for Chinese patients with advanced cancer**

Based on Erikson's theory, Confucian thoughts on human development, our previous findings, and the literature, a life review program was specifically designed for Chinese patients with advanced cancer. Compared with other life review programs, the program that was developed has four unique characteristics: (1) Common life themes for Chinese people have been added to enhance the cultural sensitivity of the program; (2) Cancer-related life themes are addressed to increase the specificity of the program for advanced cancer patients; (3) A life

review booklet is produced for patients to value their entire life and leave a personal legacy for their loved ones; and (4) Reviewing a life conducted from the present to childhood helps patients to appreciate that the life review program is relevant to their present situation.

### **10.1.2 Enhance quality of life through the life review program**

This is the first RCT to implement and evaluate life review among Chinese advanced cancer patients. The findings indicate that the life review program has a positive effect on the QOL of advanced cancer patients, including overall QOL, support, negative emotions, sense of alienation, existential distress, and value of life. Among them, patients benefit most from the life review program in the aspect of improving the value of life. This study provides new evidence to support that the life review is an effective psycho-spiritual intervention in palliative care, particularly in improving QOL among Chinese advanced cancer patients.

This study also indicated the need to integrate the life review program into usual care for Chinese patients with advanced cancer because it is effective in improving QOL, but its effectiveness cannot be maintained after the discontinuation of the program. The use of life review will not only enrich the nurses' knowledge and skills in psycho-spiritual care, but also enhance their feelings of professionalism and self-esteem. Usually, palliative care providers have difficulties in finding job satisfaction, since death is considered a failure in health services (Ding, 2000). Mastel-Smith et al.'s (2006) study has indicated that delivering a successful life review may improve the job satisfaction of home

workers as facilitators, because their input is valued and deemed important to the patients.

### **10.1.3 Undertake preparations for death through the life review program**

This is the first descriptive, qualitative study to explore perceptions of participation in a life review program among advanced cancer patients. The study showed that the life review program enables such patients to make future orientations, such as making arrangements for the disposal of money and properties, and for their funeral, and leaving words for the bereaved in the life review booklet. This finding indicates that the program is a challenge to customary beliefs about death, which is considered to be a social taboo. The findings provide evidence for using life review to help Chinese patients undertake preparations for death.

### **10.1.4 Facilitate ego integrity through the life review program**

The qualitative results of this study showed that patients are able to accept their unique life, achieve a sense of meaning in life, and make future orientations after participating in a life review program. The results contribute to a better understanding of how the life review enables Chinese patients with advanced cancer achieve ego integrity.

## **10.2 Implications for practice**

### **10.2.1 Application of life review in the context of China**

This study has revealed some suggestions for implementing a life review program in the context of palliative care in China to enhance advanced cancer

patients' psycho-spiritual well-being, which involve reviewers, implementers and implementation.

### **Reviewers of a life review**

What kind of Chinese patients with advanced cancer patients is appropriate to participate in the life review program? First, the patients should know their diagnosis, prognosis, and therapy. In the context of China, physicians used to tell family members about their loves' diseases, particularly advanced cancer, rather than the patients. In order to protect their loves, family member often do not tell them the truth. Before conducting a life review program, the facilitator should make sure that the patients have known their diagnosis, prognosis, and therapy.

Secondly, the patients' functional performance status should be good enough for reviewing a life, for example, their KPS is not less than 40%. In the life review program, the participants are required to recall, evaluate and integrate the entire life. If they are too weak, they will unable to complete the whole program. Consequently, the life review program will not benefit them but give them burdens.

Thirdly, it is not necessary to exclude patients with painful life experiences. In the life review sessions, the facilitator of this study observed that three patients' life experiences were painful which temporarily trigger their negative feelings; while they still wanted someone there to listen to their stories. One of them even sat outside her door to wait for the facilitator's coming. Furthermore, our RCT indicated that the experimental group had a higher overall QOL after the life

review program, comparing with the control group. However, it is a good point to be aware of such issues in the future studies. Some suggestions for dealing with this issue are (1) to terminate the life review interview; (2) to refer the patients to psychologist; (3) to more closely observe and more sensitive to detect patients' emotional change when conducting a life review.

### **Implementers of a life review**

Some writers categorized life review as a therapy, suggesting that facilitators need a high level of knowledge and skills to engage in life review work (Trueman & Parker, 2004). However, some authors contested that facilitators do not need to be a specialist in life review because the goal of life review is not in-depth psychotherapy (Mastel-Smith *et al.*, 2006; Haight & Haight, 2007). Our experiences of implementing the life review program suggest that nurses or other health providers can be the life review facilitators. Some competencies are required to ensure that they are adequately prepared, which involve knowledge, skills and attitudes.

### ***Knowledge***

To provide a life review for patients with life-threatening diseases, for example advanced cancer, facilitators need to know medical knowledge related to the illness, such as diagnosis, causes, disease progression, treatment and prognosis. Facilitators should also be familiar with health problems encountered by the patients, including physiological, psychological, social and spiritual aspects. This will help facilitators in understanding patients' illness experiences and major concerns.

Facilitators are required to have knowledge associated with life review, including its theoretic basis, components, benefits and limitations. This enables facilitators to acknowledge the mechanism of life review, informing facilitators how life review works. The limitations will remind facilitators be sensitive to patients' emotional reactions and know when to refer patients to psychological professionals. This is helpful in preventing patients from emotional distress resulting from reviewing negative events.

The facilitators should also have understanding of religions and traditional values and beliefs, which have a great impact on patients' lives. Particularly, familiar with Confucian thoughts, Buddhism and Taoism will contribute to understand Chinese patients' views on various life events, and their coping strategies when confronting with difficulties. This will help facilitators in guiding patients how to affirm positive events and reconcile negative ones.

### ***Skills***

The facilitators have to be proficient in interview skills. Fostering a good working relationship with patients is particularly important. A warm-up visit prior to life review sessions is helpful in getting familiar with each other. It also contributes to prepare patients for talking their life experiences with a facilitator as a therapeutic listener. Some friendly, appropriate, small talks at the beginning of each session of life review also help the facilitators to establish close relationship with the patients.



During the process of life review, attentive behaviors, such as facial expression, eye contact and appropriated posture, ensure that the facilitators show their interest in patients' stories. Encouragement to talk prompts the patients to tell their stories and feelings and views. Affirming helps the facilitators to guide patients how to acknowledge their unique personal Characteristics derived from life events (e.g., tough, brave, full of love), as well as reinforce possible contributions of life events. Summarizing is helpful in highlighting the main points at the end of each session and leading the patients to a happy end of this session. Integrating is another technique used in a life review. When patients' life stories consist of disparate events that seem to have no clear point but yet told with great energy and emotion by the patients, the facilitators have to use this technique to puts those events together, helping patients make an acceptable whole of separate parts. Meanwhile, integrating helps the patients to thread the past, present and future.

Counseling skills are also needed. Reconciling negative experiences is an important task in a life review. Reframing helps the patients to see negative events in different perspectives so that the patients may have a new interpretation or new meaning on the events. Letting go is helpful in relieving the patients from negative experiences and begin with a clear paper. Using religion or traditional values and beliefs to facilitate an acceptance of negative experiences is another skill the facilitators can adopted. Furthermore, the facilitators should be sensitive to the patients' emotional reactions. The facilitator should provide emotional supports or refer the patients to psychological professionals according to the level of the emotional reactions.

Additionally, the use of the guideline of life review is emphasized. The facilitators structure the process of life review by asking the probing questions from the guideline of life review. The facilitator should start from the general questions at each stage in order to gain a general picture of the patients' lives of this stage. The following questions are not required to be asked in the chronological order and wording of the questions because it is a semi-structured interview. Patients are allowed to move back and forth from one life stage to another when telling their stories but their life reviews should cover each life stage.

### ***Attitudes***

An unconditional acceptance is the first priority for facilitating the patients to review a life. The facilitators should respect all participants, and accept their stories regardless of good or evil. This acceptable attitude is also applicable to the situation that the patients decided to withdraw the life review program.

More than accepting patients, caring presence is suggested for the facilitator during the process of life review. The facilitators should be intentionally authentic to response to the patients' life stories. Presence at the end of life involves "talking soul to soul". The facilitators should also be patient to listen to the patients' stories. This creates a no hurry conversation atmosphere. It allows the patients to have enough time to recall and evaluate their life experiences. Consequently, the patients are able to freely talk about their stories and express their feelings and thoughts. Furthermore, the facilitators have to be empathic to

share the patients' stories. This will help patients to reveal more life events and work more pains.

There is no fixed number of hours for training to be a qualified facilitator. It all depends on potential facilitator's professional background, knowledge and skills on psychology, counseling and communication, experiences in conducting psychological interventions, working experiences for palliative care patients, et al. In average, if they are nurses with bachelor degree in nursing, around 20-30 hours of training is necessary.

### **Implementation of a life review**

This study also reveals some key points for implementing a successful life review for advanced cancer patients. First of all, physical discomfort should be well managed before a life review so that patients can actively engage in reviewing their life. Second, a privacy and confidential environment should be provided for patients. The facilitator needs to privately ask patients whether it is fine for members of their family to participate in their life review. If a patient has any concern about the participation of family, family members should not be present in that patients' life review. Third, if patients are overwhelmed by painful life experiences during or after the life review, they should be referred to a professional psychologist.

In hospital settings, life review can be adopted as usual care. It can be well organized by primary nurses. The nurses can divide a life review into several small reviews, with each review addressing one or several related life themes,

based on their daily available time and the patients' preferences. Due to the limited hospital stay, a shorter-term life review program is recommended. However, the role of a life review booklet should be highlighted in the life review program since the booklet can enhance the effect of the life review on the psycho-spiritual well-being of advanced cancer patients. Given that formulating a life review booklet is a time-consuming task, the format and content of the booklet can depend on the patients' preferences and available resources (e.g., nurses' time) in clinical practice. Importantly, the objectives of the booklet in helping patients to value their life and leave a tangible legacy should be addressed. In home settings, our life review program is more appropriate. Home visiting nurses can follow our design to implement the life review weekly for three weeks in an individual approach.

It is worth mentioning that some life themes are overlapped in the life- stage-based review. This often caused patients to move back and forth from one life stage to another as they talked about their stories. It might be better to organize a life review by life themes rather than life stages. Importantly, the review should cover the whole span of a person's life. No matter the life review is stage-based or theme-based, talking about the illness should be a start point since it is the patients' most significant concern.

### **10.2.2 Implications for physical management in palliative care services**

This study indicated that the life review program is not effective in reducing physical discomfort and food-related concerns among advanced cancer patients. However, these physical problems are major concerns of the patients, as food-

related concerns and physical symptoms attained the first and the third lowest score in QOL concerns, respectively. If physical symptoms are not well managed, they will adversely affect the patients' psychosocial and spiritual well-being. Indeed, symptom control is basic to palliative care, and medication and therapies are available to tackle the problem. Thus, it is urgent for nurses and other health providers to enhance symptom control in clinical practice. For physical discomfort, nurses can provide a continuous assessment (e.g., of intensity, duration, frequency, and influencing factors), monitor patients' compliance with treatment, and use appropriate alternative therapies (e.g., acupuncture or massage). For food-related concerns, nurses can identify existing and potential factors or reasons for the problem (e.g., loss of appetite, dissatisfaction with the food, negative feelings), and then plan and implement a multi-disciplinary care program.

### **10.2.3 Implications for nursing education and professional training**

Although nurses are well-positioned to assume their responsibilities in palliative care, in their daily practice in mainland China they rarely go beyond physical care to meet the needs of palliative care patients for psycho-spiritual care. The main reason for failing to take on psycho-spiritual care is the lack of relevant knowledge and skills (Hua et al., 2007). This study has explored a unique approach for Chinese nurses to provide psycho-spiritual support through helping patients to review their life. This requires adequate knowledge and skills on how to conduct a life review and interviews, and on the religious and traditional values and beliefs of Chinese people. To help nurses to learn such knowledge and skills more effectively, training in psycho-spiritual care should be fostered in

the undergraduate nursing education curriculum and continuing training should also be provided to further equip them with the relevant skills.

### **10.3 Limitations of this study**

There are several limitations in this present study. First, the participants were recruited from one hospice in Fuzhou. The homogeneous characteristics of the participants, in terms of socio-demographics and clinical conditions, also limit the generalizability of the results of the study to the whole population of Chinese advanced cancer patients. The findings of the study will not only be applied to advanced cancer patients in Fujian receiving hospice services, but also to advanced cancer patients in other cities of mainland China, whose socio-demographics and clinical characteristics are similar to those of the study sample and who are receiving similar hospice services as those provided by the Fujian hospice.

The second limitation is that this study is neither double nor single blinded because it is impossible to blind participants to what intervention they received and to blind the student researcher of the study intervention and group assignment. To some extent, the positive changes in the experimental group may result from the subjects' awareness of the intervention and the student researcher's expectations.

Other limitations related to the collection and analysis of the qualitative data. The student researcher acted as both the implementer of the life review program and the collector of the qualitative data. This might have prevented the patients

from freely expressing their personal views on the program. Negative perceptions may be hidden. In addition, considering the patients' state of ill health, they were not invited to verify the qualitative findings. However, agreement on the qualitative results was sought between the student researcher and her chief-supervisor, who separately analyzed the qualitative data. The qualitative results were verified by two co-supervisors and an independent reviewer.

#### **10.4 Recommendations for further study**

Further studies on the use of the life review program could be improved in some aspects. One possible improvement that could be made is to expand the scope of this study. This study was conducted in one hospice in Fujian among Chinese advanced cancer patients. Additional research needs to be done to explore the effect of the program on Chinese advanced cancer patients from various palliative care settings in other cities of mainland China. Apart from patients with advanced cancer, it would also be useful to examine use of the life review program in patients with other life-threatening diseases.

The life review program is another important consideration in further studies. The program of this study constructed an approach to reviewing a life according to the stages of a life, based on Erikson's theory. However, some life themes overlapped in different life stages. Therefore, it was not unusual for patients to move back and forth from one life stage to another as they talked about their stories. It might be better to organize a life review by life themes rather than life stages, but the review should cover the whole span of a person's life. Further studies are needed to refine the life review program and test its efficacy.

Another aspect to be considered is the outcome measures of the life review program. Due to the scope and purpose of this study, this study did not explore the facilitator's perceptions of performing the program. Further studies exploring the experiences of facilitators may contribute to proving its effects on enhancing staff feelings of professionalism and self-esteem. In addition, the patients gave the life review booklet a high appraisal, indicating that they saw the booklet as a personal legacy to leave for the bereaved. It is worth exploring perceptions of the booklet among the bereaved to see whether the booklet helps to alleviate their grief or that of others.

Beyond the objectives of this study, an extra finding of this study was that food-related concerns were the greatest concern among advanced cancer patients over the study period. Future studies should develop interventions to address this issue.

### **10.5 Conclusion**

This is the first study in mainland China to develop a life review program for advanced cancer patients and evaluate its effects. This study integrated Chinese culture and the characteristics of advanced cancer patients into Haight's structured life review to produce a specific life review program for Chinese patients with advanced cancer. Unlike previous studies on life review, which have focused on reviewing a life, this program combines reviewing a life and formulating a life review booklet to enhance the effects on psycho-spiritual well-being. Different from previous studies, which have started a life review from childhood to the present, this program adopts a reverse sequence, reviewing a life from the present to childhood, in order to address the current major concerns of



the patients. Although, in common with previous programs this program includes death as a life theme, this program poses a challenge to customary beliefs about death in Chinese culture.

This RCT is a pioneer study concerning life review in palliative care. This is the first study with strong scientific rigor in design, overcoming the aforementioned weakness in previous studies on life review for cancer patients, such as the lack of a control group, no randomized assignment, and a small sample size, with less than 30 subjects in each group. Furthermore, this study adopted some QOL concerns, apart from overall QOL, as outcomes. The program has been demonstrated to be effective in improving QOL, particularly in support, negative emotions, sense of alienation, existential distress, and value of life.

This is the first study to elicit the perceptions of advanced cancer patients of their participation in a life review program. The patients' perceptions indicate that the program enables patients to undertake preparations for death through making future orientations. In mainland China, no intervention study concerning preparing for death is available, possibly because death is regarded as a social taboo. However, preparing for death is essential for a good death, which is considered as one blessing among the Chinese Five Blessings and Longevity (i.e., longevity, wealth, health and peace, the living of a virtuous life, and a good death) (Mak, 2007). This study is the first to indicate that life review is an approach for helping Chinese advanced cancer patients to make preparations for death.

The patients' perceptions of their participation in the life review program also indicate that the program can help advanced cancer patients achieve ego integrity through accepting their unique life, achieving a sense of meaning in life, and making future orientations. From a theoretical perspective, some authors have suggested that the life review is an appropriate approach for helping palliative care patients achieve ego integrity since they are confronted with a similar crisis as that which older people face—the fact that they are approaching death (de Ramon, 1983; Ufema, 2002; Trueman & Parker, 2004, 2006). However, no empirical study has directly explored the relationship between life review and ego integrity among advanced cancer patients. This is the first qualitative study to do so, and it indicates that a life review can facilitate ego integrity among Chinese advanced cancer patients.

From the clinical perspective, the life review program can be integrated into daily care to enhance the psycho-spiritual well-being of Chinese advanced cancer patients. Nurses should be adequately trained to deliver a life review. The use of life review will not only benefit patients, but also enhance the job satisfaction of nurses or other providers as facilitators. Further research should be carried out on advanced cancer patients from various palliative care settings in other cities of mainland China to confirm the effect of the life review program.

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**INFORMATION SHEET**  
**(Development and evaluation of a life review program**  
**for Chinese advanced cancer patients)**

I am Huimin Xiao, a PhD student at The Hong Kong Polytechnic University. You are invited to participate in a study conducted by me, and supervised by Dr. Enid Kwong (chief supervisor), Prof. Esther Mok (co-supervisor), and Prof. Samantha Pang (co-supervisor).

This aim of this research is to develop a life review program and test its effect on the quality of life of patients with advanced cancer. The participants will receive hospice services as usual. If necessary, the participants will be invited to share their life experiences with the researcher at their own homes and the interviews will be tape-recorded. The participants will be visited three times to collect data. Furthermore, the participants' medical records will be reviewed by a research assistant in order to copy disease-related information for the study. It is hoped that this study will facilitate the provision of palliative care and improve the quality of life of advanced cancer patients.

In this research, a few questions designed to guide you to integrate the events of your life into a meaningful whole may cause you temporary discomfort. You have the right not to answer them. All of the information relating to you will remain confidential, and will be identifiable by codes known only to the research team. You have every right to withdraw from the study before or after it has commenced without penalty in terms of the services that are provided to you by the Hospice.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Mr. Eric Chan, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in person or in writing (c/o Human Resources Office in Room M1303 of the University).

If you would like more information about this study, please contact Ms. Huimin Xiao at 2766, 4820 or Dr. Enid Kwong at 2766, 6385.

Thank you for your interest in participating in this study.

**Ms. Huimin Xiao**

Research student



## 有關資料

### 晚期癌症患者人生回顧干預措施的發展與評價專案

我是香港理工大學博士研究生 肖惠敏，誠邀閣下參加由鄭惠容博士、莫孫淑冰教授、彭美慈教授負責監督，由我負責執行的研究計劃。

這項研究的目的是發展一個人生回顧干預措施，並探討其對晚期癌症患者的生存質量的成效。參與者將照常接受寧養院的服務。必要時，研究者將邀請與參與者在其家中傾談參與者的人生經歷，訪問的內容將被錄音。病人將接受 3 次的調查評估。此外，研究助理將查閱參與者的醫療病歷，以收集與疾病相關的資訊和體能水平的資料。本研究將促進舒緩護理和提高晚期癌症患者的生存質量。

在這項研究中，個別引導閣下將人生事件整合成一個有意義整體的問題可能引起閣下暫時不適的感覺。閣下有權利不予回答。凡有關的資料均會保密，一切資料的編碼只有研究人員知道。閣下享有充分的權利在研究開始之前或之後決定退出這項研究，而不會受到任何對閣下不正常的待遇或被追究責任。

如果閣下對這項研究有任何的不滿，可隨時與香港理工大學人事倫理委員會秘書聯絡（地址：香港理工大學人力資源辦公室 M1303 室轉交）。

如果閣下想獲得更多有關這項研究的資料，請與肖惠敏女士，電話 2766，4820，或與鄭惠容博士，電話 2766，6385 聯絡。

謝謝閣下有興趣參與這項研究。

肖惠敏  
博士研究生



**CONSENT TO PARTICIPATE IN RESEARCH**  
**(Development and evaluation of a life review program**  
**for Chinese advanced cancer patients)**

I \_\_\_\_\_ hereby consent to participate in the captioned research conducted by Ms. Huimin Xiao, supervised by Dr. Enid Kwong (chief supervisor), Prof. Esther Mok (co-supervisor), and Prof. Samantha Pang (co-supervisor).

.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e., my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained. I understand the benefits and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Name of participant \_\_\_\_\_

Signature of participant \_\_\_\_\_

Name of Parent or Guardian (if applicable) \_\_\_\_\_

Signature of Parent or Guardian (if applicable) \_\_\_\_\_

Name of researcher \_\_\_\_\_

Signature of researcher \_\_\_\_\_

Date \_\_\_\_\_





## 參與研究同意書

### (晚期癌症患者人生回顧干預措施的发展与评价)

本人\_\_\_\_\_同意參加由肖惠敏負責執行,由鄺惠容博士、莫孫淑冰教授、彭美慈教授負責監督的研究項目。

我理解此研究所獲得的資料可用於未來的研究和學術交流。然而我有權保護自己的隱私,我的個人資料將不能洩漏。

我對所附資料的有關步驟已經得到充分的解釋。我理解可能會出現的風險。我是自願參與這項研究。

我理解我有權在研究過程中提出問題,并在任何時候決定退出研究而不會受到任何不正常的待遇或被追究責任。

參加者姓名: \_\_\_\_\_

參加者簽名: \_\_\_\_\_

父母姓名或監護人姓名: (如需要) \_\_\_\_\_

父母或監護人簽名: (如需要) \_\_\_\_\_

研究人員姓名: \_\_\_\_\_

研究人員簽名: \_\_\_\_\_

日期: \_\_\_\_\_

## **Haight's life review and experiencing form**

### Childhood

1. What is the very first thing you can remember in your life? Go as far back as you can.
2. What other things can you remember about when you were very young?
3. What was life like for you as a child?
4. What were your parents like? What were their weakness, strengths?
5. Did you have any brothers or sisters? Tell me what each was like.
6. Did someone close to you die when you were growing up?
7. Did someone important to you go away?
8. Do you ever remember being very sick?
9. Do you ever remember having an accident?
10. Do you remember being in a very dangerous situation?
11. Was there anything that was important to you that was lost or destroyed?
12. Was church a large part of your life?
13. Did you enjoy being a boy/girl?

### Adolescence

1. When you think about yourself and your life as a teenager, what is the first thing you can remember about that time?
2. What other things stand out in your memory about being a teenager?
3. Who were the important people for you? Tell me about them---parents, brothers, sisters, friends, teachers, those you were especially close to, those you admired, those you wanted to be like.
4. Did you attend church and youth groups?
5. Did you go to school? What was the meaning for you?
6. Did you work during these years?
7. Tell me of any hardships you experienced at this time.
8. Do you remember feeling that there wasn't enough food or necessities of life as a child or adolescent?
9. Do you remember feeling left alone, abandoned, not having enough love or care as a child or adolescent?
10. What were the pleasant things about your adolescence?

11. What was the most unpleasant thing about your adolescence?
12. All things considered, would you say you were happy or unhappy as a teenager?
13. Do you remember your first attraction to another person?
14. How did you feel about sexual activities and your own sexual identity?

### Family and Home

1. How did your parents get along?
2. How did other people in your home get along?
3. What was the atmosphere in your home?
4. Were you punished as a child? For what? Who did the punishing?  
Who was “boss”?
5. When you wanted something from your parents, how did you go about getting it?
6. What kind of person did your parents like the most? The least?
7. Who were you closest to in your family?
8. Who in your family were you most like? In what way?

### Adulthood

1. What place did religion play in your life?
2. Now I'd like to talk to you about your life as an adult, starting when you were in your twenties up to today. Tell me of the most important events that happened in your adulthood.
3. What was life like for you in your twenties and thirties?
4. What kind of person were you? What did you enjoy?
5. Tell me about your work. Did you enjoy your work? Did you earn an adequate living? Did you work hard during those years? Were you appreciated?
6. Did you form significant relationships with other people?
7. Did you marry?  
(No) why not?  
(Yes) what kind of person was your spouse?
8. Do you think marriages get better or worse over time?  
Were you married more than once?
9. On the whole, would you say you had a happy or unhappy marriage?

10. Was sexual intimacy important to you?
11. What were some of main difficulties you encountered during your adult years?
  - a. Did someone close to you die? Go away?
  - b. Were you ever sick? Have an accident?
  - c. Did you move often? Change jobs?
  - d. Did you ever feel alone? Abandoned?
  - e. Did you ever feel need?

### Summary

1. On the whole, what kind of life do you think you've had?
2. If everything were to be the same would you like to live your life over again?
3. If you were going to live your life over again, what would you change? Leave unchanged?
4. We've been talking about your life for quite some time now. Let's discuss your overall feelings and ideas about your life. What would you say the main satisfactions in your life have been? Try for three. Why were they satisfying?
5. Everyone has had disappointments. What have been the main disappointments in your life?
6. What was the hardest thing you had to face in your life? Please describe it.
7. What was the happiest period of your life? What about it made it the happiest period? Why is your life less happy now?
8. What was the unhappiest period of your life? Why is your life more happy now?
9. What was proudest moment in your life?
10. If you could stay the same age all your life, what age would you choose? Why?
11. How do you think you've made out in life? Better or worse than what you hoped for?
12. Let's talk a little about you as you are now. What are the best things about the age you are now?
13. What are the worst things about being the age you are now?
14. What are the most important things to you in your life today?
15. What do you hope will happen to you as you grow older?
16. What do you fear will happen to you as you grow older?
17. Have you enjoyed participating in this review of your life?

## Guiding questions for reviewing a life among advanced cancer patients

## 晚期癌症病人人生回顾引导性问题

Session	Life theme	Guiding question
Session 1 The present (cancer experiences)  单元一 现阶段 (癌症经历)	Cancer 癌症  Death 死亡	Tell me about your disease. 告诉我你的病情。  How does the disease affect you and you life? 疾病对你和你的生活有哪些影响?  How do you deal with disease? 你是如何应付疾病的?  What have learned from the disease? 你从疾病中学到哪些?  What do you think about birth, aging, illness and death? 你是如何看待生、老、病、死的?
	Family 家庭	What are your concerns for your family in the current situation? 在目前疾病情况，你对家人有哪些担心?  If your disease becomes worse, what hopes, blessings, and advice do you have for your family? 如果疾病恶化，你对家人或他人有什么希望、祝福、建议?
	Belief in Heaven 命运	How did you perceive destination in related to your disease? 你觉得命运与你的疾病有怎样的联系?
Session 2 Adulthood  单元二 成年时期	General 综合性	Tell me important events that happened in your adulthood. 告诉我你成年后发生的重要事情。
	Dealings with people	How do you deal with people? 你是如何待人处事的?
	Work 工作	Tell me about your work. 告诉我你的工作情况。
	Sex 性	Did you marry? 你结婚了吗?  (No) Why not? (否) 为什么没有结婚?  (Yes) What kind of person was your spouse? (是) 偶配是怎样的人?

		<p>How was your marriage over time?</p> <p>随着时光的流逝，你的婚姻怎样？</p>
	<p>Family</p> <p>家庭</p>	<p>Please tell me about your family member.</p> <p>请告诉我你的家庭成员情况。</p> <p>What have you done for your family?</p> <p>你为家人做了些什么？</p>
	<p>Hardship</p> <p>艰难</p>	<p>What were the main difficulties you encountered during your adult years? 你成年后经历了哪些艰难困苦？</p>
	<p>Religion</p> <p>宗教信仰</p>	<p>What place did religion play in your life?</p> <p>宗教信仰在你生活中有多重要？</p>
<p>Session 3</p> <p>Childhood &amp; Adolescence</p> <p>单元三</p> <p>儿童时期</p> <p>青少年时期</p>	<p>General</p> <p>综合性</p>	<p>What things impress you most at your childhood and adolescence?</p> <p>令你印象最深刻的儿童和青少年时期的事情是什么？</p>
	<p>Relationship</p> <p>关系</p>	<p>How is your relationship with your family?</p> <p>你跟家人的关系如何？</p> <p>Please tell me about your friends</p> <p>请谈谈你的朋友。</p>
	<p>School 上学</p>	<p>How were your studies? 你的学习怎么样？</p>
	<p>Labor 劳动</p>	<p>How was your work as a child?</p> <p>你小时候做工怎么样？</p>
	<p>Food 食物</p>	<p>What do you feel about insufficient food in childhood or adolescence?</p> <p>你对儿童、青少年时期没有足够食物有什么感受？</p>
	<p>Grief/Fear</p> <p>伤心/害怕</p>	<p>What do you feel about being left alone, abandoned, and not being loved or cared as a child or adolescent?</p> <p>你对儿童与少年时期被单独留下，被遗弃，不被爱与呵护有什么感受？</p>
	<p>Religion</p> <p>宗教信仰</p>	<p>What place did religion play in your life?</p> <p>宗教信仰在你生活中有多重要？</p>

## **Protocol of the life review program**

This protocol was developed to guide a facilitator to conduct the life review program for Chinese advanced cancer patients.

### **1. Purpose of the life review program**

The life review program aims to help patients with advanced cancer achieve ego integrity through recalling, evaluating, and integrating their various life experiences into a more acceptable or meaningful whole.

### **2. Content of the life review program**

The life review program includes reviewing a life and formulating a life review booklet. Reviewing a life is divided into three sessions. The first session is to review the present, addressing the life themes of cancer, family, belief in heaven and death. The second session focuses on reviewing adulthood, and involves the life themes of work, sex, hardship, religion, family and dealing with people. The final session addresses childhood and adolescence, reviewing the life themes of school, religion, relationship, grief, fear, food, and labor. The life review booklet is documented with patients' significant experiences, views on life, and words for their loved ones. The patients' favorite photos and pictures will be pasted in the booklet.

### **3. Guidelines of the life review program**

#### **3.1 Guidelines for reviewing a life**

The facilitator in the life review program is required to guide advanced cancer patients to review a life by following the guidelines for reviewing a life. The guidelines involve: (1) showing attentive behavior; (2) stimulating patients to recall memories; (3) facilitating patients to affirm positive experiences; and (4) reconciling negative experiences, as shown in Table 1.

**Table 1 Guidelines for facilitating a life review**

Facilitator's skills	Guidelines
Show attentive behavior	<ul style="list-style-type: none"> <li>*Sit with a leaning forward posture.</li> <li>*Make and maintain eye contact with patients.</li> <li>*Attentively listen to patients' stories with empathy, understanding, and unconditional acceptance.</li> <li>*Encourage patients with words and facial expressions, such as nodding.</li> </ul>
Facilitate patients to recall memories	<ul style="list-style-type: none"> <li>* Use the guiding questions from the guidelines for reviewing a life (Appendix 3.2) to stimulate patients to recall life experiences at each stage of life.</li> <li>*Be sensitive to patients' emotional responses during the program.</li> <li>* The guidelines should be used flexibly according to the patients' stories rather than strictly following the sequence of the questions in the guidelines.</li> <li>* Patients are allowed to move back and forth from one life stage to another, as they talk.</li> </ul>
Facilitate patients to affirm positive experiences	<ul style="list-style-type: none"> <li>* Encourage patients to share happy moments.</li> <li>* Encourage patients to express the feelings and thoughts on positive experiences.</li> <li>* Encourage patients to identify and appreciate contributions and achievements.</li> </ul>
Facilitate patients to reconcile negative experiences	<ul style="list-style-type: none"> <li>* Encourage patients to share negative experiences.</li> <li>* Encourage patients to express their feelings and thoughts on their negative experiences.</li> <li>* Help patients to let go of negative experiences using Taoist philosophy.</li> <li>* Help patients to accept negative experiences using their belief in heaven.</li> <li>* Guide patients to reinterpret the meaning of negative experiences from different perspectives.</li> </ul>



### **3.2 Guidelines for managing patients' unpleasant emotions during the program**

3.2.1 If a patient displays unpleasant emotions during a review of his or her life, the facilitator should assess whether or not the emotions are strongly unpleasant.

3.2.2 If the emotions are slightly unpleasant, the facilitator may continue the interview in accordance with the following principles:

- \* The facilitator observes and asks the patient whether s/he can continue discussing that life theme.

- \* If the patient does not want to continue discussing that life theme, the facilitator can provide the patient with a choice of other life themes to discuss in this session.

3.2.3 If the patient shows strong unpleasant emotions during a review of his/her life, the facilitator may do the following:

- \* The facilitator should terminate the interview immediately.
- \* The facilitator will provide counselling for the patient immediately.
- \* The facilitator will inform staff from the study hospice. The staff will provide a follow-up assessment of the patient's emotions and refer him or her to a professional psychologist, if necessary.

### **3.3 Guidelines for formulating a life review booklet**

#### **3.3.1 Preparations for making a life review booklet**

- \* Tell patients that a life review booklet will be made for them during the program.

- \* Ask patients to prepare their favorite photos and pictures.

- \* Ask patients to select what will be recorded in the life review booklet.

- \* Prepare a blanket booklet for patients.

### 3.3.2 Booklet format

- \* The first person narrative can be used to document the booklet.
- \* The patients' favorite items, such as photos and pictures, can be affixed to the booklet.

### 3.3.3 Suggestions on content

Although it is suggested that the content of the life review booklet be as follows, patients should decide what will be added to or moved from the booklet.

- \* ***Personal information:*** name, age, gender, birth place, religion, hobbies, address, and telephone number.
- \* ***Childhood:*** family, friends, school, and games.
- \* ***Adulthood:*** work, marriage, family, children, friends, dealing with people, difficulties, and achievements.
- \* ***Present:*** cancer experiences, views on illness and life, words (e.g., advice, hopes, blessings) for loved ones.

### 3.3.4 Key points in making the life review booklet

- 4.1 The life review booklet is made by the facilitator, while patients decide the format and content of the booklet.
- 4.2 Both positive and negative experiences can be documented in the booklet.
- 4.3 Patients are invited to comment on the booklet at the beginning of each life review session and revisions are made based on the patients' preference.

Chinese version

## 简短操作智力状态问卷 (SPMSQ) 中文版

指导语：请回答下表所列的问题，询问受访对象并且将结果记录下来(如果受访对象家中没有电话，可将第 4 题改为第 4a 题)，答错问题记录下来。

问 题	回 答	答错 “√”
1. 今天是几号？		
2. 今天是星期几？		
3. 这是什么地方？		
4. 您的电话号码是几号？		
4a. 您住在什么地方？		
5. 您几岁？		
6. 您的出生年月日？		
7. 现任的国家主席是谁？		
8. 前任的国家主席是谁？		
9. 您妈妈叫什么名字？		
10. 从 20 减 3 开始算，一直减 3 减下去。		

总分： \_\_\_\_\_

功能状态： \_\_\_\_\_

结果的判断标准：共 10 项，答错一项得 1 分，总分为 10 分 。

0-2 分为认知正常

3-4 分为轻度认知障碍

5-7 分为中度认知障碍

8-10 分为严重认知障碍

English version**The short portable mental status questionnaire (SPMSQ)**

Instructions: Ask questions 1 through 10 on this list and record all answers. (Ask question 4a only if the patient/resident does not have a telephone.) Record the total number of errors based on the answers to the 10 questions.

Questions	Response	(√) if incorrect
1. What are the date, month, and year?		
2. What is the day of the week?		
3. What is the name of this place?		
4. What is your telephone number?		
4a. what is your street address? (ask only if patient/resident does not have a telephone)		
5. How old are you?		
6. When were you born?		
7. Who is the current president?		
8. Who was the president before him?		
9. What was your mother's maiden name?		
10. Can you count backward from 20 by 3's?		

**Total errors:** \_\_\_\_\_

**Cognitive functioning:** \_\_\_\_\_

**Scoring:** 0-2 errors: intact intellectual functioning

3-4 errors: mild cognitive impairment

5-7 errors: moderate cognitive impairment

8 or more errors: severe cognitive impairment

Chinese version

## 患者资料调查表

## A. 个人资料

A1. 年龄: \_\_\_\_\_

A2. 性别: 1. ☐男 2. ☐女A3. 文化程度: 1. ☐未接受正式教育3. ☐小学程度4. ☐中学程度5. ☐大专及以上A4. 婚姻状况: 1. ☐未婚 2. ☐已婚 3. ☐离婚 4. ☐丧偶

A5. 你觉得目前家庭的经济状况如何?

1. ☐ 足够有余2. ☐ 刚刚足够应付日常开支3. ☐ 不足够应付日常开支4. ☐ 十分不足够应付日常开支

A6. 你现在与谁居住?

1. ☐与家人居住2. ☐与亲戚居住3. ☐与朋友居住4. ☐ 独居5. ☐其它(请列出) \_\_\_\_\_

A7. 现在主要是谁在照顾你?

1. ☐ 父母2. ☐配偶3. ☐子女4. ☐兄弟姐妹5. ☐亲戚6. ☐朋友7. ☐保姆8. ☐自己9. ☐其他(请列出) \_\_\_\_\_

A8. 你现在有无使用其它社区卫生服务? (除宁养院提供的服务之外的社区服务)

1. ☐有 (请列出) \_\_\_\_\_2. ☐无

A9. 你现在有无参加各种社区活动?

1. ☐癌症俱乐部2. ☐社区老年活动中心3. ☐其他 (请列出) \_\_\_\_\_4. ☐无

## B. APGAR 家庭功能评估表

指导语：借由下列的问题，我们希望对您与您有家庭能有更清楚的了解。如果你对这些问题有更多的见解，或有更多的资料要提供，请您写在补充说明空白之处。在这份问卷中，我所谓的家人是指通常与您住在一起的人员，如果您是自已一个人住，请把目前与您感情联系最密切的人，当作您的家人。每个问题请选择一个答案在空格内打钩。

条 目	经常	有时	几乎很少
1. 我满意于当我遇到困难时，可以求助于家人 补充说明：			
2. 我满意于家人和我讨论事情及分担问题的方式 补充说明：			
3. 我满意于当我希望从事新活动，或是有新发展方向时，家人能接受并给予支持。 补充说明：			
4. 我满意于当家人对表达情感的方式，以及对我的情绪（如愤怒、悲伤、爱）的反应。 补充说明：			
5. 我满意于家人与我共处时光的方式。 补充说明：			

## C. 疾病资料（根据医疗病历填写）

B1. 疾病诊断：	
B2. 癌症转移的位置：	
B3. 癌症的病程：	
B4. 曾接受的治疗方案：	1. <input type="checkbox"/> 外科手术    2. <input type="checkbox"/> 化疗    3. <input type="checkbox"/> 放射治疗 4. <input type="checkbox"/> 其他（请列出）

## D. 体能评分（KPS 得分） \_\_\_\_\_

English version**Patient Information Form****A. Personal information**

A1. Age : \_\_\_\_\_

A2. Gender: 1. ☐ Male 2. ☐ Female

A3. Education: 1. ☐ No formal education

2. ☐ Primary school education

3. ☐ Secondary school education

4. ☐ Tertiary education

A4. Marital Status: 1. ☐ Single 2. ☐ Married 3. ☐ Divorce 4. ☐ Widowed

A5. How do you think your family financial status at present?

1. ☐ More than enough 2. ☐ Barely enough for daily expenses

3. ☐ Not enough for daily expenses 4. ☐ Very insufficient

A6. Whom you are living with?

1. ☐ Families 2. ☐ Relatives 3. ☐ Friends

4. ☐ Live alone 5. ☐ Others(please specify) \_\_\_\_\_

A7. Who is your primary caregiver at present?

1. ☐ Parents 2. ☐ Spouse 3. ☐ Children 4. ☐ Sibs 5. ☐ Relatives

6. ☐ Friends 7. ☐ Maid 8. ☐ Myself 9. ☐ Others (please specify) \_\_\_\_\_

A8. Do you use any community health service, except the services from the Fujian Hopsice?

1. ☐ Yes (please specify) \_\_\_\_\_

2. ☐ No

A9. Do you participate in any community activity?

1. ☐ The cancer Club 2. ☐ The elderly centre

3. ☐ Others (please specify) \_\_\_\_\_ 4. ☐ No

## B. Family APGAR Index

The following questions have been designed to help us better understand you and your family. You should feel free to ask questions about any item in the questionnaire.

Comment space should be used if you wish to give additional information or if you wish to discuss the way the question applies to your family. Please try to answer all questions.

“Family” is the individual(s) with whom you usually live. If you live alone, consider family as those with whom you now have the strongest emotional ties.

For each question,  
check only one box

Item	Almost Always	Some of the Time	Hardly Ever
1) I am satisfied that I can turn to my family for help when something is troubling me. Comments:			
2) I am satisfied with the way my family talks over things with me and shares problems with me. Comments:			
3) I am satisfied that my family accepts and supports my wishes to take on new activities or directions. Comments:			
4) I am satisfied with the way my family expresses affection and responds to my emotions, such as anger, sorrow, and love. Comments:			
5) I am satisfied with the way my family and I share time together. Comments:			

## C. Disease related information (According to medical records)

B1. Diagnosis of disease	
B2. Site of metastasis	
B3. Months on cancer	
B4. Previous treatments	1. <input type="checkbox"/> Surgery   2. <input type="checkbox"/> Chemotherapy   3. <input type="checkbox"/> Radiotherapy 4. <input type="checkbox"/> Others (please specify)

**D. Functional performance (the score of KPS):** \_\_\_\_\_



Chinese version**生存质量问卷**

**访问指引：**评估受访者过去两天的情况，所有答案没有对错之分。从 0 至 10 的数字当中圈出最能代表答案的程度。若受访者不欲回答，把该问题留空。

**1. 单条目量表 (SIS)**

**SIS** (综合身体、情绪、物质、精神、与其它人关系各方面的考虑)  
整体来说，你觉得过去两日的生活的质量怎样…

极差      0   1   2   3   4   5   6   7   8   9   10      极佳

**2. 晚期生存质量量表 (QOLC-E)**

1, 2, 3 题：问受访者有些什么不舒服的地方。先让受访者说出所有不舒服的情况，如气促、关节痛、头晕等，问他最不舒服的是什么，并由 1-10 给评分。如此类推。若受访者只有 1 个不适，2 及 3 题给打 0 分。

5 题：若受访者在回答不舒服的地方时，提及胃口差，则在这题填写，避免重复。

13-22 题：是了解受访者的情绪和感受，发问时先问他有否这感受，若无，给打 0 分；若有，问他感到有多严重，以 1-10 给评分。

其它的问题：向受访者读出句子，及两极的形容词，问他哪个形容词较能表达他的感受，再以 1-10 给评分其同意程度。

Q1	你最不舒服的地方是… 注明病征：_____	没问题	0	1	2	3	4	5	6	7	8	9	10	极大问题 (不舒服的程度)
Q2	你第二不舒服的地方是… 注明病征：_____	没问题	0	1	2	3	4	5	6	7	8	9	10	极大问题 (不舒服的程度)
Q3	你第三不舒服的地方是… 注明病征：_____	没问题	0	1	2	3	4	5	6	7	8	9	10	极大问题 (不舒服的程度)
Q4	你觉得身体…	没有不适	0	1	2	3	4	5	6	7	8	9	10	极度不适
Q5	你的胃口/食欲…	没问题	0	1	2	3	4	5	6	7	8	9	10	极大问题
Q6	你食到合口味的食物…	完全不是	0	1	2	3	4	5	6	7	8	9	10	十足十的
Q7	整体来说，对病征的控制满意程度是	十分不满意	0	1	2	3	4	5	6	7	8	9	10	十分满意
Q8	你觉得医生有让你参与决定治疗方案	完全没有	0	1	2	3	4	5	6	7	8	9	10	积极参与
Q9	医护人员满足到你的要求/意愿	从不	0	1	2	3	4	5	6	7	8	9	10	经常
Q10	整体来说，你满意医院(医疗机构)给你的治疗/护理	十分不满意	0	1	2	3	4	5	6	7	8	9	10	十分满意

Q11	你觉得这个世界是… (你觉得这个世界是有情或无情的…)	一个冷酷无情的世界	0	1	2	3	4	5	6	7	8	9	10	一个有关怀和爱的世界
Q12	你是得到支持及关心的…	完全不是	0	1	2	3	4	5	6	7	8	9	10	十足十的
你感到…														
Q13	情绪低落	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q14	紧张	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q15	担心	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q16	伤心/难过	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q17	寂寞	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q18	没有希望	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q19	一切无能为力, 没有人可以帮到我	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q20	无论自己再做什么, 结果也是一样	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q21	害怕去想以后的日子	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q22	给照顾者/家人带来麻烦	完全没这感觉	0	1	2	3	4	5	6	7	8	9	10	极之严重
Q23	你有否宗教信仰… (拜神或去教会)	<input type="checkbox"/> 否 <input type="checkbox"/> 有(请注明信仰: _____), 你觉得这宗教对你有多重要…												
		完全不重要	0	1	2	3	4	5	6	7	8	9	10	非常重要
Q24	回想一生, 对于你的人生目标, 你觉得…	没有达到目标	0	1	2	3	4	5	6	7	8	9	10	已完全达到
Q25	回想一生, 你觉得自己活得有价值…	完全无价值	0	1	2	3	4	5	6	7	8	9	10	非常有价值
Q26	你觉得自己做人做得相当不错…	完全不同意	0	1	2	3	4	5	6	7	8	9	10	完全同意
Q27	你觉得做人…	完全无意思	0	1	2	3	4	5	6	7	8	9	10	非常有意思
Q28	对你来说, 过去两天是…	一个担子	0	1	2	3	4	5	6	7	8	9	10	赚来

English version**Quality of Life Questionnaire**

**Questionnaire administration guide:** The questions are to assess the interviewees' quality of life concerns in the past two days. These are no model answer. Please circle the rating that can best represent your perception. Please leave the question blank if the interviewee does not want to answer.

**1. Single Item Scale (SIS)****SIS**

Generally speaking (include physical, psychological, emotional and social aspects), how did you feel about yourself in the past two days

Worst    0 1 2 3 4 5 6 7 8 9 10    Best

**2. Quality of Life Concerns in the End of Life Questionnaire (QOLC-E)**

Item 1, 2, and 3 are to assess what physical discomforts have you suffered from over the past two days. The interviewer first lists all discomforts, and then asks interviewees to rate the level of discomfort from 0 to 10. If the interviewee has only one physical discomfort, item 2 and 3 will be marked with 0.

Item 5: If the interviewee mentions about poor appetite. It will be filled in item 5 rather than Item 1, 2, of 3.

Item 13 to 22 are to assess the interviewees' feelings. The interviewer first asks them whether they have such feelings. If no, it is marked with 0. If yes, the interviewers need to ask them to choose an appropriate number to show their feeling.

For other questions, read the descriptors at the two extremes and ask the person to rate from 0 to 10 to represent the level of agreement.

Q1	Most troublesome discomfort...	No	0 1 2 3 4 5 6 7 8 9 10	Severe
	Name of symptom: _____		(degree of discomfort)	
Q2	Second most troublesome discomfort...	No	0 1 2 3 4 5 6 7 8 9 10	Severe
	Name of symptom: _____		(degree of discomfort)	
Q3	Third most troublesome discomfort...	No	0 1 2 3 4 5 6 7 8 9 10	Severe
	Name of symptom: _____		(degree of discomfort)	
Q4	How do you feel about body?	No	0 1 2 3 4 5 6 7 8 9 10	Severe
Q5	How is your appetite?	No	0 1 2 3 4 5 6 7 8 9 10	Severe
Q6	Are you satisfied with the food provided...	Very dissatisfied	0 1 2 3 4 5 6 7 8 9 10	Very satisfied
Q7	Are you satisfied with control of symptoms...	Very dissatisfied	0 1 2 3 4 5 6 7 8 9 10	Very satisfied
Q8	How frequently have you participated in health care decision...	Never	0 1 2 3 4 5 6 7 8 9 10	Always

Q9	Do the health professionals meet your needs...	Very dissatisfied	0 1 2 3 4 5 6 7 8 9 10	Very satisfied
Q10	Are you satisfied with the overall care services you received...	Very dissatisfied	0 1 2 3 4 5 6 7 8 9 10	Very satisfied
Q11	How do you perceive the world	An impersonal unfeeling place	0 1 2 3 4 5 6 7 8 9 10	Caring and responsive to my needs
Q12	How much support do you received?	Inadequate	0 1 2 3 4 5 6 7 8 9 10	Adequate

Have you experienced the following feelings in the past week?

If yes, how serious is the feelings?

Q13	Low mood	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q14	Nervous	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q15	Worried	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q16	Sad	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q17	Lonesome	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q18	Hopeless	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q19	Powerless	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q20	Helpless	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q21	Are you afraid of looking into the future	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q22	Do you feel yourself as a burden to others?	None	0 1 2 3 4 5 6 7 8 9 10	Very serious
Q23	Do you have religious beliefs (e.g. worship ancestors or go to church)	<input type="checkbox"/> No <input type="checkbox"/> Yes(please indicate: _____), Not at all	0 1 2 3 4 5 6 7 8 9 10	Very important
Q24	Have you achieved your life goals?	Not at all	0 1 2 3 4 5 6 7 8 9 10	Complete achieved
Q25	Do you find your life meaningful...	Meaningless	0 1 2 3 4 5 6 7 8 9 10	Meaningful
Q26	Do you feel good about yourself as a person...	Very disagree	0 1 2 3 4 5 6 7 8 9 10	Very agree
Q27	Do you find your life worthwhile...	worthless	0 1 2 3 4 5 6 7 8 9 10	Worthwhile
Q28	How do you feel about your life at this point...	A burden	0 1 2 3 4 5 6 7 8 9 10	A gift

Chinese version

患者参与人生回顾活动的感受  
访谈内容

指导语：下列问题帮助我们更好理解您参与人生回顾活动的感受，请就您的想法或感觉自由回答。

1. 您觉得您所参加的人生回顾活动怎么样？
2. 您认为人生回顾访谈让您受益与否？它是如何让您受益的（或是不受益的）？
3. 您认为人生回顾手册让您受益与否？它是如何让您受益的（或是不受益的）？
4. 在人生回顾活动中，您最喜欢或最不喜欢的是什么？
5. 您对人生回顾活动的改进有什么建议？

English version

**A semi-structured questionnaire  
about patients' perceptions of the life review program**

Instructions: The following questions have been designed to help us better understand your perceptions of participating in the life review program. Please feel free to tell us your views about the program.

1. What do you think about the life review program that you participated in and completed?
2. Do you think that reviewing your life benefited you or not?  
In what ways did it benefit or not benefit you?
3. Do you think that the life review booklet produced in the program benefited you or not? In what ways did it benefit or not benefit you?
4. What do you like and dislike most about the life review program?  
And why?
5. What are your suggestions for improving the life review program?