A Qualitative Case Study Analysis of the Development of End of Life Care in Macao

Kuai In Tam

譚瑰賢

PhD in Nursing Studies

The University of Edinburgh

2018

Declaration

I hereby declare that this thesis has been composed by me and is entirely my own work. This thesis has not been submitted for any other degree or professional qualification.

Kuai In Tam

Acknowledgements

I am indebted to many people for their support and encouragement throughout my PhD. I am very fortunate to have them by my side in this long, difficult and emotional journey.

First and foremost, I would like to express my sincere gratitude to my academic supervisors, Dr Sarah J. Rhynas and Dr Elaine Haycock-Stuart for their immense support, guidance and encouragement throughout the study. Your inspiration, patience and kindness have given me the strength to persevere in challenging times. I would like to thank Professor Graeme Smith and Professor Kath Melia who have given me PhD support at the beginning of my studies.

I would like to express my sincere appreciation to all my participants in Macao for their interest, passion and time to participate in my research. Heartfelt thanks to my friends and colleagues in Macao who have contributed to the successful completion of this study. Special thanks to Kiang Wu Nursing College of Macao and Kiang Wu Hospital for the enormous support during the data collection process. I would like to express my heartfelt appreciation and admiration for Professor Iat Kio Van for her unconditional guidance, support, kindness and encouragement throughout the research process and my life.

My immense appreciation to my lovely and supportive friends, especially to Javita (thank you mera pyaar for your unfailing support and love), Nauman (thank you for giving me clarity), Rita (thank you for all the laughter and late night support), Edgardo (I will always smile, sparkle and shine!), Margarita, João, Jae, Jing, Shaun, Edgar, Vanitha, Ari, Mia, Ilayda, and many more. You all have made this PhD journey a tiny bit more exciting.

I extend my gratitude to my friends and colleagues from St Christopher’s Hospice London, especially to Grace, Nirmala, Sarah, Annabel and many more. Special thanks to Ms. Liz Bryan for the invaluable advice and encouragement. I would like to sincerely thank you for giving me the honour to work with you in promoting the work of end of life care in Beijing. The experience has made a huge positive impact on my PhD journey.

Last but not the least, I owe my deepest appreciation to my family, especially my parents, Kam Wa Tam 譚錦華 and Gar Bo Lau 劉嘉寶 for their unconditional love, unlimited patience, unremitting reassurance and endless encouragement. I also want to express my deepest gratitude for all the laughter, love and continuous support my brother Kuai U Tam 譚瑰儒 has given me, even though I have taken over his place as the favourite child of the family. I would never have completed my PhD without you.

爸爸，媽媽，譚瑰儒，感恩沿路有你們的支持鼓勵，我愛你們。

Dedication

I dedicate this thesis to my late grandmothers Lin Ieng Sou 蘇蓮英 and Pui Chun Chan 陳佩珍 for their unconditional love, nurture and wisdom. They had been the inspiration and motivation for me to embark on this journey in the field of end of life care. I know they would be very proud of the achievement I have accomplished today.

I love you and I will always miss you.

Abstract

Background

Since the concept of end of life care was first introduced in the late 80's in Hong Kong (Chan, 2002) and Taiwan (Glass et al, 2010), research interests examining the influence of Chinese culture in respect of death, dying and end of life issues has gained popularity (Bowman & Singer, 2001; Chan & Chow, 2006; Chen et al, 2014; Hsu et al, 2009; Mjelde-Mossey & Chan, 2007; Tung, 2011; Zhou, 2016). However, there is a dearth of empirical examination on the process of the establishment and development of the concept and service of end of life care, within a socio-cultural Chinese environment. In the context of Macao, there is only one study (Lo, 2002) describing the establishment of the inpatient hospice, and to date, there is no empirical evidence on the establishment of end of life care, nor on factors that influence the development of end of life care in the context of Macao.

Aim

The aim of this case study was to develop a theoretical understanding of how the end of life care was introduced, established and developed, and to examine the factors that had shaped the end of life care in Macao.

Methods

A qualitative case study research approach (Stake, 1995) was conducted and the end of life care in Macao was the case of this research. Data was collected through in-depth, semi-structured interviews with the initiators (n=3) and developers (n=8), from three different settings that provide and promote end of life care in Macao. Interviews were digitally recorded and transcribed. Qualitative data analysis software, Nvivo 11, was used to organise the data and facilitate analysis. All data was analysed based on the principle of thematic analysis (Braun & Clarke, 2006).

Findings

Through thematic analysis, the emergence of end of life care in Macao can be understood to some extent to have developed through a social movement formation. Initiators with diverse backgrounds collectively conceptualised that the suffering of people as experienced at the end of their lives in Macao was a social problem needed to be changed, and they subsequently developed different approaches in pursuing for change. This findings also revealed that the growth of end of life care has become stagnant after the initial wave of establishment. The framing perspective (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986) was adopted in this research in aiding the conceptualisation of end of life care in Macao as a social movement, and the development of a theoretical understanding regarding the development of end of life care in Macao.

This research identified three key conceptual perspectives elucidating the developmental trajectory and factors contributing to the growth and then stagnation of end of life care in Macao. These three conceptual perspectives were:

- The conceptualisation of the problem with dying: the suffering of people as experienced at the end of their lives (the grievance in the context of the framing perspective)
- The incoherent strategies developed by initiators in establishing end of life care (the lack of internal frame cohesion)
- The variety of contextual and conceptual constraints that influenced the subsequent development and then stagnation of end of life care (the lack of external frame cohesion) within the context of Macao

The findings indicate the integration of these three conceptual perspectives has led to a holistic, theoretical understanding of the development of end of life care in Macao addressing the research aim and contributes to knowledge about end of life care. With specific regard to the socio-cultural environment of Macao, the study has taken a unique theoretical approach in developing understanding of the end of life care as a social movement by way of the framing perspective. This thesis has proposed a new way to examine the emergence of end of life care, which would facilitate the exploration of end of life care development in other cultural contexts.

Lay summary

Since the concept of end of life care was first introduced in the 80's in Hong Kong and Taiwan, research interests examining the influence of Chinese culture in respect of death, dying and end of life issues has gained popularity. However, there is a lack of research examining the process of the establishment of end of life care, within a Chinese environment. Focusing on the socio-cultural Chinese environment of Macao, this research sought to understand how the end of life care was introduced, established and developed, and to investigate the factors that had shaped the end of life care in Macao. A qualitative case study was conducted. Data were collected from in-depth interviews with initiators and developers of the end of life care in Macao. This research found, initiators of the end of life care in Macao had collectively identified the same problem, that is, the suffering of people as experienced at the end of their lives, and the end of life care in Macao was established for the purpose of resolving this problem. Whilst the initial wave of establishment was successful, this research found that the subsequent growth of end of life care has become stagnant. This stagnation of growth was found to be attributed by a number of factors, including the incoherent strategies developed by initiators in establishing the end of life care and the variety of contextual and conceptual constraints encountered during the developmental process in Macao. This study has developed understandings in respect of the establishment and development of the end of life care in Macao and it has proposed a new way to examine the emergence of end of life care, which would facilitate the exploration of end of life care development in other cultural contexts.

Table of contents

List of tables

List of figures

Preface

The subject of end of life care in Macao is very close to my heart. My motivation for conducting this study was based on my personal experience relating to the end of life care in Macao. I had always shared a very close relationship with my grandmother. However, in the spring of 2002 when I was 16 years old, she was diagnosed with terminal cancer involving multiple metastases. My grandmother did not have a good death in that she did not know her terminal diagnosis, she did not know she was dying, she despised having to stay in a place where people die (hospice), her pain was not well controlled while at the hospice and at the last stage of her life she was profoundly delirious. It was an immensely heart-breaking experience to see a person you loved so dearly having to suffer so much at the end of her life, despite being in a place where reducing a person's suffering was supposedly the priority. It has been 15 years since my grandmother's death and during that time there has been only very limited development in the landscape of end of life care in Macao. I wanted to find out the causes of this lack of progress. In order to do so, I needed to first understand 'how?' and 'why?' end of life care began in the first place. These questions had led me to embark on a journey to try and understand the end of life care in Macao.

1. Chapter One: Introduction

1.1. Introduction

Since the first hospice in Macao started 18 years ago, there have been no observable developments in the field of end of life care. There is no legislation relating to end of life care or advance care planning, no government agenda directed towards end of life care, and no professional bodies representing palliative, end of life care professionals. Further, there is a dearth of empirical examination on the establishment of the concept and service of end of life care, and no empirical evidence on factors that influence the development of end of life care in the context of Macao. However, the Macao society is rapidly changing with the increasing life expectancy and demand for better quality of life and better health care. In addition, more people are now living with, and dying from, multiple chronic illnesses; a situation which will require more complex end of life care to ensure people die without undue suffering. The aim of this thesis is therefore to examine why end of life care in Macao was introduced 18 years ago and how it was being established and subsequently developed within the socio-cultural environment of Macao. Within this thesis, I also seek to examine the factors that had shaped the concept and the professional practice of end of life care in Macao. In this thesis, a qualitative case study approach by Stake (1995) is adopted and the framing perspective (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986) is implemented as the theoretical framework to facilitate the interpretation and theorisation of the study findings.

1.2. Background to this research

Located at the South-Eastern part of China, with a population of 653,100 (Documentation and Information Centre of the Statistics and Census Service, 2017a), with a total land area of 30.5 square kilometres, Macao is well-known as one of the most densely populated cities in the world (Macao Information Bureau, 2017). During the expansion years of the Portuguese empire in the 15th century, Macao was rented out to the Portuguese in 1573 and, since the Opium war, Macao was occupied by the Portuguese. In 1987, the Sino-Portuguese Joint Declaration was signed and official agreement was made for China to resume the exercise of sovereignty over Macao from 20th December, 1999 onwards; so ending more than four centuries of Portuguese administration. Macao returned to Chinese sovereignty as a ‘Special Administrative Region’ (SAR) of China. Following the Basic Law, Macao has a high degree of autonomy, although the central government of China in Beijing has control over the matters of foreign policy and defence. The Chinese (88.4%) make up the biggest ethnic group in Macao. Chinese is the official language, although Portuguese may also be used as an official language. Cantonese (a variation of Chinese) is the spoken language in Macao.

In terms of religion, Macao SAR does not recognise a state religion; however, the freedom of religion is protected by the Basic Law (Macao Information Bureau, 2017). Considering the long co-existence of the East and West, Macao is also a cultural melting pot due to the international trading which took place for four centuries under the Portuguese administration; as a result, Macao embraces a diversity of religions. In addition to the main belief systems of Chinese Buddhism, Taoism and Confucianism, Catholicism, Protestantism and Islam are also adhered to by local communities. The majority of the Chinese population in Macao adhere to the combination of Chinese Buddhism, Taoism, Confucianism and the traditional beliefs associated with ancestor worship. The significance of these beliefs is realised through the declaration of public holidays for a number of important events, such as Buddha’s birthday and the Ching Ming festival, also known as Tomb-Sweeping Day or Ancestors' Day. The combination of these different beliefs would have inevitably impacted on how the people in Macao conceptualised death and dying, and would therefore have an effect on the development and conceptualisation of end of life care.

A discussion relating to the effect of the combination of Chinese Buddhism, Taoism, Confucianism and traditional ancestor worship on Chinese people’s perspective of death and dying will be presented in Chapter Two, section 2.5.

The high degree of autonomy of Macao informed the liberalisation of the gaming industry in 2001. This was one of the most important policies undertaken by the Macao SAR’s government as it liberalised the monopoly scheme by introducing foreign competition (Macao Information Bureau, 2002). The reform significantly strengthened Macao’s economy and since the liberalisation the gaming industry has contributed substantially to the monetary growth of the Macao SAR government. In 2017, there were a total of 40 casinos in Macao, generating an annual gross gaming revenue of 266,607 billion patacas, or approximately 33 billion USD (The Gaming Inspection and Coordination Bureau of Macao, 2017). This total was 3 times higher than the revenue of Las Vegas in 2017 (just over 11 billion USD) according to the official figure reported by the Nevada Gaming Control Board (2017). Tourism is the second largest industry in Macao. According to the

Documentation and Information Centre of the Statistics and Census Service (2017b), the total number of visitors to Macao in 2017 totalled 32 million. The total spending of those visitors amounted to 61.32 billion patacas, approximately 7.59 billion USD.

In terms of demographics, Macao shares the same global concerns associated with a growing ageing population, while the prevalence of chronic diseases and comorbidity continues to rise. According to statistical predictions, the birth rate in Macao has been, and will carry on, falling over the next couple of decades as the population continues to age. By the end of 2031, the population over 65 years of age will out-number the youth population (0- 14 years) and make up 18% of the general population (Documentation and Information Centre of the Statistics and Census Service, 2008). In terms of public health, prior to the economic boom, acute conditions were predominant; however, the growing prevalence of chronic diseases has already taken over. Cancer, circulatory diseases and other chronic illnesses have become the major causes of Macao residents' deaths in recent years. Cancer, in particular, became the number one cause of death since 2012, and the number of people suffering and dying from cancer continues to rise (Documentation and Information Centre of the Statistics and Census Service, 2017a). The number of deaths in 2017 was 2120, and malignant tumours were the main cause of dying, accounting for 726 deaths (Documentation and Information Centre of the Statistics and Census Service, 2017a).

In the wake of the prospering socio-economic situation, Macao now provides more new opportunities to address health issues related to the SAR's ageing population, as well as the increasing prevalence of chronic conditions. Focusing on Macao's health care provision, the next section provides an account of the health care system of Macao and the types of health care services available.

1.2.1. Health care provision in Macao

The Macao government has focused significant attention on the development of health care. The allocation of medical resources is now considerable and has been steadily increased over the last couple of decades to optimise medical services and cater for the population's increasing health care demands. A total of 6.31 billion patacas (781 million USD) was invested in health care in 2016, compared to 2.73 billion patacas (338 million USD) back in 2009 (Macao Information Bureau, 2010; 2017).

To a great extent, the main health care agenda of the government of Macao is still focusing on issues such as developing better primary health care in order to fulfil the “Health for all” framework set out by the World Health Organisation (WHO) since the 1980’s. Expanding from “Health for all”, the government of Macao promoted a new policy, “A sound health care system and putting prevention first” in 2003, in order to facilitate public health protection and disease prevention. In addition, maternal and child care were still high on the health care agenda.

Taking into consideration the public health challenges resulting from the ageing society, the Macao government recently directed its emphasis towards two additional goals on elderly care. The first goal was to establish a network of medical and social services for people with dementia. The second goal was to introduce the concept of ‘active ageing’ and was dedicated to improving support for the elderly who were / are physically weak, through the provision of home care services and optimising specialist medical services via out-patient services and clinics. The key objective for both goals was to integrate treatments and rehabilitation services from multiple specialists, so reducing the impact of chronic diseases on the elderly. Despite the Macao government placing emphasis on the care for older people, who would be more likely to have chronic health issues and comorbidities, the primary health care agenda was still focusing on infectious disease prevention (Macao Information Bureau, 2017).

Neither palliative care nor end of life care was being listed in the government’s health care agenda. Government health care services and non-governmental sectors both play an equally important part in providing health care services for the people in Macao. In terms of end of life care, both sectors were found to have engaged in introducing and developing end of life care in Macao; therefore, a detailed account of the establishment of end of life care in the context of Macao will be provided in Chapter Two.

As mentioned above, rapid monetary growth after 2001 enabled the Macao government to fund substantial medical resources, particularly in building and upgrading health care facilities. Nevertheless, according to the government’s latest report (Macao Information Bureau, 2017), the resources were mainly focused on issues relating to disease prevention and acute conditions. Examples of these resources include the new Emergency Care Building at the government Conde San Januário hospital, and the Public Health Clinical Centre with its isolation wards specialising in the control of infectious diseases.

There are three hospitals in Macao at the moment. The first hospital ever established in Macao was Kiang Wu hospital, created in 1871. Kiang Wu hospital is a non-government, charitable institution founded and managed by Chinese people, since the time when Macao was under the administration of the Portuguese. The hospital is run by the Kiang Wu Hospital Charitable Association of Macao. Kiang Wu hospital is where the only hospice in Macao is located and it also held full administration over the only hospice in Macao, since that facility's establishment in 2000. The government's Conde San Januário hospital was established in 1874. Previously a military hospital for the Portuguese officials, Conde San Januário gradually opened up its service for the people in Macao and it remains the only government hospital. The University Hospital, established in 2006, is funded by the Macao University of Science and Technology Foundation. Services offered by Kiang Wu hospital and the University hospital are not free, whilst most services offered by the government's Conde San Januário hospital are subsidised by the government of Macao. Permanent residences of Macao and people whom have certain conditions, for examples, cancer, infectious diseases and pregnancy, are qualified for cheaper and sometimes free health care from the Conde San Januário hospital. The government of Macao also offers medical subsidies for some services at Kiang Wu hospital, for instance, the inpatient hospice service is completely free of charge. The hospice is under a unique management situation; while it is administered by Kiang Wu hospital completely, its operation is overseen by the government for the hospice is fully funded by the Macao government. As a result, referral to the hospice ought to be made through the Conde San Januário hospital regardless of where the person is receiving treatment/medical consultation from.

Despite the recent economic expansion which has led to the improvement of overall health care provision in Macao, end of life care is not considered as part of the health care development agenda. This lack of priority is evident from the omission of any official discussion relating to end of life care in government reports. Further, it is hard to find any public information on end of life care and its related service, as applied to Macao's particular situation.

The preceding section has provided the historical background of Macao, emphasising the health care provision in Macao, which has helped to provide an understanding of how Macao's economy and social circumstances have changed, particularly after the return to China in 1999. This chapter has discussed the existing health care system in Macao. Despite the government recognising the ageing population to be a growing issue creating different types of health care demands and challenges, the government’s focus is still very much placed on acute conditions and infectious disease prevention. The issue of end of life care is not observed or evident in any health care agenda listed by the Macao government. Nevertheless, the government of Macao was supportive in funding the establishment of the hospice, while the non-government Kiang Wu hospital has been fully responsible for administration of the hospice facility. This ambiguous approach of the Macao government, in relation to the development of end of life care merits further investigation in order to understand how and why end of life care in Macao was initiated and developed.

1.3. Research aim and questions

This research set out to understand the development of end of life care within the specific socio-cultural context of Macao. Considering the increasing emphasis, albeit limited information, on the development of end of life care, and the factors that had influenced the process of its development, the following research questions were developed by adopting a qualitative case study approach, and the end of life care in the specific socio-cultural context of Macao was established to be ‘the case’.

1. Why and how did end of life care emerge in Macao?
2. What factors have influenced the subsequent development of end of life care in the context of Macao?

As I will detail the rationale in a later section of this chapter, a qualitative case study was decided as the main research design, and end of life care in the specific socio-cultural context of Macao was established to be ‘the case’ in this case study research.

1.4. The structure of the thesis

Chapter One introduces the study. The aim and research questions, and my personal reflections on the research, are provided. The background of Macao is also included in this section, presenting an overview of its history, political transitioning, economic growth and health care provision in Macao. This chapter sets the scene for this research.

The review of literature pertaining to the context of this study is presented in Chapter Two. Included in the chapter is a review of literature relevant to the emergence of the modern hospice movement. Empirical studies on the development of end of life care in the international context, as well as the Chinese context, are discussed and compared.

Relating to the context of this study, literature on the Chinese perspective regarding death and dying, as well as the role of nursing with respect to the development of end of life care, are discussed. Gaps in existing knowledge about the development of end of life care within the specific context of Macao were identified, including the limited available studies on this subject.

Chapter Three discusses the research methodology, which includes the rationale for adopting a qualitative case study as the main research design for this research. A detailed description of the data collection and analysis is provided. Ethical considerations, the quality of the study, issues on reflexivity and the limitations of the study are also considered.

The theoretical underpinnings of the study are presented in Chapter Four. Included in this chapter is the rationale in adopting the framing perspective on social movement (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986). The detailed application of the framing perspective in the interpretive, analytic and theorising process in the study is discussed.

The research findings are presented in Chapters Five and Six. Corresponding with the two research questions, Chapter Five begins by investigating the establishment of the end of life care in Macao. Divided into three parts, the first part explores the personal journey of the three initiators and their individual motivation to be involved in the creation of end of life care in Macao. The second part of Chapter Five discusses the key problem jointly conceptualised and identified by the three initiators: *'suffering in death and dying in the socio-cultural context of Macao'*. The final part of Chapter Five illustrates how each of these initiators constructed end of life care in Macao, conceptually and structurally, with respect to their professional areas. Chapter Six considers the contextual and conceptual factors that have influenced the development of end of life care in Macao. The contextual factors discussed include: i) systemic control from the government of Macao on the overall development of end of life care, and ii) the incoherent strategies employed by initiators in developing end of life care. The conceptual factors discussed include: i) Chinese cultural beliefs of life preservation and cure orientation, ii) the emergence of misconceptions about end of life care, and iii) the different understanding of suffering between curative care and end of life care.

Underpinned by the framing perspective, Chapter Seven integrates the themes developed from the two 'findings' chapters and establishes a theoretical understanding of the case of end of life care in Macao. The theoretical understanding elucidates the development of end of life care in Macao informed by two findings: i) the incoherent strategies developed by initiators in establishing end of life care (the lack of internal frame cohesion), and ii) the variety of contextual and conceptual constraints that influenced the subsequent development of end of life care (the lack of external frame cohesion). This theoretical understanding of the development of end of life care answers the research questions posed and addresses the research aim.

Chapter Eight concludes the study with reflections on implications of the research findings for the development of end of life care. Future research recommendations are also considered.

2. Chapter Two: Literature review

2.1. Introduction

Since the introduction of the hospice movement in the 1960's, palliative and end of life care has gained increasing emphasis in the dominant health care culture; research interest on topics related to end of life care has also gained popularity. In Chapter One, I presented the background and motivations for conducting this study in order to develop an understanding on 'why' and 'how' end of life care in Macao was started. Chapter Two provides a review of the relevant literature on three main themes: i) the emergence of the modern hospice movement from the United Kingdom (UK) to the international level, ii) the development of end of life care in four Chinese contexts, including Mainland China, Hong Kong, Taiwan and Macao, and iii) the Chinese perspective on death and dying. This literature review draws on studies of end of life care within the Chinese cultural context of Mainland China, Taiwan and Hong Kong, mainly because the Chinese culture adhered to in these areas is more relevant to the Chinese cultural context of Macao, therefore enabling better comparisons to be made in the discussions within this review. I have included literature on Chinese perspectives relating to death and dying, because there is much evidence showing the significant impact of a death taboo, as well as the strongly held desire to preserve life at all cost, on end of life care in the Chinese cultural context.

2.2. Literature search methods

A variety of methods were employed in searching the publications included in this iterative review of the relevant literature. In terms of databases, I primarily used CINAHL, Medline, Science Direct, Google Scholar, and DiscoverEd of the University of Edinburgh. Publications used in this literature review also included government reports, end-of-life-care related reports published by agencies such as the Economist Intelligence Unit, and websites from various organisations and professional bodies such as hospitals in Macao, nursing education sectors, end of life care providers and charities.

The literature search was focused on three broad subject areas: a) end of life care, b) the modern hospice movement and c) social movement(s). Within the aspect of end of life care, the search was further narrowed to the Chinese context, with both English and Chinese publications being included. The timeframe for the literature search was mostly from 2000 to the present. However, publications related to the historical development of end of life care, the modern hospice movement, and articles on theoretical perspectives relating to social movements were not limited by the timeframe. Recognising that the number of publications of end of life care, in the context of Macao, was limited, the majority of the materials relating to end of life care in the Chinese context came from Mainland China, Hong Kong and Taiwan. International aspects of end of life care were drawn from literature coming from the UK and North America.

2.3. Clarifying terminology- the definition of end of life care

End of life care is often understood interchangeably with, or perceived as identical to, hospice care, terminal care and palliative care. End of life care refers to care and support offered to both patient and family who are affected by advanced, progressive and incurable illness. Specifically, end of life care is offered to patients who are approaching the end of their lives; that is, they are likely to die within the next 12 months (National Palliative and End of Life Care Partnership, 2015). The General Medical Council of the UK also includes: a) patients who are expected to die within 12 months from general frailty and co-existing conditions, b) patients with existing conditions who are at risk of dying from their condition in a sudden acute crisis, and c) life-threatening acute conditions caused by sudden catastrophic events (General Medical Council, 2010). Furthermore, bereavement care is also recognised as part of end of life care (National Palliative and End of Life Care Partnership, 2015). Palliative care, on the other hand, focuses on the improvement of the quality of life of patients and their families who are affected by life-threatening illness. Emphasising the prevention and relief of suffering, palliative care is often implemented in conjunction with life-prolonging therapies (World Health Organisation, 1998). Therefore, the key difference between palliative care and end of life care (including hospice care and terminal care) is that the latter focuses on care given to patients who are “likely to die within the next 12 months” (General Medical Council, 2010). On the other hand, palliative care centres on working with life-sustaining treatments enabling people to lead an active life, despite having life-threatening illnesses (World Health Organisation, 1998). Nevertheless, both end of life care and palliative care provides the management of a patient’s pain and other symptoms, as well as the provision of psychological, social and spiritual care for patients and their families, and the provision of support in helping patients to maintain an acceptable quality of life, until their death (Department of Health, 2008; World Health Organisation, 2016). The focus of this research was to understand the development of end of life care in Macao. With the terminology and definition of end of life care clarified above, this research has primarily adopted ‘end of life care’ as the key term used. However, ‘hospice care’ was occasionally used interchangeably with ‘end of life care’ in this research.

2.4. The emergence of the modern hospice movement

Having discussed the current definition of end of life care, this section seeks to provide a historical overview of how the definition of end of life has emerged and evolved over time. Divided into two parts, the first part presents the emergence of end of life care from an international perspective, within which the historical development and the modern development of end of life care are both presented. In the second part, the development of end of life care within the Chinese cultural context is discussed.

2.4.1. The international context

The use of the term “hospice” can be dated back as early as the seventh century in Europe (Maruyama, 1999). “Hospice” was originally adopted to describe a place to provide lodging for travellers and pilgrims while they were on pilgrimage; a function which remains the same in some parts of Europe until today (Corr & Corr, 1983; Pastrana et al, 2008; Porter, 1996). The journey of pilgrimage was often too demanding for some individuals, and many would have been too old or ill to continue their onward journey. The hospices’ role had gradually become places providing care for the dying rather than shelter for travellers (Goldin, 1981). In 1879, the first institute dedicated to end of life care was founded by a Catholic organisation: the Sisters of Charity. Our Lady’s Hospice in Dublin was the first to have its focus purely on end of life care and the spiritual aspect observed in this hospice was exceptionally strong. Operated entirely by nursing-trained nuns, the principle of the first hospice was to provide the relief of physical suffering and the offering of comfort, warmth and hope of admission to heaven to the terminally ill (Mulholland, 1895).

Towards the 20th century, the opening of St Christopher’s Hospice by Dame Cicely Saunders was a significant event in the history of end of life care. Re-adopting the term “hospice”, Saunders integrated the old hospice ideologies of holistic care with modern medical technology and this integration had marked a new chapter in end of life care (Saunders, 1981; 1990). Since its establishment, St Christopher’s Hospice has become a renowned institute and pressed forward the clinical excellence of end of life care to an international level and this drive is widely recognised the modern hospice movement.

The beginning of the modern hospice movement was also grounded in Christianity. There was evidence that Cicely Saunders' motivation in working with the terminally ill stemmed from her personal calling. Expressed in her personal correspondence, as quoted in Clark's study: "I have thought for a number of years that God was calling me to try to found a Home for patients dying of cancer" (Saunders' personal correspondence to Sister Genevieve, Grandchamps, 30 March 1960)(Clark, 1998, p. 49). Adhering to this particular belief, Saunders' initial proposal of a home to care for dying people reflected the values and beliefs of a "religious community" (Clark, 1998, p. 46) . This concept of a religious community for the dying never did materialise; what evolved was a medical project embedded in Christian values. As suggested by Clark (1998), the idea of a "religious community" had unquestionably turned into "a community of religious motivation" enabling the establishment of a medical project that offered help and support to dying people; an idea which then spread across the world. This medical project was St Christopher's Hospice and its establishment in 1967 signified the beginning of the modern hospice concept which, in turn, led to a worldwide movement in developing end of life care. The ideology of the modern hospice movement was primarily focused on the relief of physical, psychological and spiritual suffering of the dying (Clark, 1999). As Saunders reflected upon the isolation and suffering of her dying patients, she dedicated herself to researching and developing ways to alleviate symptoms associated with terminal illnesses and the concept of "total pain" was born (Saunders et al, 1995b). Total pain concerns physical, emotional, social and spiritual pain, and only by addressing pain in all these aspects can a person become free of 'total pain' (Saunders et al, 1995a). The modern hospice movement in the UK, and around the globe, was built upon this principle of holistic alleviation of suffering of the dying.

Although international development of the hospice movement was largely recognised to have started after the establishment of St Christopher's Hospice, the seed of care for the dying in the United States (US) was in fact planted much earlier. According to a study on the early development of the modern hospice movement in the US by Clark (2001b), correspondence between Saunders and a number of physicians in the US who were interested in her work on caring for dying people had begun as early as the late 1950's. Detailed in Clark's study was this special relationship between Saunders and the numerous connections she had established in the US, via the work of caring for the dying.

To quote Clark, this special relationship is “a complex interweaving of personal, professional, and cultural factors that created a connectedness, a sense of synergy, between disparate groups of geographically dispersed people” (Clark, 2001, p. 24-25). This special relationship in spreading the concept of the hospice and caring for the dying, which was recognised as ‘the modern hospice movement’, aptly demonstrated the traits and strength of social movement. According to Johnston (2014), a social movement is made up of structurally diverse groups and/or individuals who are involved in collectively pursuing a goal or goals to effect social change. These goals are commonly generated from ideologies and frames (Snow & Benford, 1988; Snow et al, 1986) that suggest a problem needs to be addressed. Within a social movement is a collective identity which contributes to the continuity and cohesion of movement mobilisation (Johnston, 2014). The spread of the modern hospice movement from the UK to the US certainly reflected collective action from individuals with diverse structural and cultural backgrounds, who shared the same concern about the suffering of dying people and their families. These shared concerns subsequently warranted the setting up special services for dying people (Clark, 1998). The perspective of social movement was able to illustrate the process in which the modern hospice movement was mobilised, migrating from the UK to the US.

Whilst the modern hospice movement was acknowledged as a movement, with the processes by which it spread from the UK to the US illustrating the mobilising traits of a social movement, there is little data specifically investigating the development of the modern hospice movement informed by any theoretical framework of social movement. Equally there is little evidence examining the mobilisation of the modern hospice movement from any theoretical perspective of social movement. Very little is known about the elements that have facilitated/inhibited the mobilisation of the modern hospice movement, from a theoretical social movement perspective.

A study by Buck (2009) examined the development of end of life care by focusing specifically on understanding the role of nurses in the development of hospice care. Particularly, the author used the study to examine how the hospice concept was translated to the American hospice movement. From the study, the author identified a number of reasons that had motivated participant nurses to be involved in the initiation of hospice care in America. These examples include: a) deep spiritual / religious faith, b) a strong commitment to find meaning in their lives by way of serving others, c) a deep commitment to clinical care for the dying and crucially, d) a connection with other individuals who shared the same goal in developing hospice nursing and “camaraderie”

(Buck, 2009, p. 2707). These motivations certainly reflected some qualities of a social movement, according to the definition suggested by Johnston (2014). However, Buck's (2009) enquiry did not delve deeper into a social movement perspective; rather, the author opted to investigate how the role of nurses impacted hospice development in relation to policy making and standardisation of palliative hospice care in America.

Despite literature associated with the modern hospice movement covering a wide variety of topics, there are two main categories. The first category involves studies discuss the number of services available and the ratio of service provision in different countries (Clark & Graham, 2011; Milićević, 2002; Taylor, 1983); access to end of life care services, opioids and end of life care related education (Aranda, 1999; Sherman, 2000); there are also large-scale systemic reports focusing on the categorisation hospice-palliative care provision on all countries in the world (Clark & Wright, 2007; Wright et al, 2008a; Wright et al, 2008b). The second category of the relevant literature essentially involves discussion about the concept and principles of hospice care, and the characteristics of 'total pain' (Rhymes, 1990). Within this category, a lot of emphasis is placed on the aspect of spirituality: a) there is study focusing on the importance of integration of spirituality in palliative end of life care (Bodek, 2013); and b) there is also a study that sought to examine the relationship between the concept of "secularisation of hospice" and the spirituality introduced by the modern hospice movement (Clark, 2001a). In addition to the physical, psychological, social and spiritual aspects of hospice care, some authors investigated how the socially embedded emotions of compassion and hope impacted on the development of the modern hospice movement in the UK. As Brown & Flores (2011) found, hospice institutions established upon these emotions had mutually encouraged the practice of these emotions. There are also studies that examined how the modern hospice movement had led to a conflict between the process of institutionalisation of hospices and at the same time, enabling the personalisation of care centring upon individualistic ideals (Kubiak & Suriková, 2010).

The emergence of the modern hospice movement encouraged a shift of end of life care "from margins to centre" (Clark, 2007, p. 430). This location shift significantly changed the way society viewed the care of those dying from malignant diseases and promoted end of life care as the centre of modern cancer care. The study of social movement informs us about the past, how history was influenced or even created, allowing us to understand contemporary society and where it is going (Johnston, 2014, p.1). The inception of the modern hospice movement aptly reflected Johnston's statement, as

Clark (2007) phrased it: “the advancement which occurred is the subject of a still unfolding history and one which involves the emergence of palliative medicine as a subject of specialisation in a growing number of countries” (Clark, 2007, p. 430).

Although there were some studies, such as Clark’s study mentioned above, focusing on the development of end of life care through the lens of a social movement, the results of these studies concerned a wide range of topics. There was lack of empirical data on understanding the development of end of life care through the perspective of social movement, despite that development being generally described as the ‘modern hospice movement’. This gap in the literature led me to develop an interest in understanding further the modern hospice movement, through the perspective of social movement.

The influence of the modern hospice movement has spread across the globe, impacting one of the most important phases of human life, as viewed from many different cultures. Stemming from the religious backdrop of Christianity, I was interested to know how the concept of the modern hospice movement was being translated and spread to a different cultural context with different values and beliefs i.e. from the UK and USA to China. Particularly, I was interested in how the modern hospice movement had influenced the development of end of life care in Macao, where the Chinese cultural environment is very different from the UK, especially relating to issues of death and dying.

Focusing now on Chinese cultural contexts, section 2.4.2 below reviews the literature relating to the development of end of life care in four Chinese cultural contexts: i) Mainland China, ii) Hong Kong, iii) Taiwan and iv) Macao. I will further explore the Chinese perspective on death and dying in section 2.5.

2.4.2. The Chinese context

This section summarises the spread of the hospice movement within the Chinese context, particularly Mainland China, Hong Kong (HK) and Taiwan. I was aware that some other Asian countries such as Singapore and Malaysia are influenced by the Chinese culture due to their considerable numbers of ethnically Chinese citizens. However, at the same time, these countries are also culturally and ethnically diverse. Taking into consideration the potential influence of the multicultural environment of these countries on the development of the modern hospice movement, I decided not to include literature from these two countries in this review. Further, despite countries like Korea and Japan sharing a degree of cultural similarity with the Chinese, I did not extend my literature discussion to those nations, mainly because the aim of this research was focused on, and informed by, the Chinese cultural context.

From sections 2.4.2.1 to section 2.4.2.4 the literature review focuses on the infrastructural development of end of life care in four Chinese contexts. At the end of section 2.4.2.4, I aim to gain a perspective of the level of development of Macao, by comparing it with the other three Chinese contexts.

2.4.2.1. Mainland China

According to the review of existing literature, a coherent story about the development of the hospice movement in China appeared to be lacking, in that different starting points of hospice services, and different locations where the hospice movement first commenced, were proposed. Nonetheless, most records showed that the first sign of hospice movement activity in Mainland China started in the late 1980’s. The most agreed upon movement was the establishment of the Research Centre of the Hospice Care at Tianjin Medical University in 1988 (Peng & Yongmei, 2016; Tang & Silbermann, 2017). Two years later, in 1990, Tianjin Medical University opened its first hospice ward (Kerr, 1993). On the other hand, Beijing Songtang Care Hospital, established in 1987, was reportedly the first hospice in China to offer end of life care for elderly residents, as well as medically integrated elderly care (Beijing Songtang care hospital, 2018). Another one of the more well-known hospice programmes in China was the “Heart of Gold” National Hospice Service programme funded by the Li Ka Shing Foundation. Since 1998, the “Heart of Gold” project had helped established 38 hospice services, providing end of life care in 32 cities in China (Li Ka Shing Foundation, 2018). According to recent studies, the provision of end of life care was still relatively inadequate (Hu & Feng, 2016; Li et al, 2011; Yin et al, 2017) and this observation was supported by the quality of death index conducted by the Economist Intelligence Unit (2015). The unit ranked China’s palliative care as 71st out of the 80 countries evaluated in the report. China was reported to be slow and ill-equipped to meet the rapidly growing demand for such care (Economist Intelligence Unit, 2015).

In terms of national policies relating to hospice care, that care was included for the first time China’s Subject Directory of Diagnosis and Treatment in Medical Institutions in 1994, recognising hospice as a branch with “independent diagnosis and treatment division” (Peng & Yongmei, 2016, p. 278). Since 1994, hospice care had been included in a number of national health policies, including:

- Notice on Strengthening Service in the Reform of the Medical Institutions (2000);
- Reform of the Medical and Health System (2002);
- Notice on Accelerating the Development of the Aged People Service Industry (2006);
- Twelfth Five-year Planning of the Development of the Old Age Enterprises in China (2011);
- Twelfth Five-year Planning of the Development of the Health Protection (2012).

(Peng & Yongmei, 2016)

Despite the Ministry of Health only officially endorsing the establishment of palliative care departments in hospitals in 2008, with the inclusion of hospice care featured in major national policies, there are currently no national guidelines on hospice care evident in Mainland China (Economist Intelligence Unit, 2015).

From the literatures on hospice development in China, it became apparent that despite there being efforts to implement continuous development, the huge landmass and being the most populated country in the world (The World Bank, 2017; United Nations, 2017) meant that the established services were scattered in many different areas across the country. Despite the fact that government strategies regarding the development and promotion of hospice care were evident, it was reported that they were "statements of broad intent" with no tangible strategies in place (Economist Intelligence Unit, 2015, p.24). Further, the hospice movement in China was comprised of individual efforts from different individuals/organisations with only limited cohesion, as reflected by the literature discussed in this section.

2.4.2.2. Hong Kong

Having been a British colony until 1997, the hospice movement in HK was closely linked to, and influenced by, the UK. The establishment of hospice services in HK happened in quick succession. Between the year of 1982 to 1988, five hospice services were established, including the first hospice service set up in 1982 at the Our Lady of Maryknoll Hospital (Chan, 2002), the in-patient hospice team in Ruttonjee Sanatorium in 1986 (Sham, 2004), the hospice team in Nam Long Hospital in 1987 (Sham & Yang, 1997), the hospice care unit in Haven of Hope Hospital in 1988 (Haven of Hope Hospital, 2006), and the hospice service in United Christian Hospital in 1988 (Chan, 2002). The first independent institution, the Bradbury Hospice, was established in 1992, with the support of the Society for Promotion of Hospice Care (SPHC), an organisation established in

1986. The SPHC had played an important role in promoting end of life care work in HK, including: a) the provision of hospice care, b) increasing awareness on issues relating death, dying and bereavement, c) providing education for health care professionals as well as d) educating members of the general public (Society for the Promotion of Hopsice Care, 2018).

In terms of policies, the Law Reform Commission (LRC) in 2006 recommended that the use of an ‘advance directive’ (AD) should be promoted (Law Reform Commission of Hong Kong, 2006). Since its first recommendation, the LRC had revised a number of formats of the AD document. The latest version (2014) was applicable for four categories of conditions: i) a terminal illnesses, ii) irreversible coma, iii) persistent vegetative state and iv) other end-stage irreversible life-limiting conditions, which include a) renal failure, b) chronic obstructive pulmonary disease and c) dementia (Tse, 2018). There is currently no legislation governing an AD’s format in HK, but such a directive will be held legally valid so long as it is completed in accordance with the guidance set out by the LRC (Food and Health Bureau, 2009). However, an AD can still be challenged on the grounds of incapacity or undue influence (Law Reform Commission of Hong Kong, 2006, p. 161).

In 2017, the Hospital Authority in HK published the Strategic Service Framework for Palliative Care (the Framework), providing an overarching structure and outlining strategies that would guide the development of palliative end of life care over the next five to ten years (Hospital Authority, 2017). Encompassed in the Framework were four core strategies for adult and paediatric palliative care, these being: i) enhancing governance through the collaboration and co-operation of medical and oncology palliative care specialists, ii) promoting collaboration between palliative care and non-palliative care specialists through a shared care model. The model will be informed by a) patients’ needs, b) enhancing palliative care in the ambulatory and community settings to support patients and reduce unnecessary hospitalisation, and c) strengthening performance monitoring for continuous quality improvement (Hospital Authority, 2017, p. 8).

The establishment and presence of professional organisations in HK had been an important influence on HK’s hospice movement. The Hong Kong Society of Palliative Medicine and the Hong Kong Hospice Nurses’ Association were both established in 1997 to provide professional support and encourage professional development in palliative end of life care. The specialty of Palliative Medicine was developed in the Hong Kong

College of Physicians in 1998, and the Hong Kong College of Radiologists in 2002 (Chan, 2002).

In terms of research development, there are relatively rich empirical studies relating to the subject of death and dying within the specific context of HK. There are studies focusing on Chinese people's experiences and attitudes towards death, dying and bereavement (Chan & Chow, 2006; Chan et al, 2006; Chow et al, 2007; Chung et al, 2018; Ho et al, 2013); Chinese people's experience of palliative care (Chan & Chang, 2000; Fung & Mercer, 2009); general physicians' attitudes regarding end of life care (Lam et al, 2015). However, there is a dearth of research delving the development of end of life care in the Chinese context of HK; there is no empirical data on understanding the development of end of life care in HK through the perspective of social movement.

The development of end of life care and palliative care in HK, according to the existing literature, appears to be relatively comprehensive, with support from both the government and professional bodies. However, according to the 2015 quality of death index, in which China ranked 71st, HK came 22nd. Although better than Mainland China, HK was reported to have performed relatively poorly with regard to overall health care spending, the availability of research-based policy evaluation and the capacity to deliver palliative care services (Economist Intelligence Unit, 2015, p. 22).

2.4.2.3. Taiwan

The hospice movement in Taiwan started in 1983, when a number of oncologists from the Mackay Memorial Hospital were inspired by their visit to hospices in the US. Since their visit, the first hospice programme was established in 1987 and the first inpatient hospice care service began in 1990 at the Mackay Memorial Hospital (Lai & Su, 1997). The need to provide hospice care was predominantly because of the increasing prevalence of death caused by cancer (Hospice Foundation of Taiwan, 2018). The early development of Taiwan's hospice movement was founded upon religious organisations. The Mackay Memorial Hospital was a Christian hospital and the three hospice promoting foundations were all based upon religious principles. The Sanipax Socio-Medical Service & Education Foundation (established in 1983) and the Taiwan Hospice Foundation (established in 1990) are Christian and the Lotus Hospice Care Foundation (1994) is Buddhist (Cheng et al, 2001). Since the initiation of the hospice movement in Taiwan, the growth has continued, leading to Taiwan being ranked first amongst all Asian countries and sixth in the world, according to the 2015 Quality of Death index (Economist Intelligence Unit, 2015).

In terms of laws and regulations, since 1995 the Taiwanese government recognised the importance of hospice care and therefore became actively involved in i) policy making, ii) standardising hospice care, iii) setting guidelines for symptoms control and iv) including hospice care as part of national insurance reimbursement (Cheng et al, 2001; Lai & Su, 1997). Crucially, the passing of the “Natural Death Act” in 2000 had consolidated the role of hospice care in Taiwan’s mainstream health care system by granting patient autonomy in rejecting futile medical treatments at the end of life and the patient’s right to request “do-not-resuscitate” (DNR) (Cheng et al, 2016a). Further, the passing of the “Patient Autonomy Act” in 2015, and its enactment in 2018, provides a legal basis allowing patients to make their advance decision to accept or reject medical treatment. This law applies to five categories of clinical conditions: i) terminal illness, ii) terminal dementia, iii) irreversible coma, iv) persistent vegetative states, and v) intractable symptoms and suffering (The Patient Autonomy Act, 2015).

Research development in palliative and end of life care in Taiwan is relatively progressive comparing with the other three Chinese contexts featured in this literature review. Research interest in palliative and end of life care has extended beyond cancer to other medical conditions, such as dementia (Chen et al, 2018; Chen et al, 2017), motor neuron disease (Wang, 2013), cerebrovascular diseases (Tsai & Huang, 2015), and palliative care provision in intensive care (Gillis et al, 2008). There are empirical studies relating to people’s and health care professionals’ understandings and attitudes towards death and dying in Taiwan (Chao, 2002; Cheng et al, 2008; Cheng et al, 2016b; Huang et al, 2010; Leung et al, 2009; Tsai et al, 2005; Yang & Chen, 2009). Despite there are some research on the development of the hospice movement in Taiwan (Cheng et al, 2001; Cheng et al, 2016a; Hospice Foundation of Taiwan, 2018; Lai & Su, 1997; Teng et al, 2013), no study has examined the hospice movement from a social movement perspective.

Nevertheless, the hospice movement in Taiwan has embraced and advanced the aspect of spiritual care in the direction of Buddhism. Despite the hospice movement in Taiwan originating from Christian beliefs, the nation has notably developed a Buddhist informed hospice service, such as the Lotus Hospice Care Foundation mentioned above.

2.4.2.4. Macao

With regard to the development of end of life care in Macao, the literature reporting on this aspect of health care was scarce; a paucity which was one of the key motivations for conducting this research. The aim of this section is therefore to provide the background and history of the introduction of end of life care in Macao; a more comprehensive enquiry into the development of end of life care in Macao is presented in Chapter Five, as part of the findings of this research.

The beginning of Macao's end of life care was marked by the establishment of the Association of Friends of Charity of Macao (AFCM) in 1996. AFCM was the first charity dedicated to support people affected by cancer. AFCM was a volunteer-based, non-clinical charity, offering free health education, counselling and financial advice to those who were affected by cancer (the Printing Bureau Macao, 1996). The year 2000 marked the establishment in Macao of a community home visit service, the Peace and Hope Centre, and the first hospice, the Hospice and Palliative Care Centre (HPCC). As part of the missionary service of the Macao Medical Mission (3M) (The Printing Bureau Macao, 1995), the Peace and Hope Centre provided home visits, encompassing spiritual (Christian-based) and psychological support for people living with terminal cancer, as well as their families. Further, the centre also provided education on issues relating to the 'difficult' issues of life and death, as well as offering grief counselling services. The Hospice and Palliative Care Centre (HPCC) was the first hospice established, and it remains the only clinical service that provides palliative end of life care for the people in Macao. The latest addition to the end of life care development in Macao was the establishment in 2001 of the Resources Centre for Cancer Patients (RCCP). The service provided by the RCCP included answering patients' and families' questions in relation to nursing care during cancer treatments or after having cancer; offering financial advice; ways to handle emotional problems; nutrition related issues and concerns; and even a counselling service (The Government Information Bureau of Macao SAR, 2011). Exclusively targeting cancer patients, even though the service of the RCCP was not specifically focused on the terminally ill, it meant that cancer patients in their last phase of life were still welcomed to use its services.

As a whole, AFCM, Peace and Hope Centre and RCCP offered non-clinical advisory, educational and counselling support, mainly for people affected by cancer; while the

HPCC was the only clinical and in-patient service that was also focused on people with cancer. Further, there was a substantial time gap (ten years) between the establishment of the first and last end of life care related services. There are no records of any *professional* bodies being devoted to aspects of end of life care in Macao, nor any legislation or professional guidelines specifically relevant to end of life care related issues.

In addition to the aforementioned activities relating to end of life care in Macao, there is some but limited evidence showing that nursing was involved in the pioneering of end of life care in Macao. Most notably, the initiator of the hospice was a nurse. Not only did she push for the establishment of the first hospice, but she was also the key figure of AFCM (first cancer patients support group). Secondly, the two earliest studies conducted on the topic of end of life care in the context of Macao were centred on nursing. The study of Wong et al. (2002) and Leong et al. (2007) studied the attitude and understanding of nurses and student nurses towards the hospice care in Macao respectively. The results of Wong et al. (2002) showed, most nurse participants did not have adequate knowledge about the concept of end of life care because participants felt that end of life care did not apply in their clinical practice. Further, the study found that some participants (10%) believed end of life care nursing was not challenging because of the absence of resuscitation (Wong et al, 2002). Similarly, the study of Leong et al. (2007) examining student nurses' understanding of end of life care showed participants had poor understanding of the core concepts of end of life care, only about two thirds of them were familiar with the WHO pain ladder (Leong et al. 2007). Conducted by nursing academics, these two research were the first to study specifically the aspect of end of life care in Macao, with a specific interest in the field of nursing. Taking into consideration that hospice was historically developed and operated by nursing-trained nuns (Goldin, 1981; Mulholland, 1895), and the initiator of the modern hospice movement Cicely Saunders was a former nurse before qualifying as a physician (Saunders, 1981). Despite the connection between nursing and the development of end of life care, there was little empirical research exploring this connection in either the international or the Macao context, contributing to a gap in the literature which had supported the enquiry of this research.

In terms of the professional aspect, there was evidence indicating some professionals had attempted to promote the development of end of life care practice, by proposing new developmental plans. For instance, taking into consideration the increasing ageing population and the prevalence of chronic co-morbidities amongst the ageing population, Pun (2011) suggested the desirability of introducing end of life care services into the nursing homes. Having assessed Macao's growing demand for end of life care, and the limited inpatient services available, Chan (2007) suggested a number of recommendations including the expansion of current hospice services and implementation of end of life care beds in acute hospital environments (inpatient wards, accident and emergency units); also recommended was the setting up of an end of life home-care service and a day unit for terminal patients. However, there has been no observable development, nor expansion, of end of life care since these recommendations were proposed. Macao was not included in the quality of death index published by the Economist Intelligence Unit (2015) and no assessment has thus far been found that dealt with an evaluation of the quality of end of life care offered in Macao. This research seeks to examine why there is a lack of progress with end of life care service in Macao by examining its inception and development.

In the following section, I compare and contrast the emergence of end of life care amongst the four different Chinese contexts discussed above. The purpose of this comparison is to understand how the end of life care development in Macao differed from the other three Chinese contexts, thereby generating an empirical understanding of the end of life care of Macao.

When comparing Macao with other Chinese contexts specified in this literature review, there are a number of notable differences. As explained in this chapter, the management of the Hospice and Palliative Care Centre in Macao was unique. Whilst end of life care in the aforementioned contexts (Chinese and international) was motivated by non-government individuals/organisations, the establishment of the hospice in Macao was funded and overseen by the government. However, at the same time the hospice was operated by a non-government institution - the Kiang Wu hospital. Nevertheless, the extent of government involvement in Macao's end of life care was found to be limited to the monetary support for the hospice, because there was no evidence of any further government consideration, in their health care agenda, of end of life care.

In comparison between the Chinese environments, Taiwan was the only place with established legislation dealing with end of life issues; while HK had in place official recommendations for setting up advance directives. Despite Mainland China having no established strategies, "statements of broad intent" were included in national health care policies. Macao however, had no end of life legislation nor any kind of national statement issued at the time this research was carried out. Other differences of the development end of life care include the inception time, the type of services available and levels of professional engagement. Whilst the idea and service of end of life care in Mainland China, HK and Taiwan started to emerge in the 80's, the first recorded activity on end of life care for Macao began in the late 90's. Although HK shares a very close geographical proximity with Macao, the early development of end of life care in HK did not encourage an earlier development in Macao. Secondly, clinically oriented end of life care was the main form of service provided by Mainland China, HK and Taiwan. However, Macao's end of life care provision was oriented mainly on information and advice giving and counselling support. Excepting Macao, the other three Chinese examples cited all had some form of professional bodies uniting local communities and health care professionals in developing end of life care.

In comparison with other Chinese contexts, the development of end of life care in Macao was evidently less extensive. The various services established were independent from one another; there were no professional organisations/groups uniting end of life care work and there was no infrastructure underpinning and facilitating the overall development of end of life care in Macao. In addition to that, literature with a specific focus on end of life/hospice care in the context of Macao is also very limited. There were a total of only four studies concerning the hospice service in Macao, with each focusing on different subjects, as follows: i) assessing the demand for hospice care (Chan, 2007), ii) and iii) attitudes and recognition of nurses and nursing students towards hospice care (studies that were mentioned above) (Leong et al, 2007; Wong et al, 2002), and iv) a study describing Lo's experience in developing the hospice (Lo, 2002). There was also one presentation discussing the need to improve end of life care in Macao's nursing homes (Pun, 2011). Even though Lo's article depicted the development of the hospice it was, to a great extent, a descriptive account of her personal experience of being involved in the hospice developmental process. There was no substantial investigation into the overall development of end of life care.

There were some clear gaps evident in the literature. First of all, there was clearly not enough empirical evidence on the subject of end of life care, with only four studies and one presentation available on the subject of end of life care in Macao; a knowledge gap which strongly supported the value of conducting this research. Secondly, the need to understand the development of the end of life care in Macao was reflected in the considerable differences between Macao and the three other Chinese cultural environments discussed in this review. Despite sharing close geographical proximity with these Chinese regions, comparison of the literature showed that Macao's end of life care was relatively less developed. At the time of this research, there was no study on the development of Macao's end of life care except for Lo's study. These gaps in the literature led me to develop the research questions: Why and how did end of life care emerge in Macao?

As discussed in section 2.4.1, the modern hospice movement started in the UK and was rooted in Christianity. It is arguable that Christian beliefs had, to a great extent, shaped the concept of end of life care and influenced its development. For instance, the earliest end of life care services, since the inception of the modern hospice movement, were all Christian based. Therefore, I wanted to know if any elements within the Chinese culture would have impacted on the development of end of life care in Macao. Section 2.5 below begins by exploring how the Chinese perceive death and dying.

2.5. The Chinese perspective on death and dying

This section aims to present some of the culture related factors discussed in the existing literature that influence peoples' views on death and dying in the Chinese culture context. In searching for literature related to the subject of death and dying through the prism of Chinese culture, many studies highlighted the strong association of death and dying with various religions, i.e. ancestor worships, Taoism, Confucianism and Buddhism, and how these religions had collectively influenced Chinese people's perspectives on death and dying. This section presents two key perspectives: i) death as a taboo and ii) the preservation of life, informed by the aforementioned religions that have influenced Chinese people's view on death and dying. These factors are also understood to have influenced people's perspectives towards end of life care.

2.5.1. Death as a taboo

Despite death in the Chinese culture being recognised as a natural part of life, association with death and dying is still seen as a taboo. Open discussion and conversation about death and dying is culturally forbidden because Chinese people fear that talking about death will invoke bad luck and ultimately cause death (Chan, 2009; Hsu et al, 2009; Wong, 2012; Yu, 2007). This belief continues to be prevalent amongst Chinese families today (Mak, 2011).

The taboo of death is closely related to the mixture of religious and philosophical beliefs Chinese people adhered to. Ancestor worship emphasises the continuing bond between the descendants and their ancestors (Hsu et al, 2009; Yang & Chen, 2009). Ancestors are believed to continue to exist amongst the living and influence all aspects of their descendants' lives, from family's wealth and health to success. Afterlife rituals in ancestor worship are complicated and yet significant, for Chinese people believe that misfortune, including family disharmony, economic problems and/or sickness, will befall a family if the spirits of the dead are not being respected (Yick & Gupta, 2002). These beliefs have contributed to death being a taboo subject. In Taoism, despite death being regarded as part of life's natural journey, it is not an achievement for life and is an inauspicious event that should be avoided (Hsu et al, 2009). Immortality in Taoism is the ultimate goal and it is believed that by adopting self-cultivation methods, such as using Feng Shui, doing Tai Chi and using traditional Chinese medicine, immortality can be achieved (Kleeman, 2003; Schipper, 1985). Sharing a similar outlook with ancestor worship, Taoism believes that the dead continues to share bonds with the living, in that retribution, misfortune and poor Feng Shui would explain the causes of illness and death (Lai, 2006; Yeo et al, 2005).

The attainment of immortality is also supported by Confucianism. Confucius taught that by living one's life following the four comportments: i) propriety, ii) filial piety, iii) appropriateness and iv) humanness, one can become a superior person through self-cultivation, and continue one's existence through one's descendants (Hsu et al, 2009). The understanding of death and dying in Buddhism is a combination of the original Buddhist teaching and the philosophical beliefs from Taoism, Confucianism and ancestor worship. In Chinese Buddhism, the state of mind of the dying is critical, whether good or evil, as that state will impact on the person's rebirth (Yin, 2006). The care of the dying person in Chinese Buddhism therefore emphasises his/her spiritual state, in order to allow the person to go freely in peace (Hsu et al, 2009).

In summary, the taboo of death is closely linked to the continuous bond between the dead and the living, and the negative superstitious consequence people could experience if the dead ancestors were not being respected. Further, even though death is recognised as part of life's natural journey, the state of death is not accepted or acceptable, as immortality is the ultimate goal that one should strive to pursue. Historically, the desire to become immortal is evident in Chinese emperors' endeavours in seeking remedies to preserve and prolong life throughout thousands of years of

Chinese history (Yu, 2007). Today the desire to achieve immortality is reflected in the preservation and prolongation of life through curative therapies offered by modern medical science. Focusing on the desire for life preservation regardless of the quality of that life, the next section explores literature relating to Chinese perspectives on life preservation and how these perspectives are affecting the care for the dying.

2.5.2. The preservation of life

A study by Bai et al (2010) investigated Chinese patients' and health care professionals' attitudes towards palliative care in a particular region in China. The authors conducted a cross-sectional survey using two sets of self-developed, 17 item questionnaires, for two groups of participants, patients with advanced cancer and health care professionals made up of doctors and nurses. The findings showed that despite participants from both groups accepting death as a natural life process, half of the participants continued to believe that life preservation was their major care goal. This finding is consistent with the previous discussion that according to both philosophical and religious beliefs, death is recognised to be a natural part of life but immortality is still seen as the priority. Similarly, a study by Wang et al (2004) examining Chinese oncology clinicians' practices and attitudes towards end of life care, by administering a 40 item questionnaire to assess 60 Chinese clinicians' impressions on issues relating to end of life care, competence in pain and symptom management, communication on terminal illnesses, treatment decision making, and barriers relating to end of life care provision. The study found that majority (80%) of the participating oncologists would continue to give cure-oriented anti-cancer treatments to dying patients because of i) high demand from patients and families to continue treatment and ii) oncologists' reluctance to 'give up' on their patients. The practice of delivering futile medical treatment in the hope of prolonging life of the dying was consistent with other studies within Chinese cultural contexts (Chen et al, 2017; Dong et al, 2016; Kwok et al, 2007; Luk et al, 2013; Pang et al, 2006; Zeng et al, 2008). Particularly, the use of specific life-prolonging interventions was, to an extent, related to superstitious beliefs associated with the dead; together with the potential consequences a family could suffer if they mistreated the dying. For instance, some Chinese believed that if the family member died with an empty stomach, they would come back and haunt the household, therefore, unnecessary artificial nutrition was often given to dying patients (Rifkin, 2010).

Further, the implementation of life-sustaining treatments amongst the terminally ill was still prevalent even in Taiwan, where the delivery of end of life care was believed to be more integrated compared with other Chinese regions. A recently published five-year nationwide cohort study, using the Taiwan's National Health Insurance Research Database (NHIRD) to statistically analyse the association between palliative care and life-sustaining treatments for patients with dementia in Taiwan; the study found that patients with dementia were more likely to receive active, life-sustaining treatments at their end of life phase when compared to terminal cancer patients; as a result, patients with terminal dementia were less likely to receive hospice care (Chen et al, 2018). Another methodologically similar Taiwanese nationwide cohort study conducted by Huang et al (2017) yielded similar results. Different from the study of Chen et al (2018) above, the study of Huang et al (2017) compared end of life treatment delivery on two groups of people: i) patients dying with terminal cancer and dementia, and ii) patients dying with dementia. The study found that life sustaining invasive measures were more likely to be used on terminal cancer patients with dementia and these patients were less likely to receive palliative care. Findings of both studies suggested that Chinese cultural attitudes towards life extension was a factor affecting people's decisions on life preserving treatments at the end of life, particularly amongst people dying with terminal cancer.

However, a cross-sectional questionnaire survey study conducted amongst 219 elderly patients (aged > 60 years) who had chronic diseases and were admitted as inpatients in a hospital in HK (Ting & Mok, 2011). The findings of this study conflicted with the findings in the research mentioned above, in that most participants in Ting and Mok's study were found to agree with the withdrawal of life-sustaining treatment in medically futile situations (Ting & Mok, 2011). The authors suggest that this result could be potentially influenced by the explanation of advanced directives and information relating to life-sustaining treatment given to participants during the verbal delivery of study questionnaires. Despite the result of the study by Ting & Mok (2011) being potentially biased, as explained above, it showed that without the provision of information on life-sustaining treatments and advance directives, participants would be likely to continue their support for life preservation, as indicated by other studies discussed in this section.

To conclude, the taboo of death and the pursuit for life preservation continued to be prevalent amongst the Chinese and had evidently impacted on people's preference for care at the end of their lives. Life-sustaining measures were the preferred option, despite end of life care being available. Being aware of this cultural impact could help to promote the use of end of life care and, at the same time, further the development of end of life care in a particular Chinese cultural context. However, the majority of the studies discussed were conducted in the Chinese environments of Taiwan, HK and some from Mainland China. No publications from Macao were found, which further reinforced the overall lack of knowledge in the aspect of end of life care in Macao; thereby supporting the need for this research.

2.6. Conclusion

In this literature review, the emergence of the modern hospice movement from the UK, and how it was spread internationally, was discussed. From the analysis of the literature, the success of the modern hospice movement in spreading across the globe can be attributed to the collective power of individuals across different geographical areas, and their various personal, professional and cultural connectedness. This special connection and collective goal, shared between different people, were the keys to the success of the modern hospice movement. These characteristics of the modern hospice movement reflect the traits of a social movement; however, this literature review has also indicated a lack of empirical evidence on the analysis of the modern hospice movement by way of any theoretical perspective informed by, or based upon, the concept of social movement.

In terms of the Chinese cultural context, the extent of literature on the development of end of life care was not as extensive as within the western context. This literature review has also discussed three other Chinese contexts, namely Mainland China, Hong Kong and Taiwan, in addition to Macao. When Macao is compared with the other Chinese contexts, it can be seen to have relatively less development. For instance, there is no end of life specific legislation; end of life care is not part of the Macao government's health care agenda and there were no professional bodies facilitating any professional development relevant to end of life care. The review of the literature has indicated a lack of empirical research on the development of end of life care in the Chinese contexts mentioned above. In particular, the emergence of end of life care in Macao has not been widely researched, so factors influencing its establishment and development process are unknown.

In terms of the impact of the Chinese culture on people's views on death and dying, this literature review has discussed the association of death and dying with various religions

Chinese people adhere to, i.e. ancestor worships, Taoism, Confucianism and Buddhism, and how these religions have influenced Chinese people's perspectives on death and dying. Focusing on two key perspectives: i) death as a taboo and ii) the preservation of life, this literature review discussed the connection of death taboo and immortality. Due to the historical desire for longevity and immortality, the state of death has become unacceptable. The desire to achieve immortality is reflected in the preservation and prolongation of life, and the advances in modern medical science has reinforced this pursuit. The taboo of death and the pursuit for life preservation continued to be prevalent amongst the Chinese and had evidently impacted on people's preference for care at the end of their lives. As presented in this literature review, many studies have identified that life-sustaining treatments were the preferred option, despite end of life care being available. In respect of this aspect, no publications from Macao were found, which further reinforced the overall lack of knowledge in the aspect of end of life care in Macao; thereby supporting the need for this research.

Also explored in this literature review was the relationship of nursing and end of life care in Macao, in particular, the involvement of nursing in initiating end of life care and the early research interest from nursing academics in end of life care. This connection however was based on the only two studies conducted to date within Macao, and it is evident that Macao's end of life care was initiated by a nurse, and that nursing could potentially contribute to the understanding of the end of life care in Macao. As a consequence, this research recruited experienced nursing educators as participants. A detailed account and justification of this recruitment decision is provided in Chapter Three: Methodology.

In addition to the lack of research investigating the establishment of end of life care in the Macao context, there is no research which examines the development of end of life care by using the perspective of social movement within the analysis. This is an omission which reflects the same issue as encountered by the modern hospice movement. As I will justify and explain in Chapters Three and Four, the framing perspective of social movement was adopted in aiding the analytical and theorising processes of this study. The framing perspective also provided new perspectives for understanding the process in which end of life care was being developed. Above I presented a number of knowledge gaps which have supported the development of my research questions.

3. Chapter Three: Methodology

3.1. Introduction

The review of literature has established a basic understanding regarding the beginning of the modern hospice movement, how end of life care has progressed and its impact on people's experiences during the terminal phase of life in the global sphere. Within the Chinese cultural context, literature has provided understanding regarding Chinese people's perceptions and attitudes about death and dying. There is also research looking into the impact of this existing cultural value on people's attitudes towards end of life care. However, there is a lack of research seeking to understand the journey of establishing end of life care within the Chinese cultural environment. Evidence on the impact of Chinese cultural values on the development of end of life care is scarce. Within the specific socio-cultural context of Macao, there is a dearth of research exploring the establishment of end of life care; therefore, the aim of this thesis is to address these gaps pertaining to the emergence of end of life care in Macao (for details see section 3.2). The aim of this chapter is therefore to provide a detailed account of the methodological framework adopted in the design and implementation of the present research study. I first discuss the focus of the research by outlining the research aim and questions. Having considered the ontological and epistemological underpinning, I present the rationale in using qualitative case study design and the theoretical framework, the framing perspective (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986) in this research. I then provide a detailed account of the process of data collection, data analysis, language and ethical implications in conducting this study. The issue of reflexivity is discussed. The quality and limitations of the study are also considered at the end of this chapter.

3.2. Research aim and questions

The aim of this case study is 'to understand the development of end of life care, and how this service has been facilitated and limited within the specific socio-cultural context of Macao'. The study's aim was determined at the onset and the openness of it has allowed me to refine and consolidate the research questions as I commenced the research process. The selection of research methods depend on the research aim and research questions (Punch, 2014; Silverman, 2017a). In view of the research questions and overall aim of the present study, which is to understand the establishment and development of end of life care in Macao, a qualitative research design grounded in a case study approach, was determined to be the most appropriate for the present investigation. For this study, the research questions below were subsequently constructed:

1. Why and how did end of life care emerge in Macao?
2. What factors have influenced the subsequent development of end of life care in the context of Macao?

As I will detail the rationale in a later section of this chapter, a qualitative case study was decided as the main research design, and the end of life care in the specific socio-cultural context of Macao was established to be 'the case' in this case study research.

3.3. Ontological and epistemological perspective

In view of the research aim in seeking the reasons and processes informing the origins of end of life care in Macao, I decided that an inductive approach was the most appropriate for this study. Prior to the discussion of my decision to adopt a qualitative research design, incorporating the framing perspective, for this research, I will clarify my ontological and epistemological perspectives that will guide this research throughout this thesis.

3.3.1. Ontology

Ontology concerns the nature of social reality (Crotty, 1998). Specifically, the philosophical role of ontology concerns the social reality created by humans to serve humans (Searle, 1995, p. 4). In the context of social sciences and qualitative research, the concept of ontology relates to the social reality (social phenomena) that a researcher wishes to "explore, explain, imagine or theorise" (Mason, 2018, p. 6). In this thesis, the ontological perspective I adhere to is that *reality is socially constructed, context-dependent and subjectively perceived* (Crotty, 1998), and I have therefore rejected the idea that reality is a fixed, independent entity. In this thesis, I endorse idealism or relativism, in that I support that social reality can only be comprehended through the human mind and through socially constructed meanings (Ritchie & Lewis, 2003). As a result, my ontological perspective can be narrowed down to one of subjective interpretation. Reflecting on the aim of this research, which is to understand why and how end of life care in Macao was developed, I decided that the most appropriate channel to address these enquiries is through examining the personal experience and interpretation of the initiators and developers. My main justification for this decision is that these individuals are the people who introduced the end of life care concept and pioneered the end of life care services in Macao (see also sections 3.4 and 3.5). The phenomenon of the development of end of life care in Macao that I wish to investigate cannot be universal. Therefore, my research focus is subjective and derives from the initiators' and developers' subjective interpretations regarding the experience of death and dying within the specific Chinese context of Macao. If this were not the case, I would need to acknowledge that the development of end of life care not only existed in isolation from the subjective interpretations of the pioneering initiators and developers, but also existed independently from the initiators' and developers' individual contexts: a position that I disagree with.

To conclude, my ontological position in this thesis is that the social phenomenon of end of life care development in Macao, which is the issue I aim to study, stems from the initiators' and developers' subjective interpretations of the experience of death and dying within the specific Chinese context of Macao. The issue of the development of end of life care in Macao cannot be understood if or when separated from the subjective interpretation of those pioneers' experiences, which are linked to their individual contexts. Having clarified my ontological perspective, below I discuss the epistemology position for this thesis.

3.3.2. Epistemology

Epistemology concerns "how we can know what we know" (Crotty, 1998, p. 8). Therefore, in this study, the epistemological question I need to raise is: "how can I, as the researcher in this study, know what I know in terms of the development of end of life care?" To this end, I endorse constructionism as my epistemological perspective. Constructionism disagrees with the idea of an objective truth and rejects the objective viewpoint of '*what it means to know*'; rather, constructionism advocates that '*truth, or meanings, comes into existence in and out of our engagement with the realities in our world. There is no meaning without a mind. Meaning is not discovered, but constructed*' (Crotty, 1998, pp. 8-9). By adopting the constructionist stance, my knowledge regarding the development of end of life care in Macao is constructed by way of my interaction with, and how I make sense of, the interpretations of the initiators and developers (detailed above) in relation to death and dying within the specific socio-cultural context of Macao. In trying to make sense of those pioneers' interpretations, and to construct meanings, I need to recognise my interpretive role throughout this process; particularly because the phenomenon I intend to study is constructed not only by interaction but also interpretation. I also need to emphasise that by adopting a) the constructionist stance wherein all knowledge is constructions and b) the ontological stance of subjective interpretation, it is important for me to recognise my position as a researcher cannot be objective. As a result of such a stance any knowledge/understanding I generate during this research process is also built upon the process of construction. In addressing this issue reflexivity relating to my position as the researcher in this study is considered (see section 3.6).

Reflecting on my ontological and epistemological positions, I decided that the qualitative case study approach described by Stake (1995) is most appropriate for this research. Stake's qualitative case study model is closely aligned with my constructionist orientation; it advocates the discovery and generation of knowledge of a given case is through interaction between researcher and participants. In addition, Stake's qualitative case study also recognises and advocates the interpretive role that a researcher plays in constructing knowledge relating to the case being investigated. The section below will present the rationale for choosing a qualitative case study model for this research.

3.4. Research design

On the journey to understand the end of life care in Macao, I intended to develop an in-depth understanding in relation to how the end of life care was introduced, established and developed, in that specific socio-cultural location. Qualitative enquiry is suitable for research that seeks to understand the experiences of phenomena (naturalism) or how phenomena are being constructed by human interpretations in the social world where people live (Silverman, 2017a). A qualitative design has capacity to seek a detailed understanding of social phenomena (Mason, 2018). A qualitative approach enables the researcher to understand "experiences, actions and events as they are interpreted through the eyes of particular participants, researchers and (sub)cultures" (Henwood, 1996, p. 27). The aim of the present study is to understand the development of end of life care in Macao. The process in which end of life care was being constructed through human interpretations and interactions within that particular socio-cultural context was central to this study. A Qualitative research design was considered beneficial because of its capacity to extensively explore issues that lack existing research (Patton, 2015). As discussed in Chapter Two (Literature Review), research interest in the influences of Chinese culture on death, dying and end of life issues is plentiful. However, the focus of many of these studies is on patients', relatives' or clinicians' experiences/attitudes towards end of life events, or existing end of life care services (Bai et al, 2010; Bowman & Singer, 2001; Chan & Yau, 2009; Chan & Chow, 2006; Chan & Chang, 2000; Chan & Epstein, 2011; Chen et al, 2014; Chung et al, 2018; Enguidanos et al, 2013; Gu & Cheng, 2016; Ho et al, 2013; Hsu et al, 2009; Lam et al, 2015). There is limited empirical evidence on the establishment and development of end of life care in the Chinese cultural environment, and particularly within the context of Macao. Using a qualitative research design in this study would expand the currently limited understanding on the emergence of end of life care in the socio-cultural context of Macao.

Qualitative research encompasses a variety of qualitative methodologies underpinned by various philosophical scopes, techniques and procedures (Creswell, 2018). A qualitative case study was selected for this study and the rationale for this selection is discussed below.

3.4.1. Qualitative case study

In this section, I expand the rationale behind choosing the case study approach; specifically, the qualitative case study model proffered by Robert Stake (Stake, 2000; Stake, 1995; 2003). Further to the selection of a qualitative design, a case study offers an in-depth exploration to expand understanding on a subject/phenomenon about which there is only limited prior knowledge. The main concern of Stake's case study is the "intrinsic value" of the case. Central to a qualitative case study is an understanding of the "uniqueness and commonality" (Stake, 1995, p. 1) of the case under investigation; the case is the interest and the focus (Stake, 2000; Stake, 1995). The aim of this research was to understand the emergence of end of life care within the socio-cultural context of Macao, and the end of life care in the context of Macao was made 'the case' of the present research. In the next section, I discuss how the case was being defined.

Prior to the current research, there had been very little empirical evidence available on the subject of end of life care within the particular context of Macao. As I critiqued in the literature review (see Chapter Two), only a small number of studies examined end of life care, or its related service, within the specific location of Macao. The subject of these studies was mainly exploration of people's/healthcare professionals' attitudes and awareness relating to end of life issues, end of life care and related services (Ho & Sanders, 2015; Kan et al, 2003; Leong et al, 2007; Lo, 2005; Pun, 2011; Wong et al, 2002). Whilst two articles were found to be related to the development of the end of life care service in Macao (Chan, 2007; Lo, 2002), the authors of these studies presented a more descriptive account, focusing on the practical steps taken to build the hospice (Lo, 2002), and on assessing and making recommendations for future development (Chan, 2007). Neither Chan nor Lo considered the socio-cultural context of Macao and the potential impact it could have contributed to the development of end of life care. The focus of these authors primarily remained on the practical level, with limited cultural, social or theoretical considerations in their discussions (for more details of these two papers please refer to Chapter Two). A qualitative case study design and its methods offer depth to research exploration, which is primarily underpinned by the constructionist infrastructure, allowing the researcher to systematically and intrinsically examined the case (Stake, 1995). Considering the substantial lack of knowledge regarding end of life care in the context of Macao, a qualitative case study was recognised to be the most appropriate research design in addressing this under-explored area. Within this case study approach, qualitative data gathered through interviews with the individuals who had set up and developed the end of life care in Macao, as well as interpreting and analysing those accounts, add in-depth insights and help address the research aim. In terms of the epistemological underpinning, the constructionist paradigm advocates the construction of knowledge in human beings, positing that social phenomena are established through human concepts; in other words we build meanings to comprehend the experiences we encounter (Hurd, 2010; Schwandt, 2007). Stemming from constructionism, the social constructionist perspective concerns the continuous social processes, human activities and interactions that yield the multiple realities we live in; meanings are constructed by human interpretation of the world in which ‘the builders’ reside (Berger & Luckmann, 1991). By adopting a qualitative case study model, this research examined the journeys of the individuals (n=3)[1] who initiated end of life care, and other individuals (n=8)[2] who became involved in the development of the services, by way of in-depth interviews. The personal accounts of these individuals were significant because they provided meaningful insights into why and how end of life care was being constructed in Macao.

Regarding my role of researcher in a qualitative case study, having been born and raised in Macao my native knowledge of the socio-cultural context of Macao contributed directly

---

[1] For the individuals (n=3) who initiated the concept of end of life care in Macao, I refer to them in this research as *initiators/pioneers*.

[2] For the individuals (n=8) involved in the subsequent development of end of life care in Macao, I refer to them in this research as *developers*.

to my understandings of the collected data, informing the process of data interpretation and enhancing the data analysis. Qualitative studies help us “understand the complex interrelationship among all that exists” (Stake, 1995, p. 37). By sharing connections and having insights into the subject that is being studied, I was able to be informed the process of data interpretation, analysis and synthesis, by way of my subjective judgment and by being aware of my own consciousness in these processes (Stake, 1995).

It is important to emphasise that the purpose of this study is to develop a theoretical understanding regarding the emergence of end of life care within the context of Macao. In order to fully address the research aim, I consequently decided to adopt the theoretical framework proposed by Snow et al. (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986) during data analysis for theorising the study findings (Discussion on the framing perspective is located in Chapter Four). This theoretical framework enabled an interpretation of the data to better understand the development of end of life care in Macao, so meeting the research aim and answering the research questions.

To conclude, qualitative case study methodology was used in this research because it provided the infrastructure and epistemological grounding needed to comprehensively examine and develop a deeper understanding of end of life care that currently exists in Macao. Furthermore, a case study approach offered the scope for developing a theoretical understanding of the subject of the research. A qualitative case study provided me with a structure and flexibility in several areas: i) recruiting participants who were significant for the study, ii) developing open ended questions to conduct semi-structured in-depth interviews and iii) thematically analysing data to interpret findings by way of a theoretical framework (the framing perspective); thereby constructing a theoretical understanding of end of life care within the context of Macao.

3.4.1.1. Defining the case

For the present study, it was clear from the beginning that the research interest lay in the development of end of life care within the context of Macao, primarily because the current study stemmed from my intrinsic interest on this specific subject as explained in the preface (see p. 8). A common consideration with respect to case definition is the “boundaries” of a case, as it clarifies the “unit of analysis” so enabling researchers to better focus on the research interest (Gerring, 2007; Stake, 2000). The requisition of boundaries in a case depends on the context in which the case is situated, and serves to contain the case study enquiry within limits (Yin, 2014). In some disciplines, such as nursing, medicine and social work, the case study model is commonly used in the realm of clinical research, where the unit of analysis (the case) is typically an individual (Abma & Stake, 2014; Gerring, 2007).

Reflecting on the current study, since the subject of interest was not an individual but a broader interest in a particular phenomenon (the development of end of life care) within a particular context. In adopting a qualitative case study, I needed to establish the unit of analysis, 'the case', in order to reinforce the focus of enquiry so enabling me to address the research aim (Simons, 2009). The process of case definition had been a continuous process for the study. Despite the subject of interest being clear from the beginning, 'the case' was only circumscribed during the stage of data analysis mainly because the subject of interest I had determined for the study was broad, in that I intended to seek knowledge within the aspect of end of life care in the context of Macao. The lack of existing understanding on the research subject has made it difficult to narrow down my research focus to a single unit of analysis at the beginning of the study. Nonetheless, in the process of data analysis, my interpretation of the collected data had furthered my understanding of the research subject, enabling me to determine the case for the study and develop further analysis focusing on it. Justified by Stake (2000), the process of defining the case cannot be separated from the interpretive paradigm in the research process, wherein the case can be interpreted differently depending on the perspectives it is being viewed from. Hence, the definition of 'the case' can change during the process of the research enquiry (Stake, 2000). Stake's justification for this position can be applied in the present study, in that 'the case' was defined during the process of analysis, in accordance with my interpretation on the collected data. Further, taking into consideration the 'boundedness' in case setting (Stake, 1995), I determined that 'end of life care within the context of Macao' would be 'the case' for the present study. The boundaries here imply the temporal and contextual limitations (Gerring, 2007; Yin, 2014); the case was therefore established, limiting the socio-cultural context of this research focus to within the geographical boundary of Macao. Since the study focus was on the development of end of life care in Macao, this also imposed temporal limitations from the time when end of life care was introduced until the time of the research. Despite 'the case' not being established at the onset of the study, deciding 'the case' during data analysis facilitated by my interpretive and constructionist stance, subsequently maximising the acquisition of understanding towards the subject of research interest. Further, the established 'case' had: a) helped to develop the research questions, b) improved the focus of my research enquiry and c) expanded the depth of understanding of the case.

To conclude, the aim of the current case study was to examine the development of end of life care within the specific socio-cultural context of Macao. I justified my journey in establishing 'the case' and the decision in making end of life care in the context of Macao as the unit of analysis for the current study. In the next section, I present the procedures informed by the use of qualitative case study including sample recruitments and methods for data collection and management. Since data analysis and interpretation of the study's findings were grounded in the framing perspective adopted in the study (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986), I decided to discuss the use this theoretical framework in Chapter Four.

3.5. Data collection procedures

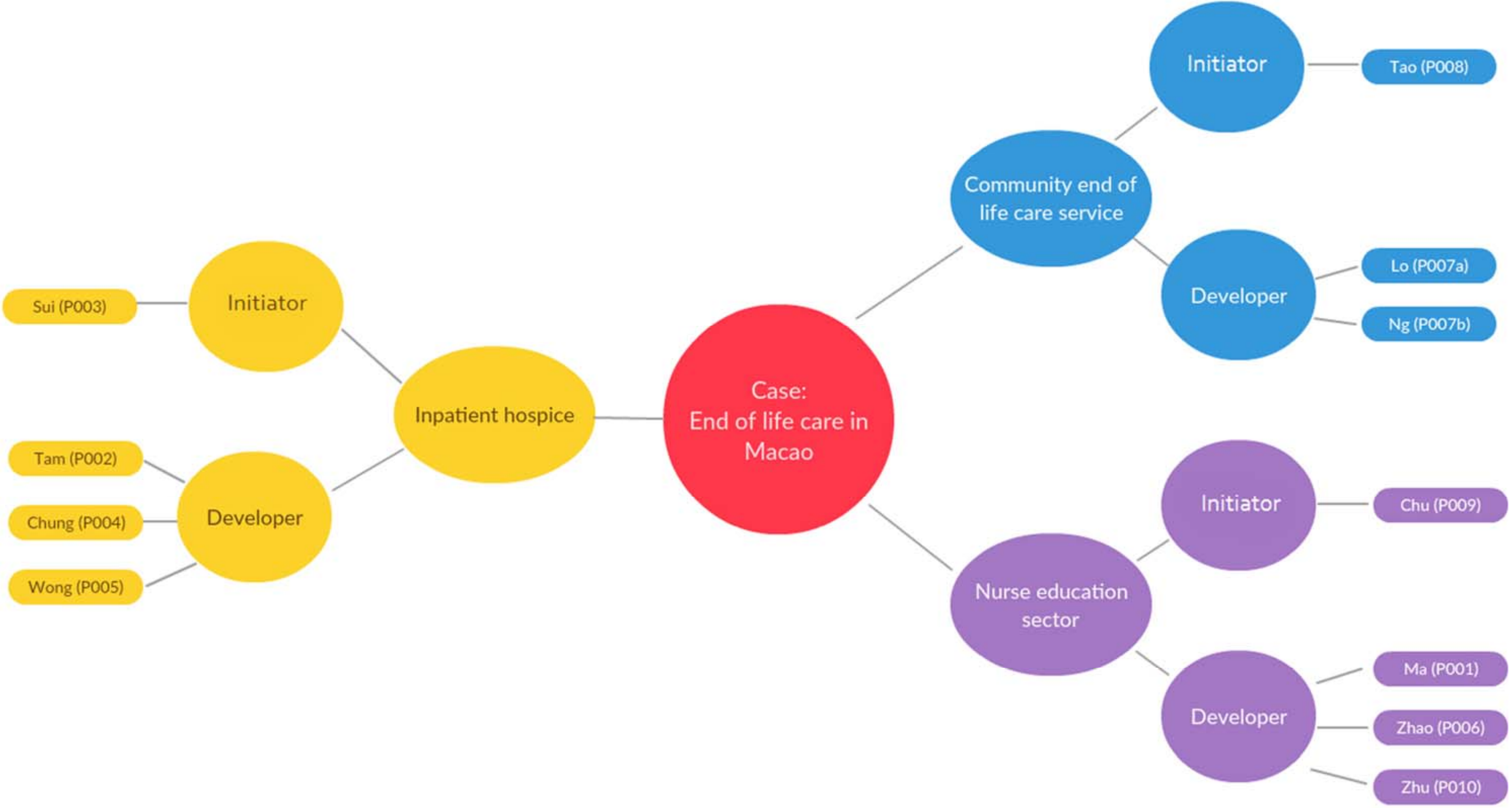
3.5.1. Research setting

In view of the considerably limited geographical area and the relatively young history of end of life care in Macao, beginning in the year 2000, the identification of settings for participant recruitment was straightforward in this study. The settings from where participants were recruited were the inpatient hospice, the community end of life care service and a nurse education sector, where public promotion of the concept of end of life care and the introduction of palliative and end of life care first began. Both initiators and developers were selected from these three settings. The descriptions of the three settings and the participants recruited from them are presented in Table 1. Figure 1 illustrates in diagram form the structure of the case attributes by the settings and participants attributing to the case of end of life care. One of the challenges in participant identification and recruitment was the maintenance of participant anonymity, please refer to section 3.5.2.2.1 (p. 62) for the detailed ethical discussion on participant recruitment considered in this study.

Table 1: Descriptions of the recruitment settings and participants (pseudonyms)

Setting	Description	Recruited participant
Inpatient hospice	Established in 2000, the inpatient hospice is the first and only palliative and end of life care service offering inpatient care in Macao. There are 30 beds in total. The hospice targets patients affected by and dying from terminal cancer. Key team players in the hospice include doctors and nurses. Other allied health care professionals are involved on a part-time basis, including physiotherapists, social workers and volunteers.	Initiator: Sui (P003) Developers: Tam (P002) Chung (P004) Wong (P005)
Community end of life care service	Established in 2003, the community end of life care service is a Christian based medical service, offering home visits to people affected by terminal cancer. The primary objective of this home visit service is to provide psychological and spiritual support for patients and families, a limited range of nursing care, i.e. wound care, and practical advice. The service is led by a nurse and a chaplain, and it remains the only end of life care oriented home visiting service in Macao.	Initiator: Tao (P008) Developers: Lo (P007a) Ng (P007b)
Nurse education sector	Established in 1923, the nurse education sector provides undergraduate and postgraduate nursing programme. It is also the first to introduce palliative and end of life care into both undergraduate and postgraduate nursing curricula in Macao, in the year 2002 and 2011 respectively.	Initiator: Chu (P009) Developers: Ma (P001) Zhao (P006) Zhu (P010)

Figure 1: Illustration of the case of end of life care in Macao



3.5.2. Participant selection and recruitment

3.5.2.1. Consideration of sample selection

In seeking to develop in-depth understanding of the development of end of life care in Macao, I needed to recruit participants who could provide insight into addressing the research questions. Particularly, I intended to develop an in-depth understanding of the processes from which end of life care emerged in Macao. By adopting a qualitative case study approach, I was able to choose participants who could share their personal experiences. Reflecting on the research aim to understand the emergence of end of life care in the context of Macao, I decided that individuals who had substantial involvement in the development of end of life care would be the most suitable participants to provide appropriate data to address the research aim.

Taking into consideration the study's aim, I decided to limit my participant recruitment to individuals who had been or were substantially involved in the establishment of end of life care; that is the initiators and developers. I also decided to include nurse educators who had been involved in introducing end of life care education into both the nursing education curricula and the public sphere in Macao. Further, the review of existing literature on end of life care in Macao revealed relatively high involvement from nurse educators, as reflected in their involvement in end of life care related studies (Ho & Sanders, 2015; Kan et al, 2003; Leong et al, 2007; Ng & Ku, 2010; Wong et al, 2002). For that reason, I decided to include individuals who were involved in the introduction of end of life care education in nursing education, as their experiences would shed light on how end of life care, in the context of Macao, was being shaped.

I did not include general nurses, or nurses involved in the work of end of life care in the study, mainly because they were not involved in the pioneering and developing phase of end of life care. For that reason they would not be able to provide any accounts of the meanings that would have been instilled into end of life care through its developmental years. Nor did I consider service users as appropriate participants, because the type of data they could offer would orient towards their personal experience of the hospice service, rather than providing insights into how end of life care was first started.

3.5.2.2. Ethical considerations on sample recruitment

This study was conducted in accordance with the Ethics Framework of the College of Humanities and Social Sciences at the University of Edinburgh (2008) where I am studying for my doctorate. The study had obtained the ethical approval from the Ethical Committee of the School of Health in Social Science at the University of Edinburgh. Since the study primarily involved interviewing individuals for their personal accounts pertinent to the case, the ethical concern was focused on ensuring informed consent, the maintenance of anonymity and confidentiality, and the right of the respondent to withdraw from the research, should they wish to do so.

3.5.2.2.1. Anonymity and confidentiality

I was aware that the stringent sampling criteria for this case study had complicated the issue of confidentiality and anonymity. Confidentiality and anonymity are well-established codes of practice amongst qualitative research. As observed by Tilley & Woodthorpe (2011), many researchers only addressed such issue briefly because they usually remain unproblematic. However, Tilley & Woodthorpe (2011) also raised their concern that "confidentiality is a complex process that involves more than merely disguising the identities of research participants or sites". A further proviso was offered by Lancaster (2016) who warned researchers that they mustn't assume anonymised data would always ensure confidentiality. For this case study, the challenge in maintaining anonymity and confidentiality was primarily related to the highly specific scope of the case focus. Participants were basically limited to two categories: initiators and developers. Whilst participants involved in the study were not identified as vulnerable, potential ethical issues could arise from the shared professional relationships amongst participants in the case of end of life care in Macao. Such professional proximity of the respondents could make them identifiable to one another; the restricted categories of participants within the case would also increase the risk of participants being identified. For this reason, I was aware that the implementation of pseudonyms might not be adequate in protecting participants' confidentiality.

As is evident through the interview guide (see Appendix 1), it was necessary that a number of questions asked were directly related to participants' personal experience and their contributions towards the development of the study, specifically in relation to their role within the research subject. In the invitation pack, I had also made it clear that the purpose of the study was to establish understanding relating to how the end of life care emerged and was shaped by the participants as result of their positions and efforts. From the beginning, I had made it transparent that the personal experience of participants was an integral part of this research. By communicating clearly, verbally and in text, I had provided participants adequate information to help them make an informed decision about consenting to participate in this study, or to decline to do so. This approach, of allowing participants to take responsibility in considering the risk involved regarding issue of anonymity, is not uncommon (Wiles et al, 2008). Taking into consideration that the participants in this study were passionate individuals who had actively engaged in developing and promoting the work of end of life care in Macao, who were also professionals who held senior positions of authority, I decided that with adequate information provision, these participants were fully capable and should be able to analyse any potential risks involved before agreeing to participate in this study. Furthermore, throughout the research process, I had made clear that participants could terminate or withdraw from the study at any point.

I had taken extra caution with the adoption of additional safeguards during the research process, in order to ensure confidentiality. First of all, following the advice from Vainio (2013), in deciding the data I intended to present in the study, I would only consider information pertinent to the research questions and aim. Any irrelevant information that could potentially lead to the identification of participants was not included. The second safeguarding technique I adopted was one supported by researchers such as Lancaster (2016) and Wiles et al (2008), in that all participants were offered a copy of their interview transcript, for them to review and amend the interview content should they wish to do so. The purpose of this option was not only to enhance accuracy of the collected data, but also for participants to have greater control in making decisions about the interview content that they wished or did not wish to be disclosed (Lancaster, 2016).

Other practical steps taken to ensure anonymity and confidentiality in all research materials include assigning codes for each participants instead of the real name; all participants' names referred in the research were pseudonyms to reinforce their anonymity and protect confidentiality. I was the only person who had access to all the material resulting from this research and I personally transcribed all interviews. These two steps further ensured all participants' confidentiality. All digital research materials were stored in my personal laptop protected by a password which was known only to me.

All hard-copies of the data and research materials were kept in a locked cabinet situated in the 'secure' postgraduate office at the University of Edinburgh. In terms of accessibility, I was the only person that had full access to all research data. My two university supervisors had partial access to anonymised data I provided in the form of supervision reports and in research findings. All materials related to, and emerging from, the research would be kept for a maximum of five years after the end of the study, and would then be destroyed safely and securely.

Being a nurse who had also worked in the field of end of life care, I felt that I was equipped with the necessary compassion, attentiveness, sensitivity and professionalism to competently interview participants on this sensitive topic. I also ensured that participants recruited for this study were limited to professionals who had been actively engaged in developing end of life care in Macao, and as a result, end of life care would be a familiar subject for them to discuss. Nevertheless, I was aware that whilst participants were passionate about, and familiar with, the research subject, there was still a risk of triggering distress amongst participants (Dickson-Swift et al, 2008; Takesaka et al, 2004), despite that risk being relatively small (Casarett, 2005). Following advice by researchers, such as Casarett (2005), Henry & Scales (2012) and Kavanaugh & Campbell (2014), the adequate provision of information is the key to minimising potential harm, as well as ensuring participants are sufficiently informed to consent to their participation. I had dedicated a section in the invitation pack (see Appendix 2), explaining the potential emotional risk participants might experience during their interview. I had also repeatedly made clear to participants that they were free to terminate or withdraw from the interview and the research at any time. As discussed earlier, I took the initial few minutes prior to each interview to explain again to participants about the research, potential risks involved, their right to withdraw, and also allowing them to raise any questions or concerns. I had employed all the steps discussed above to ensure the current case study was conducted in accord with the Ethics Framework of the College of Humanities and Social Sciences at the University of Edinburgh (2008).

Prior to the discussion of informed consent, I will first present how I gained access and recruited participants for this study in the section below.

3.5.2.2.2. Access to participants

For the present study, I primarily relied on my own professional network in gaining access to prospective participants. I had a unique advantage in that I was aware of the existence of two initiators (Sui and Chu), three nurse educators (Ma, Zhao and Zhu) and a hospice developer (Tam). I knew these participants through attending various nursing seminars and academic events when I was in Macao. These prospective participants were approached in accordance with purposive sampling approach, which is used to select individuals whose experiences can make a maximum contribution to the understanding of the research subject; in the current study that is end of life care in Macao (Bryman, 2015; Stake, 1995). On approaching these six individuals for recruitment purposes, I explained to them my professional background and provided a brief introduction to the study, including its purpose. Having obtained their verbal consent to participate in the study, I proceeded to send them the invitation pack (see Appendix 2) for both the Chinese and English version) containing detailed information about the study, methods and procedures involved in conducting the research. Information relating to confidentiality and voluntary participation was also included to emphasise that they were not obligated to participate in the study and they were allowed to withdraw or terminate their involvement at any point during the study. Attached with the invitation pack were my contact details and a consent form. During my conversations with the six individuals, I adopted the snowball sampling approach as I sought to enquire if any of them would be able to recommend any other key figures whom they knew had been involved in the establishment and development of the end of life care within Macao. The snowball sampling approach allowed me to reach out to participants who I would otherwise have no access to, particularly with the highly focused research interest of the current case study (Gary et al, 2015). As a consequence, three more hospice developers were recommended to me and I subsequently gained access to them by introducing myself at the hospice where I repeated the same recruitment process as discussed above. Two hospice developers (Chung and Wong) were further recruited for the study, whilst the remaining developer chose not to participate. In terms of participants from the community end of life care service, I was in touch with a chaplain whom I knew had been involved in the developmental work of the service, and she then suggested for me to contact the creator of the community service (Tao) and two developers (Ng and Lo). I then established contact with these individuals by way of electronic communications (e-mails) and by me visiting the community service and meeting the three in person. I repeated the same steps mentioned above in providing the invitation pack other detailed information about the study. The three individuals agreed to take part in the study. However, the chaplain I initially contacted did not want to participate in the study.

I then presented myself once more at the hospice, in order to gain access to more developers, when I was able to recruit Chung and Wong as they were suggested by the hospice initiator Sui and developer Tam, as the key figures in the developmental work of the hospice. In total, eleven participants were successfully recruited for the case study as I had exhausted the number of participants who had fulfilled the inclusion criteria.

It is not unusual for qualitative case studies to have small sample sizes (Gerring, 2007) and it depends on the study aim, the enquiry, the purpose and the context of the case study (Thomas, 2016). For the present study, the intrinsic and specific interest of end of life care within Macao had justified the stringent inclusion criteria for participant recruitment. The study’s participants included three initiators and eight developers; a research population placing the current case study in a unique and valuable position facilitating an in-depth analysis of end of life care in Macao. Table 2 and Table 3 below detail the profiles and background of the initiator and developer participants.

Table 2: Profiles of the initiators

Setting	Name (Code)	Background
Inpatient hospice	Sui (P003)	Sui was the matron of a private charity hospital and she started the first inpatient hospice service in Macao. Prior to the establishment of the hospice, Sui was involved in a community group, supporting people who were affected by cancer. The group is non-clinical and mainly acts as information provision for cancer patients and (their) families.
Community end of life care service	Tao (P008)	Tao is a physician who has attained his medical degree in the US. Arriving in Macao in the late 1980's, Tao began his work as the medical director at a missionary clinic. Working closely with the nursing team at the clinic, Tao and the nurses recognised the need for a community care service for people who were affected by end of life situations. Under such circumstances, Tao started the first community based end of life care service in Macao. The service mainly includes nursing care (limited to wound care), information-giving and spiritual and psychological support for families affected by terminal cancer.
Nurse education sector	Chu (P009)	Chu is a nurse and has been working in nursing education since the 1970's. Since the late 1980's Chu has pioneered the concept of end of life care in the public domain. Mainly involved in the work of information-giving, Chu wrote articles to introduce end of life care, and its related care oriented concept, to the population of Macao. Chu was also the first to introduce palliative and end of life care into undergraduate nursing education in Macao.

Table 3: Profiles of the developers

Setting	Name (Code)	Background
Inpatient hospice	Tam (P002)	Tam is a nurse manager in the private charity hospital and she is the first nurse manager of the inpatient hospice since its opening in the year 2000. Tam received training on palliative and end of life care from Hong Kong prior to the opening of the hospice. Since becoming the first nurse manager of the hospice, Tam has dedicated her work to facilitating the clinical aspect of the hospice, as well as promoting the concept of care orientation and end of life care amongst other nurses in the hospice. Tam has left the hospice since 2004.
Inpatient hospice	Chung (P004)	Chung is a senior nurse in the private charity hospital, working in the haemodialysis unit. Similar to Tam, Chung is amongst the first to be recruited to work for the hospice, when it was established in 2000. Selected by nurse manager's team at the private charity hospital, Chung was given training in palliative and end of life care prior to her work at the hospice. As well as clinical work, Chung is also involved in information-giving. Targeting public audiences, Chung promotes the concept of end of life care in the community, through giving seminars and talks to various societies. Chung is also involved in providing trainings for other health care professionals, as well as giving practical advice to those in the private charity hospital. Chung has progressed from senior nurse to the nurse manager of the hospice, succeeding Tam.
Inpatient hospice	Wong (P005)	Wong joined the hospice in the year 2002. Unlike Chung and Tam, Wong joined the hospice on her own initiative. Inspired by her experience at the hospice as a student nurse, Wong is keen to be involved in the clinical work of end of life care. Prior to joining the hospice, she self-

		funded to attend a palliative and end of life care course in Hong Kong. Since joining the hospice, Wong is involved in providing public seminars to various societies in Macao. Wong is also involved in giving clinical advice to other health care professionals by joining the multidisciplinary team meetings at the private charity hospital.
Community end of life care service	Lo (P007a)	Lo is a qualified nurse and she used to work as a nurse at the missionary clinic of Tao's. Recruited by Tao, Lo then joined the community end of life care service and received training as a chaplain in Hong Kong, focusing on end of life spiritual needs. Being the first chaplain in Macao, Lo is the first to offer spiritual care for local terminal patients and their families. Being part of the first end of life care service, an important part of Lo's work is to familiarise the public with the care oriented concept and reinforce the value of end of life care. In addition to working for the community end of life care service, Lo has recently been allowed to provide spiritual care for terminal patients at the state hospital in Macao.
Community end of life care service	Ng (P007b)	Ng is a qualified nurse who attained her nursing degree in Australia. Also recruited by Tao, Ng was the first nurse manager in charge of the community end of life care service. Prior to the start of the service, Ng received palliative and end of life care training in Hong Kong. Ng's responsibility is to carry out home visits to terminally ill patients. The home visit service includes providing some degree of nursing care, i.e. wound dressing and advice on medications. Nevertheless, a big part of a home visit is to provide psychological, social and spiritual support for the dying patients and their families. Ng is also involved in promoting the concept of end of life care in the public domain through delivering talks and seminars to schools and communities.

Nurse education sector	Ma (P001)	Ma is an experienced nurse with more than 10 years' clinical experience. Ma began her career of nursing education in 1990. As well as undergraduate nursing, Ma is also responsible for the only training programme for health care assistants (HCA) in Macao. All HCAs in Macao must attend Ma's programme before they can be qualified and work in any health care settings in Macao. In designing her programme, Ma emphasises the elements of care and caring, particularly in relation to end of life situations. The reason behind such emphasis is partly because of the ageing population in Macao. Furthermore, Ma also recognises the Chinese cure-pursuing culture is impairing the quality of life of many at the end of their lives.
Nurse education sector	Zhao (P006)	Zhao is an experienced nurse with more than 10 years' clinical experience in various specialities. In 1999 Zhao began her nursing education journey. Together with Zhu, Zhao is responsible in delivering end of life care knowledge to undergraduate nursing students. In 2011 Zhao introduced an optional independent module called 'Life Education' for third and fourth year students. The purpose of the course is to raise awareness on end of life related issues for student nurses, as well as reinforcing care for terminal patients.
Nurse education sector	Zhu (P010)	Zhu is a qualified nurse and has been in nursing education since the year 2000. Zhu is one of the 2 lecturers responsible in delivering end of life related care to undergraduate nursing students. 'Corpse care' is one of the key curriculums in the area of end of life care delivered by Zhu.

3.5.2.2.3. Informed consent

At the time of the study, I arranged meetings with officials of the nurse education sector and the private hospital (two of the three research settings where I recruited participants), in order to clarify the procedure of ethical approval. In both meetings, it was verbally clarified that in a study interviewing individuals for their personal account of end of life care, institutional ethical clearance was not required. With respect to the community end of life care setting, I had received verbal confirmation by the medical director Tao that institutional ethical approval was not required when interviewing individuals who had previously worked for the service.

I had obtained verbal and written informed consent from all participants. On initial contact, complete information about the case study, contact information about me (the researcher) was provided to all participants in accord with their native language (Cantonese or English) in the form of an invitation pack (see Appendix 2). Also included in the pack was a consent form with information about voluntary participation and each participant's right to withdraw at any point in the study. Prior to each individual interview, I specifically dedicated the initial few minutes to introducing myself and to reiterate the background and the purpose of the study. I also made sure that by the end of the session each participant was fully informed and had consented in writing that their participation was entirely voluntary. Participants were again assured that they had the right to terminate or withdraw completely from the study at any time; also they did not need to answer any questions if they did not want to and no explanation was needed or expected. They were also made aware, both via the invitation pack and in person, that the audio of the interview was recorded digitally and they had the right to refuse or stop at any point during the recording. Prior to each interview, I allowed participants time to raise any questions they might have, and written consent was obtained.

3.5.3. Data collection method: semi-structured in-depth interviews

The decision on choosing a research method is a natural process that is very much related to the research aim and the context where the research resides (Holliday, 2007). Observations, documentation analysis and interviews are often employed to collect data in a case study (Simons, 2009). However, as endorsed by Stake (1995), it is arguable that an interview is the most appropriate channel. Interviews allow researchers to take into account all of the different perspectives from the various information sources, in this case medical professionals, who will subsequently contribute to the multi-faceted understanding of the case. Taking into consideration the research aim to unveil the journey of how end of life care emerged in Macao, semi-structured in-depth interviews were conducted with initiators and developers. Their responses allowed me, the researcher, to access the various perspectives of participants contributing to the multifaceted understanding of the case (Bryman, 2015; Stake, 1995). Favoured by social scientists, the interview is a powerful data collection tool for accessing the personal perspectives of interviewees. Such a valuable information gathering tool also provides opportunities for interviewers to observe hidden messages through body language and emotional signals, which may lead to the discovery of further understanding (Rubin, 2012; Stake, 1995).

In order to ensure the quality and relevance of the materials generated through interview conversations (Bryman, 2015; Mason, 2002), I designed a semi-structured interview guide with five open-ended questions oriented to the research aim guiding the interview process and keeping focus on the subject. The open-ended questions were developed bearing in mind that I wanted to gain an in-depth understanding of participants' personal journeys involving the initiation and development of end of life care in Macao. The questions were designed to allow me to learn about participants' professional backgrounds, to understand their experiences and interpretations regarding end of life issues, and to learn about the trigger/motivation in pioneering/developing end of life care in Macao. The interview guide was developed in both Chinese and English (see Appendix 1) because of the two languages used amongst recruited participants. The English version of the interview guide was reviewed by my academic supervisors prior to implementation. Whilst the interview guide kept me focused on the enquiry subject, I used it only as a guide during each interview so allowing me to prompt and further explore new topics that emerged during the interviews.

After the first three interviews with two developers, one from the nurse education setting (Ma) and one from the hospice (Tam), as well as one initiator (Sui), I discovered that whilst the interview questions were broad, the different professional backgrounds and spheres of involvement in end of life care of participants had made some questions better suited for one participant group than another. In view of this, I revised and modified the direction of some interview questions with respect to the three research settings, to enable more targeted enquiries amongst the different groups. This modification served to maximise the relevance of the collected data. Interview questions for participants of the hospice and the community end of life care service cohorts were largely similar, whilst questions for nurse educators carried some variations (See Appendix 1). In Table 4, I listed examples of interview questions asked with all three categories of participants.

Table 4 Example of interview questions

Setting	Open-ended interview questions
Nurse education setting	• How and when did you become aware of end of life care? • What brought you to end of life care? Is there any particular (personal/professional) experience that prompted your interest? • When did you start/ begin to become involved in teaching about end of life care? Is there a particular area you are involved in?
Hospice	• How and when did you become aware of end of life care? • What brought you to end of life care? Is there any particular (personal/professional) experience that prompted your interest?
Community end of life care service	• How and when did you become aware of end of life care? • What brought you to end of life care? Is there any particular (personal/professional) experience that prompted your interest?

Overall, I did not encounter any particular challenges in conducting the interviews. Nonetheless, I took particular care throughout the data collection process as I was aware that the elite background of participants might have a potential impact on the interviewing process, possibly influencing the reliability of the data collected (Huggins, 2014). The privileged positions that the participants held in the field of end of life care within Macao, provided a unique advantage for the researcher in capturing perspectives from stakeholders which would not otherwise be accessible. Therefore, I took serious care in establishing rapport with my participants, thereby ensuring a good interviewing connection. All interviews began with a general question to explore each participant's background and their role in the respective setting. This question was aimed to allow participants and I to become familiar with each other and gain comfort in each other's presence during the interview process; an essential ritual for effective research via interview. This 'bonding' was followed by a broad question to explore each of their personal journeys as they encountered end of life care/ end of life issues. This journey-related question served to introduce subsequent and more specific questions pertinent to the research enquiry. I was aware that some of the questions raised in the interview could be sensitive and I was also aware that the case study could be potentially sensitive for participants. An in-depth and specific discussion on ethical considerations associated with the case study is already discussed in section 3.5.2.1. Further into the interview process, I explored the different aspects considered to have motivated participants to pioneer or become involved in developing end of life care within Macao. In particular, I focused on participants' interpretations of their experiences in order to probe and explore emerging issues, thereby enhancing the depth and breadth of the enquiry.

In total, ten interviews were conducted, all but one interview being a one-to-one model. One interview consisted of two participants, because the two participants felt more comfortable doing the interview together. All but one of the interviews were conducted in Cantonese, one interview was conducted in English.

All interviews were conducted between November 2012 and August 2013. Participants were given the freedom to decide the date and time of their interview, to suit their convenience. Participants were also free to decide on a location of their choice; three participants had requested me to arrange for an interview location and in those cases, I rented a meeting room at a local college. The average length of the interview was one hour and all interviews were digitally recorded with the permission of the participants. They were informed about the recording prior to the interview and written consent for the study and recording was obtained.

3.5.4. Data management

I transcribed all ten interviews verbatim myself. I also translated five interviews myself. Since my first language is Cantonese (a variation of Chinese) and second language is English, I did not encounter particular difficulties in undertaking this process. All participants were 'anonymised' meaning that any identifying information relating to participants and their respective organisations were removed from the transcripts. Pseudonyms were used where necessary to ensure participants' anonymity. The computer-assisted data analysis software (QSR NVivo version 11) was used to manage, store, organise and analyse the collected data.

3.5.5. Translation

The involvement of two different languages, Cantonese and English, in this study posed a challenge in relation to which language should I base my analysis on. All but one of the interviews were conducted in Cantonese, whilst the research findings are reported in English. My bilingual ability had minimised the problem of misinterpreting participants' meanings (Esposito, 2001). However, I found it challenging to find equivalent matches for some colloquial phrases and idioms between the two completely different languages. Reflecting on a study by Twinn (1997) that examined the influence of translation on the validity and reliability of data analysis, the author found that the use of either Cantonese or English in data analysis yielded similar themes and categories, based on data generated from semi-structured interviews. Further, the study of Twinn (1997) found that translation added to the complexity in understanding the data, due to the differences in the grammatical structures between Cantonese and English. In my study, I fully translated five interviews into English. However, I experienced similar translation difficulties as mentioned above; in particular, I found it difficult to find equivalent expressions for some idioms and wording used by participants, especially those relating to the conceptualisation of death and dying with respect to the case. Dealing effectively with these meanings was vital for me, in order to make sense of the data and generate understanding of the case. Therefore, with the intention of maximising the validity, reliability and quality of data analysis, as suggested by (Twinn, 1997), I decided to base my data analysis on the Cantonese transcripts. The analysis of the only English interview was conducted in English. Only interview segments of the Cantonese transcriptions relevant to data analysis were translated into English for the purpose of presenting the research results. Findings and respective excerpts used to illustrate the findings were subsequently translated by myself, to ensure translation consistency. I had consulted a bilingual colleague to crosscheck a few translated excerpts to ensure the accuracy of the translation (Regmi et al, 2010); they confirmed the translation to be accurate.

3.5.6. Data analysis

"There is no particular moment when data analysis begins" (Stake, 1995, p. 71). I agreed with Stake very much in that I found myself trying to make sense of the data as soon as I started listening to the recordings at the start of the transcription stage. By being involved in the transcribing process and the repeated process of listening to the recordings, and reading through the transcripts, allowed me to be fully immersed in the data and facilitated the building of my understandings of the data (Bryman, 2015; Hepburn, 2017). Further, being born and raised in Macao I belong to the social world of Macao; I understand the culture, the customs and the tacit understanding regarding death, dying and end of life issues. I also have a level of understanding regarding the institutional infrastructure of health care provision and the clinical environment of Macao, from being in touch with the cohort of professionals associated with nursing education. However, I recognised my limitations relating to end of life care context in Macao, due to my lack of experience in that area. Therefore, I recognised myself as both an insider and outsider during the process of the research (Bartunek, 2008). By positioning myself in this unique researcher role, I was able to resonate with the socio-cultural aspect of the case of Macao; a process that granted me greater understanding during data interpretation than would otherwise have been the case (Bonner & Tolhurst, 2002). Though being an outsider in the end of life care context could potentially limit the depth of understanding I sought to acquire (Bartunek, 2008), my fresh perspective gave me the flexibility to raise questions and prompt discussions that could bring depth and new insights to the subject being investigated (Bonner & Tolhurst, 2002).

By immersing myself in the collected data and utilising an inductive approach, I had the opportunity to determine a theoretical underpinning for interpreting that data through abduction, thereby developing a theoretical understanding of end of life care in Macao in this case. I did not previously determine or choose a theoretical framework, mainly because the limited empirical evidence on the research subject made it challenging to decide on a framework that might be suitable for the interpretation of the study findings. Therefore, by making this framework decision during data analysis, I had already had the opportunity to explore the breadth and depth of the case, thereby enabling me to decide on a suitable theoretical underpinning. The theoretical framework I adopted for this case study was the framing perspective (Snow et al, 1986) and it was used abductively in interpreting the study’s findings, as well as giving theoretical meaning to those findings. Due to the theoretical significance of the framing perspective, in relation to the case study, I decided to discuss this in full detail in Chapter Four.

3.5.6.1. Thematic analysis

I had adopted a thematic analysis approach to structure the analytic process for the study. The main aim of the study was to understand the processes from which end of life care emerged, by way of examining human interpretations and interactions within the context of Macao. Thematic analysis is a versatile method used widely in qualitative research, and it is compatible with various theoretical frameworks (Braun & Clarke, 2006). In view of the social constructionist perspective underpinning this research, I used thematic analysis to build understanding pertaining to participants' experiences of their involvement with end of life care in Macao. As Braun & Clarke (2006) emphasised, a transparent theoretical backbone is vital in thematic analysis, as it determines the perspective where the data is situated. In thematic analysis, the researcher is able to identify, analyse and report "repeated patterns of meaning" from collected data (Braun & Clarke, 2006). Further, thematic analysis facilitates the organisation of the rich and raw qualitative data into themes and subthemes, in accord with the patterns of meaning identified. This process reinforces a systematic, rigorous and transparent analytic process (Spencer et al, 2014). Braun & Clarke (2006) summarised six recursive processes in thematic analysis (See Table 5 below).

Table 5: Six recursive processes in thematic analysis (Braun & Clarke, 2006)

Thematic processes	Description
Familiarisation of data	Transcribing data and immersing in the data by way of repeated reading. This process also facilitates potential ideas for coding and of possible recurrent patterns of meaning.
Generation of initial codes[3]	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
Sorting and forming themes[4]	Gathering codes and data relevant to each potential theme.
Reviewing themes	Level 1: Reviewing the coded data extracts to see if they form a coherent pattern within one theme. Level 2: Reviewing the validity of the themes in relation to the entire data set; generating a thematic map of the data.
Defining themes	Detailed analysis of each individual theme, identifying the 'story' of each theme and how it fits into the overall story.
Producing the analytic report	This final step is the production of a scholarly final report, in that it should entail a "concise, coherent, logical, non-repetitive and interesting account of the story" to address the research question(s).

The transcription was initially performed in Office Word and upon completion, all transcriptions were then transferred and stored in NVivo 11. During the process of transcription, I repeatedly listened to the recordings, read and re-read the data. The immersion in the data enabled me to generate coding ideas and, at the same time, prompted me to identify repeated patterns from the data (Gilbert & Stoneman, 2016). The coding process was performed manually in Nvivo 11 with systemic support from the software. Supported by Miles & Huberman (1994), by way of an inductive approach, the

---

[3] Code represents "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998, p.63).

[4] Theme refers to the unit of interpretive analysis relating to the phenomenon that is being examined (Boyatzis, 1998).

codes and themes established were being sorted, reviewed and refined continuously; thereby allowing for a deep exploration of the construction of end of life care grounded in, and informed by, the accounts of the participants. The generation of the initial themes as a result of the inductive approach allowed me to identify the themes and then through abduction the best fitting conceptual framework which was able to inform further analysis and interpretation of the data, as well as aiding the development of a theoretical understanding of the case. The rationale for selecting the framing perspective (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986) for the theoretical understanding of the case of end of life care in Macao is presented in detail in Chapter Four.

3.6. Reflexivity

The consideration of reflexivity was pivotal in this case study. In considering my self-reflection, I was aware of how my personal background, experiences and assumptions were impacting on the research process (Hesse-Biber, 2014, p. 25). Further, I agreed with Pillow (2003) in that I equally valued the reflexivity of individual participants, mainly because the research objective was oriented towards developing understanding of end of life care in Macao. Access to this understanding is firmly based on participants' experiences and interpretations of the socio-cultural context in which they were situated at that time. Therefore, I encouraged all the participants to reflect during the interviewing process on their personal background, experiences and understanding regarding end of life care. My personal reflexivity was also informed by my encounters with the participants. As suggested by Nicolson (2003), the interaction between researcher and participant during interviews can affect the construction of meaning and understanding of the data. Reflexivity is therefore valuable as it allows the researcher to reflect on this experience of shared meaning construction. Reflecting on my encounter with participants, particularly in response to their "elite" positions, had prompted me to evaluate my interviewing behaviours and refine the questions, in order to enhance the relevance of the data collected.

On the personal front, reflexivity is the recognition of me, as the researcher, who also belongs to the socio-cultural context in which the study was situated (Palaganas et al, 2017). Reflexivity also involves a continuous process of recognising the values I have (Parahoo, 2014) and examining and understanding how these values impact on my research practice (Hesse-Biber, 2014; Palaganas et al, 2017). Throughout the research, I remained transparent in terms of the position I held as the researcher, which included my personal interest in understanding the issue of end of life care in Macao, due to a personal experience I had with my grandmother's death under end of life care in Macao. I was very aware of the involvement of my personal background belonging to the socio-cultural world of Macao, in which this research was based. As also discussed in section 3.5.6, I recognised my joint insider and outsider positions (Bartunek, 2008). My insider position is informed primarily by the cultural understanding I have relating to death, dying and end of life issues; the outsider position was warranted because of my limited understanding regarding the end of life care context in Macao. My recognition of this joint researcher position illuminates my personal reflexivity in this research process, in that I was aware of how my experiences, or lack of them, might contribute to the construction of meanings, from structuring research questions, facilitating interviews, to handling, interpreting and analysing the collected research data (Denzin & Lincoln, 2017; Hesse-Biber, 2014; Pillow, 2003). I documented my experience in participant recruitment and interviews, and I kept reflective memos during the process of data analysis (Please see Appendix 3 for examples of analysis memo and idea memo).

3.7. Quality of the study

The rigour in conducting the research process, the methods used and the credibility of the findings are all critical elements ensuring the overall quality of the research (Mason, 2018). However, there has been an ongoing debate about appropriate criteria for assessing the quality and rigour of qualitative research (Avis, 2005). For example, Silverman (2017b) adhered to the concepts of validity and reliability, while Lincoln & Guba (1985) suggested the concept of 'trustworthiness' comprising of four aspects: i) credibility, ii) transferability, iii) dependability, and iv) confirmability. The lack of consensus in the criteria for quality assessment is largely related to the wide range of theoretical and methodological paradigms relating to and informing qualitative research. These various defining characteristics of qualitative research make the unification of globally acceptable quality criteria unlikely (Avis, 2005; Ritchie & Lewis, 2003; Silverman, 2014). Furthermore, as argued by Morse et al (2002), the growth of various terms and criteria causes confusion for researchers and affects the attainment of rigour. Agreeing with Morse et al. (2002), Thomas (2016) suggested that within the context of a qualitative case study, the meaning of validity and reliability in assessing a study's quality is less clearly defined. It was suggested that any consideration should be oriented towards the "conception, construction and the conduct of the study" (Thomas, 2016, p. 71).

In this case study, I have adopted the position of quality assessment for case study, advised by Thomas (2016), to ensure the quality and robustness of this research. Firstly, I had kept clear documentation with regards to each and every step I had taken in conducting this study. I remained transparent when dealing with key issues such as: i) explaining my decision of focusing on the case of end of life care in Macao; ii) the subsequent structuring of the research questions and iii) the selection and recruitment process of key participants. The aim of the study was to develop an in-depth understandings of the end of life care in Macao (the case). In addressing this aim, I demonstrated clearly the research design and methods, the procedures in data collection and analysis (see section 3.5). In addition, I was transparent about my personal background, experience and assumptions and their influences, both actual and potential, on my role as the researcher conducting this study. This issue was addressed by the acknowledgment of the role and importance of reflexivity (see section 3.6). As discussed in section 3.5.2.2, I decided to provide participants with their interview transcripts, so allowing them to confirm their responses and to make amendments should they see the need to do so. In offering this option to the participants I not only intended to safeguard participants' confidentiality, but also wished to ensure the quality of the data (Lancaster, 2016; Wiles et al, 2008).

3.8. Limitations of the study

The quality of the study was the key concern of this research; however, there are a number limitations I need to acknowledge and discuss in this section.

Generalisation of the findings in qualitative research is often subjected to criticism, when compared to quantitative research, where the objective is primarily one of generalisation (Bryman, 2015). For the case study model in particular, the assumption that findings could be generalised to populations does not apply, as the focus is specifically on one single case (Flyvbjerg, 2006). Further reinforced by Bryman (2015), findings in qualitative studies should aim to “generalise to theory” rather than to populations, the assessment of generalisation in qualitative studies should base on the quality of the theoretical inferences from qualitative data (Bryman, 2015, p. 399). In case studies, the inferential process “turns exclusively on the theoretically necessary linkages among the features in the case study” (Mitchell, 1983, p. 207). Further, inferential validity is not determined upon the statistical representativeness of the case, rather “the cogency of theoretical reasoning” (Mitchell, 1983, p. 207) . In this case study, the focus was on the end of life care within the specific geographical area of Macao. Findings resulting from this case study could evidently not be applied to other contexts without encountering both theoretical and practical problems. By building upon the theoretical framework of the framing perspective (See Chapter Four for a detailed discussion), I developed a theoretical understanding of the end of life care in Macao (the case), which may potentially invoke theoretical inferences to comparable cases, and aid the development of similar research in other areas.

In terms of recruitment constraint, as already addressed in section 3.5.2.1, I limited participants to initiators and developers who were involved in the establishment of end of life care in Macao. I could have employed the perspective of end of life care service users in Macao, since their experiences could add useful information towards understanding the issue being investigated; perspectives regarding end of life care. Nevertheless, inclusion of end of life care service users in this case study would pose two potential challenges. Firstly, although the service users' experiences could provide a different perspective to the case, their input would not address the aim of this case study, in that the perspective of service users would not offer information relevant to the establishment of end of life care in Macao. Secondly, at the time when the research was conducted, it was unsure whether there would be robust ethics frameworks in the three end of life care services to protect the service users. This matter was of particular concern as the majority of those users would be terminal patients and/or their family members. By participating in this research, their vulnerability would be exposed and would therefore have needed to be recognised and addressed. Adding to these considerations is also the constraint of time and resources in conducting doctoral research; I therefore decided to exclude service users from this study.

Reflecting on my personal experience during the process of participant recruitment, I held an advantageous position wherein I was already professionally connected to some of the prospective participants prior to the study. I had access to two initiators and a number of developers (see section 3.5.2.2.2). However, I did experience one particular challenge, in that a couple of developers had repeatedly verbally confirmed their willingness to take part in the study after they had received the invitation pack. In the process of arranging for the interview, I had contacted the two individuals three times, and with each contact, they would verbally agree and express their keenness to take part but I would hear no more from them for a long stretch of time. So after the third attempt, I decided that if they didn't get back to me, I would draw a stop to this, which was what happened with these two developers. I identified this as a recruitment limitation, mainly because the specific recruitment criteria already restricted the selection of suitable participants and failing to recruit these developers had further limited the information I could obtain for understanding this study. Nonetheless, I had adhered to the ethics codes throughout the participant recruitment process.

In terms of data collection, semi-structured in-depth interviews were considered the most appropriate information gathering approach for this study; as a result interviews were the only way adopted in this study to collect data. On reflection, focus groups could have been a useful way of stimulating discussions amongst initiators and developers regarding their collaboration/division in the process of developing end of life care in Macao, thereby adding more depth to the study data.

Finally, my deep personal interest in this research subject, my experience as a nurse and in particular my experiences as an end of life care practitioner, all influenced the conducting of this qualitative case study. As discussed in section 3.6, the reflexivity applied throughout the research caused me to recognise the impact my experiences and assumptions could have on the research process.

3.9. Conclusion

In this chapter I explained and justified the use of a qualitative case study as the research methodology for this research. The chapter began by presenting the research aim and questions. I then presented the ontological and epistemological positions that had led to my decision to choose qualitative case study for this investigation. I then introduced the theoretical framework, the framing perspective (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986) adopted in this study which will be further illustrated in Chapter Four. Following a discussion on the definition of the ‘case’ of this qualitative case study, I further provided a detailed account of the methods and procedures of a) data collection, b) data analysis, c) language and d) ethical implications in conducting this research. The use of reflexivity was outlined; the considerations taken and the methods used to ensure the quality and rigour of the study were explained. Finally, I presented a number of limitations informing the conduct of this case study.

4. Chapter Four: Establishing the theoretical context of the study: the framing perspective

4.1. Introduction

As discussed in the literature review, there are many studies investigating the development of end of life care in countries with a range of different socio-cultural backgrounds (Bingley & Clark, 2009; Clark & Graham, 2011; Glass et al, 2010; Krongyuth et al, 2014; Lai & Su, 1997; Leong, 2003; Luczak & Hunter, 2000; Nervi et al, 2004; Nixon, 2003; Rajagopal & Venkateswaran, 2003; Rhee et al, 2017; Wright et al, 2008a; Wright et al, 2008b). However, there is a notable lack of discussion on the theoretical underpinning of the development of end of life care programmes and initiatives. Most available literature discussed issues pertinent to the practical and conceptual introduction of end of life care. Whilst the modern hospice movement was widely acknowledged as a social movement, the numbers of studies examining the emergence of end of life care/ hospice care from the theoretical perspective of social movement were limited as discussed in the literature review in this thesis. Discussion on the conceptualisation of the hospice movement was mainly oriented to the establishment of the dissemination of the principles of hospice care (Bodek, 2013; Brown & Flores, 2011; Clark, 2001a; Kubiak & Suriková, 2010; Rhymes, 1990), and the establishment of hospices and related end of life care services (Clark & Graham, 2011; Clark & Wright, 2007; Wright et al, 2006; Wright et al, 2008a; Wright et al, 2008b). Taking into consideration of the overall lack of systemic examination of end of life care as a social movement, I therefore decided to consider a theoretical construct that would fit into the research enquiry, and aid to develop a theoretical understanding of the end of life care in Macao with respect to the aspect of social movement. Having developed this specific research interest, I began to explore wider literature sources, as well as specific theories, relating to the study of social movement which had led me to the framing perspective (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986). Having explored the conceptual elements of the framing perspective, i.e., the frame alignment processes, core framing tasks and the concept of counterframing, this perspective reflected many of the features of the end of life care initiatives and programmes in Macao. I therefore decided that for this case study, thematic analysis would provide an analytical structure to facilitate the understanding of the development of end of life care in Macao; the framing perspective would provide the theoretical underpinning to aid the interpretation of initiators and developers in the process of developing end of life care in Macao whilst, at the same time, facilitating the articulation of a theoretical understanding of the case.

In this chapter, I will first present a brief synopsis of the framing perspective to aid the reader in interpretation of my subsequent analysis and findings chapters.

The theoretical features of the framing perspective include the *three core framing tasks*:

i) diagnostic framing,
ii) prognostic framing and
iii) motivational framing.

Together with the three tasks above there are *four frame alignment processes*:

i) frame bridging,
ii) frame amplification,
iii) frame extension and
iv) frame transformation.

The meanings of these features will be explored and their relevance to the analysis and interpretation of the collected data will be discussed. Finally, the rationale for adopting the framing perspective in this thesis will be concluded.

4.2. The framing perspective

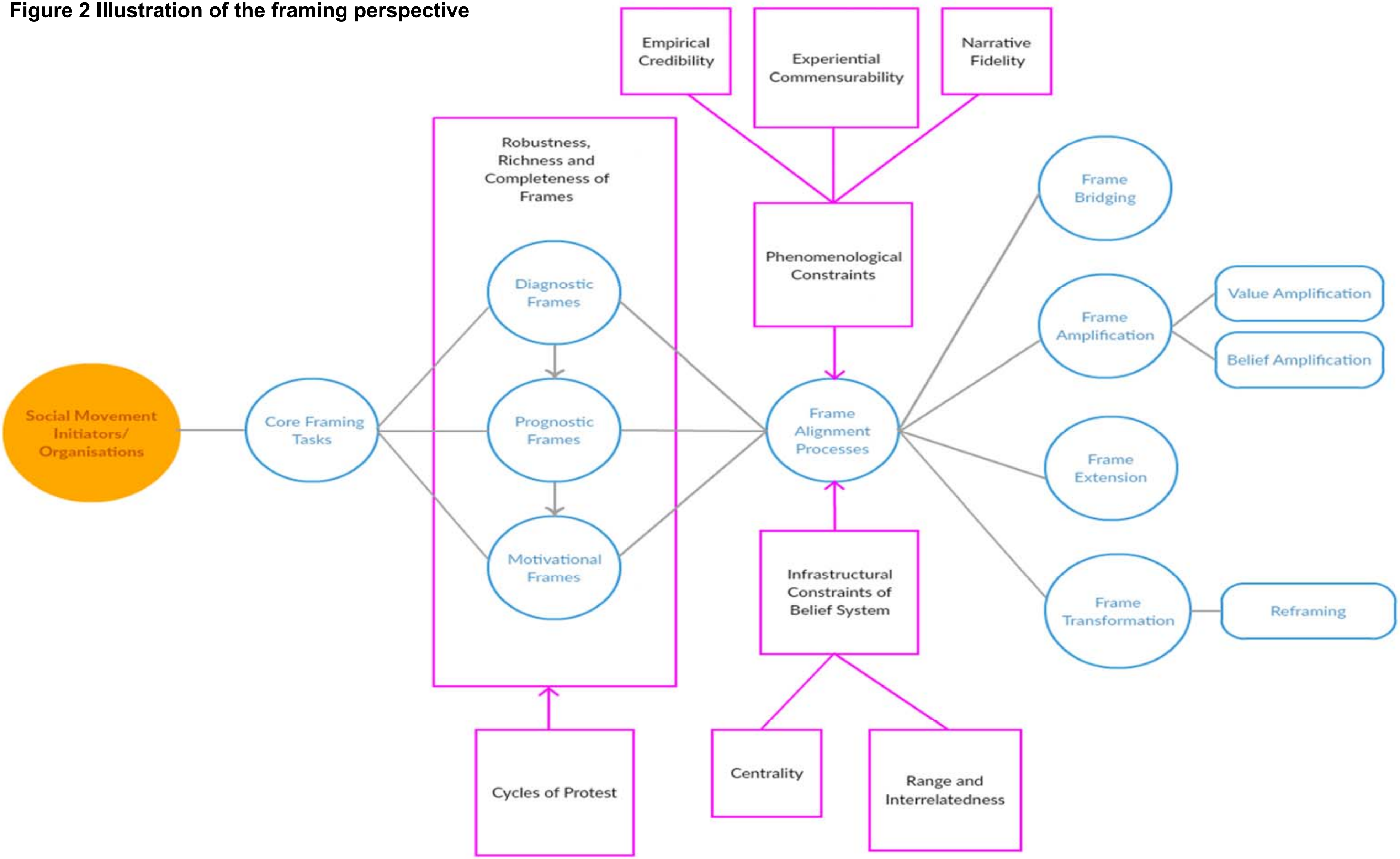
The framing perspective was first proposed by Snow, Rochford, Worden and Benford in their 1986 article: “Frame alignment processes, micromobilisation, and movement participation”. In their article, the authors initially proposed the concept of ‘frame alignment processes’; an idea which refers to the congruence of values and beliefs between social movement organisations (SMOs) and individuals (Snow et al, 1986). In the article the concept of ‘framing’ is presented as a theoretical extension of the work of frame analysis proposed by Erving Goffman in 1974, with a focus on the study of social movements (Snow et al, 2014). Theorised by Goffman (1974), a ‘frame’ is the definition of a situation one becomes subjectively involved in, signifying ‘a lore of understanding’, ‘an approach’ and ‘a perspective’ (Goffman, 1974, p. 21). Further, the process of framing is a channel for individuals to ‘locate, perceive, identify and label’ (Goffman, 1974, p. 21) their experiences. Adopting the conceptualisation of framing as offered by Goffman, in the study of social movement framing denotes an active and dynamic process of meaning construction; with such construction evolving on a constant basis (Benford & Snow, 2000; Snow & Benford, 1988; Snow et al, 1986).

Further developed from Goffman's theory, Snow et al (1986) proposed the four frame alignment processes in the study of social movements: frame bridging, amplification, extension and transformation. These four alignment processes formed the foundation of the theoretical construct of the framing perspective on social movements suggested by Snow, Rochford, Worden and Benford (1986). Explained by these authors, the purpose for establishing the framing perspective was to address the lack of theoretical apparatus in the field of social movement study, by elucidating the process of movement recruitment, participation and conversion; i.e. the frame alignment processes (Snow et al, 2014). Fundamentally, the concept of frame alignment was developed to address the conceptual gap regarding the alignment processes during which individuals, with little or no prior understanding pertaining to a particular social movement, had subsequently adopted its beliefs and practices, at the same time, redefining themselves by those beliefs (Snow et al, 2014).

In addition to the four frame alignment processes: frame bridging, amplification, extension and transformation, Snow & Benford (1988) also introduced the concept of three core framing tasks encompassing diagnostic framing, prognostic framing and motivational framing. The frame(s) constructed in these three framing tasks are those adhered to by social movement participants; stemming from these frames are actions in promoting frame alignment amongst wider audiences.

The framing perspective proffered by Snow et al (1986) was adopted in this study to aid the interpretation of the gathered data and thereby facilitate the development of a theoretical understanding of the case of end of life care in Macao. The subsequent section elucidates the various elements involved in the theoretical construct of the framing perspective, i.e. frame alignment processes and core framing tasks. The discussion also involves the relevance of these individual elements with reference to the end of life care in Macao. Figure 2 below illustrates the framing perspective proposed by Snow and colleagues, by summarising all the elements and influential factors that could affect the movement process (Benford & Snow, 2000; Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986). As I explain below the framing perspective in more detail, I make reference to my subsequent chapters where the theory is being adapted or adopted in respect of my study data and findings.

Figure 2 Illustration of the framing perspective



4.3. Core framing tasks

As introduced, core framing tasks involve three specific tasks: i) diagnostic framing, ii) prognostic framing and iii) motivational framing. Collective action frames are constructed by way of core framing tasks allowing movement adherents to “negotiate a shared understanding of some problematic conditions or situation they define as in need of change (the grievance), make attributions regarding who or what is to blame (diagnostic frame), articulate an alternative set of arrangements (prognostic frame), and urge others to act in concert to affect change (motivational frame)” (Benford and Snow, 2000, p. 615). The development of core framing tasks was to provide a focused conceptual specification to encompass the “dynamic interactive relationship among ideational elements, movement activity, and participation” (Snow and Benford, 1988, p. 199). This development is seen as an extension of the concept of action mobilisation and consensus mobilisation initially proposed by Klandermans (1984) to gain an understanding of participant mobilisation in social movements. You can see where my data illuminates these processes in the case of end of life care in Macao through examining how initiators had developed a shared understanding of a problematic condition or situation they defined as in need of change (the grievance) in section 5.3, make attributions regarding who or what is to blame (diagnostic frames) in section 5.2, articulate an alternative set of arrangements (prognostic frame) in section 5.4 and urge others to act in concert to affect change (motivational frame) also in section 5.4.

In Klandermans’ (1984) theory on participation mobilisation, consensus mobilisation is the attainment of people’s support for the beliefs and values proposed by the movement. Action mobilisation is the success in mobilising people to participate in the movement; however, in order to achieve action mobilisation, consensus mobilisation must first be achieved (Klandermans, 1984). Introduced in the framing perspective, frame alignment processes are steps enabling the attainment of consensus and/or action mobilisation. Consensus mobilisation can be achieved by way of motivating individuals, through frame alignment processes, to adopt diagnostic and prognostic frames proposed by a social movement; action mobilisation is achieved when individuals are also aligned with the motivational frames proposed. The success of social movement is contingent upon the achievement of consensus and/or action mobilisation, both of which also depend on the “robustness, completeness and thoroughness” of the core framing effort (Snow and Benford, 1988, p. 199). To identify with these components in my data analysis please see the specific sections in Chapter Five, and see Chapter Six for discussions on issues relating to frame alignment (section 7.2.1, section 7.3.1 to 7.3.3) in the development of end of life care in Macao.

4.3.1. Diagnostic framing

The rise of a social movement usually intends to change a problematic situation (the grievance) identified by the movement's adherents. Diagnostic framing is a process wherein movement adherents conceptualise "attribution of blame" (Snow & Benford, 1988, p. 200) that require a remedy or alteration (Snow et al, 1986). In terms of conceptualising diagnostic frames, consensus agreement is often attained in regards to problem identification; attributional consensus is however, more problematic (Snow & Benford, 1988). Often a movement's initiators agree on a/the problem that is needed to be addressed by the movement; however, the initiators might hold different understanding or perceptions regarding the underlying attribution(s) of the identified problem (Snow & Benford, 1988; Snow et al, 1986). The diverse attributions from initiators may have potential impact on the subsequent strategies ascertained to solve the identified problem and lead to intra-movement conflict (Benford & Snow, 2000). Data from this study indicated that initiators of 'end of life care in Macao' had reached consensus regarding the issue they perceived as the grievance, that is, the suffering at the end of life (see section 5.3). However, agreeing with Benford & Snow (2000), this study found that the nature of the problem adhered to by the three initiators varied; a variation which subsequently led to the conflict of prognostic framing (see section 6.2.2) which I will discuss in the section below. A detailed analysis of initiators' different attribution of blame is situated in Chapter Five where the different experiences of initiators are discussed, and the identification of the same grievance is also presented in Chapter Five section 5.3.

4.3.2. Prognostic framing

Following the identification of the grievance and the diagnostic frames (the problem(s) identified by initiators that are attributing to the grievance), prognostic framing suggests solutions to those problems. The process of prognostic framing is both strategic and goal driven at the same time, as well as specific and focused (Snow et al, 1986). The issue discovered through diagnostic framing is often projected onto prognostic framing; hence, these two categories of frames frequently correspond to one another, in that, the solution (prognostic frame) identified primarily aims to address the problem (diagnostic frame)

(Snow & Benford, 1988). In addition to the strategies used in addressing the problems identified, prognostic framing is also found to conceptualise meanings (frames) that are intended to oppose existing values and beliefs that are in conflict with those promoted by the social movement; this process is labelled as "counterframing" (Benford, 1987, p. 75). Counterframing does not only stem from social movement(s), but also from the opponents of the movement located in the wider environment. Whilst counterframing from a movement's opponents can put that movement's adherents on the defensive, it encourages the refinement of prognostic frames and, as a result, enhances mobilisation of the movement (Benford, 1987).

With regards to this case study, prognostic frames formulated by end of life care initiators differed, as the prognostic frames identified were corresponding with the different attributions (diagnostic frames) initiators had designated for the shared grievance, see sections 5.4 for examples for the different prognostic frames in my analysis. Despite Benford & Snow (2000) suggesting that conflict of strategies between different adherents of the same movement is common, this study found that this prognostic frame disagreement, also known as "frame disputes" (Benford, 1993), interrupted the collectiveness amongst the movement's initiators, and thereby negatively impacted on the development of end of life care in Macao. According to Diani (1992), the definition of social movement involves multiple individuals/organisations/groups that have become collectively connected with one another through joint action, and which share the same vision pertinent to a social conflict, building on a collective identity (Diani, 1992, p. 3). The end of life care in Macao does not have this collectiveness, i.e. not a full social movement by way of the definition (see Chapter Six section 6.2.2 and Chapter Seven section 7.2.1, for detailed discussions of this problematic issue). The study data also found that counterframing had a significant impact on the developmental journey of end of life care in Macao, in that counterframing was observed as both a counter-response to the introduction of end of life care (See Chapter Seven section 7.3.3 for a more detailed discussion of this matter).

4.3.3. Motivational framing

Expanding beyond diagnosis and prognosis, the motivational frame concept provides the rationale for engaging in the collective action of social movement: a "rationale for action" (Snow and Benford, 1988, p.202) in order to acquire action mobilisation (Snow et al, 1986). As explained, even if individuals have accepted values and beliefs promoted by a given movement (consensus mobilisation), it does not mean that the same individuals would now join in that movement's actions (action mobilisation). The aim of motivational framing is therefore to conceptualise meanings and promote those meanings in order to appeal for individuals' participation. According to Snow & Benford (1988), motivational frames frequently conceptualise or involve moral ideals for a movement's adherents, as it is arguable that individuals are more likely to participate in action when the rationale for action is morally inducing.

In the case of end of life care in Macao, data indicated that attention of movement initiators and developers was noticeably focused on a) the identification of the grievance (see section 5.3), b) the identification of the problem(s) (diagnostic frame) contributing to the grievance (see section 5.2) and c) the developmental approaches (prognostic frames) (See section 5.4) in order to achieve consensus mobilisation for the end of life care movement. In terms of motivational framing, the accounts of initiators did not indicate any construction of motivational meaning in order to promote people's engagement/acceptance of end of life care. As section 7.3.2 will further explain, during the establishment of end of life care in Macao, initiators were found to have omitted the consideration of the Chinese cultural value of life preservation, which had led to the emergence of counterframing towards the end of life care movement (section 7.3.3). As a result, much of initiators' and developers' effort was found to have emphasised on rationalising the establishment of prognostic frames and the approaches devised and their importance to address the problems identified, in their respective fields. Hence, the framing of motivational values was not particularly evident amongst initiators as presented in the study data.

In addition to the articulation of core frames, Snow & Benford (1988) also proposed a number of other factors that might influence the mobilising potency of a movement's framing effort. These factors include: i) the infrastructural constraints of belief systems, ii) the phenomenological constraints and iii) the cycles of protest. Whilst the core framing tasks can be seen to be closely related to the case of end of life care in Macao, the case was found to reflect certain phenomenological constraints see section 6.3 and 7.3. In considering the relevance of the framing perspective and this research, I decided to further elucidate only the phenomenological constraints and forgo discussing other factors, specifically infrastructural constraints of belief system and cycles of protest (For a full illustration of the theoretical structure of the framing perspective, please see Figure 2).

4.4. Phenomenological constraints

Phenomenological constraints concern the limitations in linking the proffered frames with the phenomenological life of a potential movement's participants (Snow & Benford, 1988). Narrative fidelity, experiential commensurability and empirical credibility are the three conditions pivotal in mobilising framing potency in social movements. Narrative fidelity refers to the relevance of the proposed framings with the dominant cultural values and beliefs; experiential commensurability is a term coined by Snow & Benford (1988) to describe the level of relevance between the proposed frames and the everyday experiences of potential participants; empirical credibility explores whether or not proposed framings can be substantiated by evidence based on events of the world (Snow & Benford, 1988). In order for a social movement to achieve consensus mobilisation, and which can potentially lead to action mobilisation, the fulfilment of at least one of the three aforementioned conditions is necessary (Snow & Benford, 1988). In this study however, there were a number of limitations concerning all three aspects of these phenomenological constraints. Specifically, the limitation on narrative fidelity was the most poignant influence on the end of life care in Macao (see section 6.3.1.1). The following sections begin by introducing the three aspects of phenomenological constraints, and then discussing their relevance to this case study.

4.4.1. Narrative fidelity

The main concern of narrative fidelity is about the resonance of proffered framings from social movements when informed by the existing cultural narrations (Snow & Benford, 1988). Generally speaking, culture can be understood as a set of internalised shared values and norms that are rooted in a society and accepted by the members in that society (Kagawa Singer et al, 2016). Culture is not only about shared understandings, but also the practices that are based on those understandings (Napier et al, 2014). Whilst social movements may support a different set of understandings, they are still embedded in these shared cultural contexts; movement supporters and potential participants of social movements co-exist within the same cultural context (Benford & Snow, 2000; d'Anjou & Van Male, 1998). The successful mobilisation of a social movement is therefore contingent on the alignment of frames proposed by (a) social movement and the shared cultural norms within the shared cultural context. Narrative fidelity is a term adopted from Fisher (1984) to describe the resonance between the frames proffered by a social movement and the existing cultural values wherein a social movement is situated.

Some frames articulated in a social movement appear to be more potent than others in influencing mobilisation, mainly because they share more cultural resonance than other frames (Gamson & Modigliani, 1989). The level of cultural resonance is usually correlated with the level of narrative fidelity (Hunt & Benford, 1994). One of the greatest challenges in mobilising a social movement is to articulate frames that contest the dominant culture and yet, at the same time, comply with certain values of that dominant culture (d'Anjou & Van Male, 1998).

With respect to the current study, narrative fidelity was found to be a significant influence on limiting the mobilising potency of the end of life care movement in Macao. Data analysis revealed that end of life care in Macao reflected difficulties in achieving narrative fidelity, in that the values proposed by initiators were unable to be aligned with some extant cultural beliefs in Macao. A more detailed analytical discussion relating to this alignment issue is presented in Chapters Six section 6.3.1, section 6.3.2 and Chapter Seven section 7.3. Whilst the end of life care in Macao was unable to achieve narrative fidelity, the misalignment of values elicited counterframing from the wider context of Macao (see section 7.3.3), mainly because the newly introduced values had challenged the existing dominant culture. The refutation of the proposed values was a response to such challenges (d'Anjou & Van Male, 1998).

4.4.2. Experiential commensurability

When it comes to measuring the fit between proposed framings and the everyday lives and experiences of potential participants, experiential commensurability is employed. In other words, the problems (diagnostic frames) and solutions (prognostic frames) informing the problems suggested by social movements are needed to be in parallel with the situations experienced by movement audiences (Snow & Benford, 1988). The level of experiential commensurability reflects the tendency of audiences to accept the suggested frames and participate in the movement (Snow & Benford, 1988). Reflecting on the current case study, in addition to the difficulty in aligning with existing cultural values, frames proposed by the end of life care movement also struggled to relate to the everyday lives and experiences of potential participants in the context of Macao see sections 7.3.1 and 7.3.2. According to the account of initiators and developers, the practice of end of life care directly confronting death and dying was found to be conceptually removed from the everyday experience of death and dying in Macao, where end of life situations were routinely being avoided. Whilst the proposed values of end of life care were found to mismatch the experiences of the people in Macao, analysis of the data suggested that the constraint of narrative fidelity also came into play. Since the experiences of people in Macao were primarily grounded in the cultural context of Macao, it would be likely that their cultural values and beliefs would influence one's interpretation of those experiences. Therefore, I argued that the level of influence from narrative fidelity would have an impact on experiential commensurability; an outcome which was reflected in the research data (See Chapter Seven, section 7.3).

4.4.3. Empirical credibility

Empirical credibility refers to the overall alignment of movement frames and events of the world. Rather than focusing on the alignment of frames at the individual level, empirical credibility is concerned with the overall credibility of the proposed frames in relation to the world. In other words, the concept concerns the credibility of the proposed diagnostic, prognostic and motivational frames, and whether they are able to be substantiated by evidence in the 'real' world (Snow & Benford, 1988). Empirical credibility sits less well in the case of end of life care in Macao compared with narrative fidelity and experiential commensurability in that the frames proposed by initiators and developers were centred on the mortality of humans, which is a shared reality amongst most people in the world where we reside. Therefore, empirical credibility suggested in the framing perspective was not reflected as a concern in the case of end of life care in Macao.

To conclude, data gathered in this research reflected features relating to narrative fidelity and experiential commensurability. As discussed, these two factors were found to be particularly related to the context of this research. Since the case of end of life care in Macao is fundamentally concerned with the shared reality that humans are mortal beings, the constraint of empirical credibility did not apply in this research context. Having discussed core framing tasks and phenomenological constraints within the framing perspective that were of relevance to this research, the section below moves onto explaining the four frame alignment processes which are used to explain how the proposed frames of a social movement can be translated to potential participants.

4.5. Frame alignment processes

After a movement's adherents have constructed collective action frames (diagnostic, prognostic and motivational frames), frame alignment processes offer a theoretical explanation as to how these frames are being negotiated between the social movement and individuals. Frame alignment processes are developed in addressing the lack of theoretical apparatus in the study of social movement(s) to explain the process of movement recruitment, participation and conversion (Snow et al, 2014). Building on Goffman's frame analysis theory, Snow et al (1986) introduced four further processes: i) frame bridging, ii) frame amplification, iii) frame extension and iv) frame transformation. Fundamentally, all four alignment processes are primarily directed to facilitate the dissemination and integration of frames proposed by social movements to individuals, by calling for collective action. Frame bridging is a process that facilitates structural links between individuals/organisations and social movements. An example of such a link's value is when individuals/organisations share an understanding regarding the grievance and the attribution of blame, but those involved participants do not have a structural basis to support their expression of discontent (Snow et al, 1986). The pre-requisite for the frame bridging process is the ideological coherence between individuals and a social movement. Interpretive frames proposed by social movements may not be immediately apparent to potential supporters; therefore, frame amplification is a process to clarify and invigorate interpretive frames proposed by a social movement in order to aid frame alignment and inspire collective action (Snow et al, 1986).

In some cases, the values and beliefs advocated by a social movement may reflect little of the life situations and interests of potential supporters (Snow et al, 1986). Under such circumstances, frame extension is a strategy used to expand the boundaries of frames originally proposed for the purpose of including views and beliefs that would strike a responsive chord with a movement's potential supporters. Suggested by Snow et al (1986), frame extension is a common frame alignment technique, in that social movement adherents frequently expand their movement's goals in order to include the values and beliefs of potential supporters, thereby mobilising their participation. Different from the three alignment processes mentioned, frame transformation is a process wherein values and beliefs originally proposed by a social movement are being completely reframed into new values, in the hope of garnering participatory support (Snow et al, 1986). The reframing of already established interpretive meanings was developed from Goffman's concept of "keying", which implies a "systemic transformation on already meaningful schema of interpretation" (Goffman, 1974, p. 45). In some cases, a transformation of a frame (or even frames) in a social movement is necessary in order to create resonance with bystanders and encourage their active participation.

With respect to this research, the data demonstrated that the frames proposed by the end of life care in Macao struggled to be accepted in the context of Macao. This dissonance was primarily attributed to the frames misalignment with the existing beliefs of Macao's Chinese residents. As I will discuss further in Chapters Six section 6.3 and Chapter Seven section 7.3.1 and 7.3.2, data from this research did not indicate any frame alignment processes committed by movement initiators in calling for participation from potential supporters.

4.6. Conclusion

This chapter elaborated upon the implementation of the 'framing perspective' as the theoretical construct underpinning this case study. The chapter has presented the conceptual features of the framing perspective as it informs the study of social movement. The relevance of the framing perspective was further illustrated in relation to the case of end of life care in Macao. As a conclusion the framing perspective was decided to be a suitable and innovative way to inform the analytical and theoretical discussion of this case study of end of life care in Macao.

5. Chapter Five: Inception of end of life care in the context of Macao

5.1. Introduction

The following two chapters (Chapters Five and Six) present the research findings and the analytical discussions of this case study. The study aim, as set out in the methodology chapter (Chapter Three), was consolidated during the analysis process; specifically, the research enquiry was focused on examining the establishment and development of the case of end of life care in Macao, together with how this service has been both facilitated and limited within that case. Building from this research objective, the following research questions were developed:

1. Why and how did end of life care emerge in Macao?
2. What factors have influenced the subsequent development of end of life care in the context of Macao?

In the process of analysis, the emergence of end of life care was found to be congruent to the emergence of a social movement. The lens of the framing perspective (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986) was used to aid the analytic and theorising process. In Chapter Seven (the discussion chapter), the interpretation of the study's findings were also grounded in this theoretical construct. The research findings presented in this chapter primarily address research question number one. Divided into three parts, the first part begins by introducing the initiators of the end of life care in Macao, elucidating the experiences of these individuals and how they became involved in initiating end of life care. This section allows readers to learn the experiences of these initiators, their backgrounds, their personal journeys and their interpretations in relation to death and dying. This information will help readers to relate the initiators' personal experiences to the inception of Macao's end of life care. Building on this understanding, the second part of the analysis examines the problem identified jointly by these initiators. The grievance: 'the suffering of people as experienced at the end of their lives' was found in this study to be the main reason for the inception of end of life care in Macao. The third part details the practical steps taken by initiators in introducing and conceptualising end of life care in Macao.

5.2. Discovering end of life care – the initiators personal journeys

The establishment of the end of life care in Macao, together with its allied services, is based on the efforts of three individuals: Sui, Tao and Chu. They are the first people to introduce the concept of end of life care, not only in their respective professional fields, but also to the society of Macao. The journeys of these initiators will provide understanding of the origins of end of life care in Macao, and how it has impacted on the establishment of end of life care and the challenges and limitations as a consequence of this.

Illustrated below are the individual backgrounds of these initiators and their pioneering efforts in starting the service and conceptualising end of life care in their respective professional fields: a) community home visiting service, b) inpatient service, and c) education on end of life care in nursing education and information-giving in the public domain.

Based on the initiators' narratives, this section aims to present their personal journeys and at the same time, to scrutinise their individually structured interpretive foundations upon which the end of life care movement in Macao was built. In Chapter Seven: Discussion, I will interpret these findings through the framing perspective (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986) illustrating the development of end of life care by way of a social movement perspective.

5.2.1. Sui – Initiator of Macao's inpatient end of life care

Sui is a nurse with more than 40 years of experience. During her nursing career, she has been primarily based in a part private, part charity hospital in Macao. Sui was initially trained and worked as a midwife for more than a decade before moving to the surgical department in the later part of her career. With respect to death and dying, Sui's early encounter was mainly oriented to the acute emergency incidents that occurred in the labour and surgical units. On the whole however, Sui described her experience in nursing care as predominantly occupied by happy outcomes.

> *"In terms of my career, in the first 13 years, I worked in obstetrics and gynaecology, I was a midwife. I was mostly in touch with happiness, relatively more joy. But of course, being a midwife, you will also encounter sudden situations, especially when pre-natal health care was not as popular then. If it is a smooth delivery then everyone is happy, but if it is not a smooth delivery, or there are some sudden events, it is threatening and soul-stirring. So, I have been really lucky. In fact, my encounter with death associated with delivery was limited. (…) After 13 years, I was transferred to the surgical department. My encounter was mostly related to post-surgical patients. After the surgery, they stayed in the hospital happily for a month or so, some even shorter, 10 days or 8 days, then they would say goodbye." (Sui, Initiator, Hospice)*

According to Sui's professional experience, the majority of times she perceived her encounters with patients were positive and filled with happiness. However, it was later in her nursing career when she started noticing the increasing number of terminal cancer patients and the suffering they experienced; suffering that she attributed to the lack of organisational and systemic concern over death and dying.

> *"… once (cancer patients) entered the terminal stage of their illness, if they needed to stay in the private hospital, they had to pay for the second class and they couldn't stay in the cheapest class. So, during terminal stage, a lot of patients had suffered a lot before being admitted. This was before the hospice service. (…) At the time, according to the system of the private hospital, the cheapest third class beds were charity beds, so according to the policy, patients with no acute emergency care needs could not be allocated to those beds. In the government hospital, they would accept those patients, but often patients were treated in A&E and once treated, they would be sent home. Many patients were carried in and out of the hospital all the time." (Sui, Initiator, Hospice)*

Of predominant concern to Sui was that terminal cancer patients were not the priority for either the private charity hospital or the government. As a direct result of this situation, terminal cancer patients in Macao suffered. On a personal level, working in the environment where suffering of terminal cancer patients were increasingly witnessed, Sui scrutinised her experience and interpreted it in terms of her moral obligation as a nurse to care for patients in situations involving death and dying. Particularly, Sui reflected on her encounter with a young female patient. After the patient's terminal diagnosis, she was abandoned by her husband whom had also taken her children away. The abandonment the dying patient experienced is likely related to the attitude of death avoidance prevalent in the Chinese culture (Lin & Huang, 2003). In response to the patient's suffering, Sui questioned:

> *"We as nurses, apart from providing daily care, helping patients with showers, feeding them, chatting with them, what we actually do for them? So, from that moment onwards, I started to learn more and read more about end of life care." (Sui, Initiator, Hospice)*

Grounded in her experience with the female patient, Sui interpreted her experience through the lens of moral obligation. Revisiting the problematic circumstances of the patient, Sui understood it as a moral obligation for her, as a nurse, to care for patients who were dying. The suffering of the dying, as observed by Sui, was poignant in the case of the young female patient in that her suffering, specifically existential suffering, was instigated by the phenomenon of abandonment by her family.

> *"During the time when the patient fell ill, her husband had taken her two children away and left her. Her family left her alone. So, she fell into a state of loss and helplessness (無茫). As she approached the terminal stage, she suffered even more, she became more lost and helpless. Her suffering (辛苦) was immense and she was not able to speak." (Sui, Initiator, Hospice)*

In this particular case Sui not only illustrated the young female patient's physical suffering, but also the emotional and physical abandonment by her husband. The term 辛苦 (San Fu) contains two separate words and each of the word carries individual meaning. 辛 (San) carries the meaning of hardship and 苦 (Fu) has the meaning of bitterness. The combination of 辛 (San) and 苦 (Fu) indicates being in an environment of suffering and bears the bitterness within. The notion of suffering experienced by the patient was centred on the state of feeling lost and helpless (無茫). Being lost was the situation of suffering she ended up in after her husband abandoned her; the state of helplessness was manifested in the bitter feeling she had after being abandoned and had her children taken away from her. The type of suffering experienced by this female patient was, as depicted by Sui, predominantly existential.

Existential suffering has been frequently discussed in the context of palliative and end of life care; particularly regarding the concept, its definition, and its relationship with spiritual suffering (Boston et al, 2011). In a literature review on existential suffering at the end of life, Boston et al. (2011) found that over the years, researchers have accumulated various factors in trying to elucidate the notion of existential suffering. Most of the definitions relating to the notion, as identified by Boston et al. (2011), carry overlapping qualities.

Despite the definition of existential suffering being varied, amongst those identified many carry overlapping qualities. Summarised below are the main definitions of existential suffering cited in the literature: meaninglessness in life, futility, hopelessness, and disruption of personal identity. The latter state is somewhat complex as it includes: i) the loss of social functional role, ii) feeling emotionally irrelevant, iii) remorse, iv) guilt, v) grief, vi) loss of dignity which entails fear of being a burden on others and vii) loneliness (Blinderman & Cherny, 2005; Henoch & Danielson, 2009; Jones et al, 2010; Morita et al, 2000). With particular regard to the suffering of helplessness, researchers have explored how that feeling manifests itself in end of life situations. In a study by Montoya-Juarez et al. (2013), the feeling of helplessness is strongly associated with the threatening thought that life is short in end of life patients. Another research found helplessness in terminal patients is attributed by those patients to their physical conditions (Block, 2000). The finding of this study is consistent with previous research findings, where the suffering experienced by Sui's patient was subjectively described as being 'lost' and of 'helplessness'. The suffering felt was, as illustrated by Sui, primarily attributed to the loss of her role as a mother because of the loss of her children and being abandoned by her husband. Further to being lost and helpless, Sui's patient also experienced the loss of her functional role as a mother, and the feeling of being emotionally irrelevant after being abandoned by her husband. According to the female patient's experience in Sui's account, the finding indicates possible connections between the feeling of helplessness, the loss of personal identity as a mother, and the cultural element of filial piety.

In accord with the virtue of filial piety, each member of a family has a clear functional role that one must adhere to. Failure in fulfilling the functional role is considered as breaking the principle of filial piety. Such conduct is considered unacceptable, not only within the familial setting, but there will also be social implications relating to the person who, for whatever reasons, does not oblige (Creel, 1937).

Following the principle of filial piety, the historical role of women is predominantly to be active within the household. As described by Ayscough (1938), the role of mothers within a household is equated to ‘yin’, while the role of men is ‘yang’ involving matters outside the household wall (p. 296). In filial piety therefore, the role of motherhood holds fundamental significance, not only for the person who is responsible for that role, but also for the entire familial structure. In the case of Sui’s patient, her physical deterioration as a result of her terminal illness has taken away her ability to perform the motherly role in her family. The departure of her husband with their children could be linked to her failing to fulfil her motherly role in caring for her children with respect to filial piety. In her case the balance of the family structure was being ‘threatened’ (Creel, 1937) as a result of the loss of the functional role of the dying patient.

Adding to the above findings, the act of abandonment experienced by Sui’s dying patient can be understood when informed by the aspect of filial piety. In the case of Sui’s patient, under the principle of filial obligation the loss of her functional role as a mother and wife could be a likely explanation for the familial abandonment by her husband. The relationship between filial piety and familial abandonment, in the specific context of end of life care, has not been subjected to extensive study.

One of the principles of filial piety is the repayment of gratitude and the reciprocity of love and care (De Guzman et al, 2012). In caring for elderly members in a family unit, reciprocity necessarily entails physical caring and the provision of emotional and financial needs for the ageing members of the family, often in the same physical environment (Zhan et al, 2011). With respect to the relationship between familial abandonment and filial piety, most existing studies in the field agreed that the failure to exhibit filial piety triggers the feeling of abandonment by the elderly, as well as the societal view of ‘dumping’ the elderly in institutions (De Guzman et al, 2012; Liu et al, 2012; Zhan et al, 2011). The studies cited above highlight the moral obligation of Chinese families in taking care of the elderly. The principle followed here is the reciprocation of physical and emotional care that these elderly members have provided in facilitating the lives of the younger generations during their capable years. Relating this understanding to the case of Sui’s patient, the loss of her motherly role signifies the loss of her ability to provide care for her family. In the context of filial piety, where reciprocity is considered as one of the most important virtues, the fact that the young terminally ill female patient was no longer able to provide for her family implies that she was also no longer in the position to receive reciprocation from her family.

In fact, such tacit understanding of the relationship between the loss of functional role and familial abandonment had been expressed by Sui.

> *"After a lot of communication and effort, the patient's mother managed to bring the two children to see the patient. During that time, I was there with the patient she looked really helpless (無助). Tears were falling as she looked over to her children. But during the final stage, the patient felt that her wish had been fulfilled. Although that was the end, at least she knew that her children were being taken care of by her husband. She knew she was not able to take care of them, but at least the patient could see her children at the end." (Sui, Initiator, Hospice)*

The language of Sui's quote exposed the almost palpable and yet unspoken rule of filial piety, in that one's ability in fulfilling one's functional role affects whether the person is deserved to receive love and care from the family. For Sui' s patient, not only was she acutely aware of her inability to care for her children, at the same time, she felt helpless (無助) in her own inadequacy as a mother. Feeling helpless with no other option, the patient accepted the reality of being abandoned by her husband as a consequence and sought comfort in seeing her children for the final time.

The connection between filial piety, family abandonment and reciprocity of love and care in the end of life context does not appear to have been discussed in previous literature. Discovered in the present study is the recurrent emergence of the connection between family abandonment and the dying individual's diminished ability to carry out their functional role under the framework of filial piety. Tao, the community end of life care initiator whose experience is presented below, had also made similar observations regarding this connection.

On reflection of the overall experiences of Sui, and her interpretation of these experiences, she questioned the capacity of existing health care institutions and professionals, particularly nurses, when it came to supporting the dying and their families, as well as alleviating the terminally ill patients' suffering during their end of life period. The suffering in death and dying is therefore the primary concern of Sui; a focus which has subsequently triggered the initiation of the end of life care movement in Macao.

By conceptualising suffering as the key problem in the context of death and dying, Sui has in fact illustrated the conceptualisation of grievance within the theoretical structure of the framing perspective of social movement. Further, Sui attributed the grievance (suffering at the end of life) to the absence of end of life care, which illustrated the conceptualisation of a diagnostic frame. Grounded in the theoretical basis of the framing perspective, grievance reflects the discontent people have interpreted from their experiences while diagnostic frame is an issue being conceptualised as a problem that contributes to the grievance and requires a remedy or alteration (prognostic framing) (Snow et al, 1986).

Reflecting upon the account of Sui, discussed above, the grievance articulated is the suffering experienced by terminally ill people during the stage of dying and the subsequent suffering as a result of death in the family. The identification of this grievance is predominantly informed by Sui's interpretation of her experiences of encountering patients who were dying. The interpretation of experience has been a subject of attention regarding its significance in the framing perspective. Snow et al. (1986) were concerned that many social scientists do not adequately focus on the interpretation of experiences of those involved in movement participation. In studying the emergence of social movements, the enquiry into the interpretation of grievances and other ideational elements is considered a pivotal part in understanding individuals' experiences that had triggered their original motives (Snow et al, 1986; Turner, 1969). The acquisition of interpretive frameworks can facilitate understanding of how individuals or social movement organisations choose to support and participate in social movements (Snow et al, 1986).

Illustrated in the above discussion is a strong account of Sui, as an initiator of end of life care, in interpreting her individual experience when encountering death and dying. The grievance identified by Sui is the sufferings of people during the end of life process; a situation which eventually led to the establishment of the hospice in Macao. With regard to the grievance identified by Sui, it was found to be shared by the other of Macao's end of life care initiators. In agreeing that this is a key issue that needed to be remedied, the physical and psychological suffering associated with death and dying has become the founding impetus of the end of life care in Macao

The above section has examined Sui's interpretation of her experience of death and dying, and the trigger for her desire to start end of life care services. Further, Sui's account has revealed a deep level of influence stemming from the perceived cultural virtue of filial piety; an influence which contributes significantly to the fear and avoidance towards death and dying. The influence of filial piety in the context of end of life is found to be a common concern amongst the initiators and developers of the end of life care movement in Macao. The following section will discuss Chu, an initiator who is primarily active within the realm of nursing education and public promotion of end of life care.

5.2.2. Chu – Nurse Educator Initiator

Chu has been professionally involved in nursing education since 1977. From the account of Chu, her interpretation of death and dying, and her attitude towards the care for the dying is divided into two parts. The first part is centred on her experiences as a nurse and a student nurse, with particular regards to the practice of corpse care. The first part of Chu's experience mainly reflects a sense of fear and avoidance towards death. The separation of the meaning of life from death is observed; which implies that death does not carry any sign that symbolises life, as Chu's data on corpse care will show later. However, Chu's interpretation relating to death and dying, and her attitude towards caring for the dying is changed after her experience of a loved one's death in her family, which has subsequently motivated her initiation of end of life care education. Different from Sui, Chu's journey entails her personal experience encountering death of a loved one which has changed her fear and avoidance of death to realising the suffering of death and dying.

This section begins by exploring Chu's initial experience in death and dying. As data of this study show, Chu initially found it difficult to relate to the deaths of the patients she nursed at a personal level.

> *"During my time as a student nurse, I had wrapped many corpses and encountered many deaths. But none, none of them has left me with deep memories. Or maybe I have forgotten about them, but if something has left you with deep memories, you will definitely remember." (Chu, Initiator, Nurse Education)*

Revealed in Chu's quote above, the experience of death and dying for her is predominantly focused on 'wrapping corpses'. Underpinning this interpretation, I propose, is the separation of the meaning of life from death. Specifically, the life here entails not only the notion of vitality, but also the humanness by which the person is recognised as a living human being. Furthermore, Chu illustrated the lack of connection with those who died in her care; a perception which could also potentially stem from the notion of separation. On further examination, Chu attributed her interpretation of separation to the structure of nursing education she received, in which the attention given to death and dying is primarily centred on the practice of ‘corpse care’.

> *“In early nursing education, there was no involvement of end of life care. There was only one skill, called ‘corpse care’ 屍體護理.” (Chu, Initiator, Nurse Education)*

Displayed in Chu’s quote is a clear division of care treatment before and after death. Despite being termed as ‘care’, corpse care (屍體護理) is in fact, categorised by Chu and her fellow nursing colleagues as a skill; one that only focuses on the containment of fluid, facial correction and the wrapping of the corpse.

> *“Corpse care is purely a skill. Our teacher did not say it is a continuation of care for the person. This was not the approach they used. They would say: “This is how you should wrap the corpse nicely”, “This is how you should clean”. During the whole process, we could feel the teacher’s respect to the entire process; she did not despise it nor did she treat it as nothing. (…) Nurses would tell you “you should be doing this and that, to wipe the body clean”. (…) Usually after the patient has passed away, we help them change their trousers, change their tops. If there is excrement, we will change them, and wipe them clean. If there are any appearance changes, we need to sort that too, by fixing them or lifting their chin, closing their eyes. I think the most common action is to close their eyes. After we have fixed everything, we will contact the mortuary to come and remove the body.” (Chu, Initiator, Nurse Education)*

From the account of Chu (above) treatment towards the dead patient (the corpse), is conceptualised as a procedure and a skill. The procedure and skill needed for appropriate corpse care is centred solely on clinical elements. The containing, correcting and binding of the corpse are the foremost concerns. Immediately after these issues have been addressed, the corpse is then removed. To a great extent, the focus on these clinical elements relating to the corpse has, as I suggested earlier, removed the life component that embodies the humanness of a person.

In fact, the maintenance and removal of humanness in a dead person has been a subject of research interest. Many existing studies have looked into the relationship between nurses and the maintenance of relationship with the deceased during the process of last offices (Blum, 2006; Forster & Windsor, 2014; Hadders, 2007). Williams (2016) reported that nurses in the study continued to maintain the nurse-patient relationship with their deceased patients during post-mortem care, in that, they continued to communicate with the deceased as though they were still alive. The maintenance of a relationship with the deceased is recognised as being 'aware of the patient's humanness' (Wolf, 1986); this type of relational effort is also being seen as a 'humanising effort' and an attempt to 'demedicalise' the process of last offices (Williams, 2016). Contradicting data from the existing literature, the current study shows that corpse care in Macao is a process of 'removing humanness' from the deceased.

Before all else, the use of 'corpse care' in describing the process of caring for the deceased body has already detached the element of humanness from the living being the body once contained. Corpse care, in its literal sense, conceptualises the care as categorically for the corpse, for the dead body. Secondly, despite the word 'care' being used, it is a debatable concept in which corpse care is essentially a set of skills encompassing a specific procedure that is isolated from mainstream medical and nursing care. The 'care' referred to, is oriented towards a set of skills concerning the hygiene, containment and presentation of the deceased body. Despite the process of corpse care being performed with respect, any demonstration of emotions in performing the task is discouraged and suppressed.

> *"The process of corpse care is repressed, it is a psychologically and emotionally repressed process. In fact, we were scared. We were young too and there was a sense of 'parting forever in life and death', so we were scared as well. The relatives would cry or make other emotional responses, we didn't really know how to deal with it, or we had turned a blind eye to it." (Chu, Initiator, Nurse Education)*

Interpreted by Chu is the issue of repressed emotions in the process of corpse care, which is linked to fear associated with death. The fear indicated by Chu here is associated with the cultural concept that death infers eternal separation. The meaning of 'parting forever in life and death' 生離死別 is a Chinese idiom commonly used to describe people who are in love, or in a loving relationship like family, but who are now being separated unwillingly and forever in life and in death. This association, to a great extent, can be related to the earlier suggestion I made, in that the cultural anticipation of eternal separation as a result of death, could be an underpinning trigger for the separation of life from death in the practice of corpse care. Presented in this findings is the view that the cultural belief of eternal separation from death triggered nurses' reactions of fear and emotional dissociation in end of life situations. As a result, Chu admitted that she was unable to response appropriately to the family's distress after death. The inability to address distress of the family is, in my opinion, failing to provide care and therefore, further strengthens my proposal that, at least in the minds of nurses, the meaning of life and humanness is being separated from death in end of life situations.

Chu's experience has therefore indicated the conceptualisation of the connection between death, eternal separation and negative emotions. On the other hand, the fear indicated by Chu, when dealing with a corpse, encompasses more than the fear of death and the eternal separation death brings; her fear also reflects the anticipation and fear of one's own death. This perhaps illuminates Chu's hesitation in engaging with death and the caring for the dying, which she has epitomised as one of many challenges in developing end of life care in Macao. In fact, the fear of one's/other's death is found in this study to be related to the Chinese cultural desire for life preservation in Macao. The cultural belief of 'parting forever in life and death' 生離死別 is, according to this current study, linked to the yearning for immortality and the longevity of life highlighted in Chinese culture. This desire is, I argue, a big inhibitor interfering with the implementation and acceptance of the end of life care movement in the context of Macao. The findings of this study also show that all three of the initiators have expanded on this particular topic. I have devoted Chapter Six, section 6.3, to an extensive discussion regarding how the desire for, and the pursuit of life longevity in the Chinese culture of Macao has impacted on the development of end of life care in Macao.

Nevertheless, the changing point for Chu arrived when she encountered her father-in-law's death. His death was the first personally 'close' death she ever experienced and from which she learned the pain of loss in death and dying. The following excerpt is extensive, with the intention of providing a rich context for readers to understand Chu's personal experience and the extent of influence it has had on her subsequent interpretation in relation to death and dying.

> *"I wish to talk about the death of my father-in-law. It happened so quickly, he had cancer and it happened very quickly. He fell ill in 1982, he died in 1983. It was only a 'short year'. I accompanied him to Guang Zhou for surgery, to Hong Kong for inpatient admission. So our relationship was close. And at that time, I was pregnant too (…) But the deepest impact on me, was after death; his corpse, the corpse. I was with my husband at the mortuary. The deepest memory was that, the corpse was on the stretcher, a low metal stretcher. The corpse was covered with a white sheet, as the stretcher was being moved on the uneven concrete floor, his hand suddenly fell out. My heart ached so much. The feeling was so painful. He was dead, I shouldn't feel anything, but I just didn't understand why the pain was there. That moment made me realise this was 'parting forever in life and death'生離死別. That moment was the deepest memory I have ever had. So, in relation to the impetus of end of life care in Macao, I have done some early work. I have written some articles regarding this experience of mine. It was in 1983. (…) It is all because I have experienced it now, I have the feeling now. In cancer, it doesn't just affect the patient but the entire family. This is my experience; my mother-in-law, my husband and myself all had to take care of my father-in-law. I feel it is very important to help relatives of the dying to go through and cope with difficulties. This is something we have to do. This is my feeling. That is something we have to push forward, because I have experienced it personally." (Chu, Initiator, Nurse Education)*

The journey she had with her father-in-law's death has led Chu to live the hardship in caring for a dying person, experiencing the practical difficulties and emotional distress present during the process. As a result of her experience, Chu understood the significance attached to offering practical and emotional help to those who are in the same situation as she was once in. This personal experience of the suffering in death and dying had changed Chu's perspective, the separation of life from death, enabling her to understand the suffering and struggling in death and dying in Macao is real. Chu only truly understood the pain and suffering of parting forever in life and death 生離死別 after experiencing it herself.

Despite being in a different personal context from Sui, Chu has nevertheless shared a similar experience with Sui, in that they have both shared the same interpretation (grievance) relating to death and dying: the suffering of people as experienced during the end of life process. Built on this grievance is their action in introducing end of life care in Macao. The following section presents Tao's background, his interpretation of the experience of death and dying and how his interpretation translated into his involvement in the end of life care of Macao.

5.2.3. Tao – Community End of Life Care Initiator

Tao is a medical doctor who immigrated to Macao from North America more than 25 years ago. Employed by a community clinic established by the Baptist church, Tao worked as a consultant physician for 15 years before taking on the role of medical director of the clinic. Specialising in family medicine, Tao and his clinic attend to the health care needs of both immigrants and local people in Macao. Distinctly different from the other two initiators, Tao's interpretation of experience is found to be grounded in a completely different cultural heritage, compared with the other two female initiators. While Sui and Chu identified themselves with certain cultural values, but not with a specific religion, Tao clearly centred his principles on the Christian faith; his analysis of Chinese culture stemmed from an external perspective. Illustrated by the quote below, Tao approached the issue of familial abandonment as an outsider, attributing the behaviour of abandoning the dying person as a problem of the 'Asian culture'.

> *"Many of them were abandoned by family and friends because of the nature of the Asian culture. There's a lot of fear and superstitions connected with death and dying and so, when people were identified as terminal, in those years they were fortunate if one family member would remain with them to care for them. It was quite an awful situation to be found to be terminally ill. When they became extremely ill, unable to walk, eat or care for themselves, they would be accepted into government hospital care. But prior to that time, their best hope was that, one family member would stay with them as a care taker. So the situation was extremely bleak for these people. And some of that cultural fear and anxiety continues in the population." (Tao, Initiator, Community end of life care)*

A loose and detached term, 'the Asian culture', is adopted by Tao to explain the cultural aspect of the people in Macao, when they are facing death and dying. To a certain extent, the use of this term has exposed Tao's position as a foreigner, living amongst a culture that is not innate to him. This alienation between Tao and the Chinese culture will be further explored in a later section of this chapter. Proposed here by Tao is the dynamic connection between the Asian culture and death, in which fear, superstitions and anxiety are the key cultural elements that are closely linked to death. The result of this connection, as suggested by Tao, is the behaviour of abandonment of the dying by their family and friends.

In spite of the shared observations with Sui on family abandonment, there are also some contextual differences. For instance, Sui's interpretation is focused on a specific element in filial piety, in that the loss of one's role in a family is a trigger for abandonment. The observation by Tao on the other hand, involves the wider cultural context in that the Asian cultural elements mentioned: fear, superstitions and anxiety relating to death and dying are considered as the collective triggers for abandonment. Asserted by Tao is the finding that the causes of familial abandonment of the dying are, to a certain extent, attributable to the aforementioned elements in the Asian culture.

The commitment to filial piety spans both moral and practical duties to the living, as well as ancestor worship of the dead (Creel, 1937). In Mainland China, the practice of filial piety is also a moral duty reinforced by law (Chou, 2011). Opposing this fundamental practice of the Chinese culture is Tao's interpretation that the care for the dying is not necessarily obligatory for the family, because other wider elements in the Asian culture, such as fear, superstitions and anxiety towards death, are interpreted by Tao to have overridden the ingrained importance of filial duty. Revealed from Tao's statement is a sense of ambiguity/conflict relating to the care of the terminally ill. The ambiguity/conflict I propose here is between the prerequisite filial obligations to care for the dying and, the interpretation of Tao that the care for the dying does not necessarily rely on filial obligation.

Both Sui and Chu, have talked about the impact on end of life situations when informed by the element of fear. Their interpretation, as presented above, clearly stems from their perception of filial piety and its relevance to daily living. On the other hand, Tao's interpretation is underpinned by his foreign background and religious perspective, which is manifested in the inception of the end of life care community service. Regardless of the diverse background between Tao and the other two initiators, the current study discovered all three initiators have identified the same grievance, that is, the suffering of people as experienced at the end of their lives in Macao. In addition to the cultural factor of fear, superstitions and anxiety, Tao has further elaborated on the issue of causes for family abandonment. His perception shares some similarity with Sui's suggestion regarding the loss of a person's functional role within the filial system.

> *"So yeah, I think you're quite aware of the cultural superstitions and fears around death, I think it's very difficult for those not raised in Asian culture to understand the real depth of anxiety that was connected with these beliefs and still is in many circles.*
>
> *When a person became terminally ill and was no longer able to contribute to the family, it was devastating, not only for that individual but for the entire group of people, who perhaps depended on them for income, for work.*
>
> *Also in Asia, there's a higher percentage of relatively young people who have cancer, terminally ill, particularly liver cancer because of the high hepatitis B in the population, which often even in 30s, 40s, 50s can create terminal liver cancer. If that happened in the family, to a wage earner in the family, not only do they lose the wages of that individual, they lose the wages of the care taker who was probably also working and not only need to take care of (them) and that meant that children would have to leave school because there was no free school for the children in Macao at that time. So it was devastating, not only medically but economically and for generations to come." (Tao, Initiator, Community end of life care)*

Similar to the earlier finding from Sui's interpretation, Tao has also identified that family abandonment could occur once the terminally ill person has lost the functional role in contributing to the family. Tao's experience concurs with official statistics, in that China was considered an area with high levels of endemic Hepatitis B virus (HBV) (Trépo et al, 2014). Approximately 11.5% of the general population has been identified as HBV carriers, and the main transmission route is perinatal (Evans et al, 2015). The high numbers of chronic HBV carriers contribute to the higher levels of young terminal patients, as per Tao's observations. The consequence of this young, terminally ill demographic is, as explained by Tao, the loss of one's functional role in providing for their family. This concept is very much related to the practice of filial piety, in that each member of a family unit has a dedicated role and they are obliged to fulfil that role; failure to do so is considered culturally and socially unacceptable (Creel, 1937). Bearing in mind this understanding of filial piety, according to Tao's observations, these young terminally ill patients have not only lost their physical ability to make a tangible contribution to their family, but their condition also infers the loss of their functional role in the aspect of filial piety. In view of Tao's interpretations, even though he did not specifically identify with filial piety, his view certainly reflects the significance underpinning filial obligations that Chinese families follow. Considering that both Sui and Tao come from different religious, cultural and organisational backgrounds, their interpretations have concurred; both agree that filial piety plays an important role in influencing end of life situations amongst the people in Macao.

From Tao's account above it is possible to conclude that suffering, including physical, existential and socioeconomic dimensions, is identified as the dominant contributor to suffering during the period of death and dying, which is the same problem as identified by the other two initiators, Sui and Chu. I therefore suggest that, despite all three initiators come from different cultural and professional backgrounds, they have all identified the same grievance: the suffering of people as experienced at the end of their lives. Nevertheless, the solution identified by Tao to address this grievance is found to be heavily grounded in his religious background, which is different from the solutions identified by the other two initiators.

This section presented the backgrounds of the three initiators and their experiences involving the situations of death and dying in Macao. Taking into account the point made by McAdam (1999) regarding "the enormous variability in the subjective meanings people attach to their objective situations" (McAdam, 1999, p. 34), I have therefore closely examined the individual experiences of the three initiators and the subjective interpretations of their experiences. As a result of their different experiences, each initiator has created a set of different cultural values that they are informed by. These values are found to have an impact on the three initiators' actions taken towards identifying and addressing issue concerning death and dying in Macao. Even though these initiators have lived in their separate life spaces, acquiring different experiences and values, they have nevertheless shared parallel conceptualisation of the issue regarding death and dying in Macao. The three agree that the suffering experienced by the dying, together with their families, is the predominant problem that needs to be addressed. Summarising the account of all three initiators discussed above, the next section will illustrate the conceptualisation of the problem by the three initiators: suffering in death and dying. The next section will be informed by the framing perspective theory of social movements, as propounded by Snow et al (2014).

5.3. Problem conceptualisation: suffering at the end of life

The problem of suffering in death and dying was raised by the three initiators of end of life care in Macao, both implicitly and explicitly. As examined in the last section, the meaning and manifestation of suffering understood by the three initiators varied because that understanding is contingent upon the life spaces these initiators are exposed to, and their interpretations of those experiences. Grounded in their experiences within the Chinese cultural environment of Macao, all three initiators have recognised certain cultural elements that are associated with, and to some extent impact upon, the end of life situations in Macao.

Both Sui and Tao have identified filial piety as one of the cultural factors in underlying certain dilemmas observed throughout the end of life stage of the dying, and contributes to the fear and avoidance towards death and dying. Further, the fear, superstitions and anxiety associated with death and dying in the Chinese cultural environment of Macao, is identified by initiators to have been attributed to the cultural yearning for immortality and longevity; as issue which will be further discussed in Chapter Six.

It is understood that all three initiators come from relatively different cultural, religious and professional backgrounds; factors which can account for their differing interpretations with respect to the end of life issues in Macao. In spite of the different backgrounds, all three initiators are found to have conceptualised the same grievance, that is, the suffering of people as experienced at the end of their lives. The attributions for the grievance, that is, the diagnostic frames, are found to be adhered to initiators' different backgrounds, which then led to the development of various approaches in establishing end of life care in Macao. The diversity of these attributions has led to the construction of various solutions (prognostic frames) to target the different problems identified by initiators. As a consequence, the end of life care movement in Macao, as data of this study show, is being driven in different developmental directions. Further discussion on the different diagnostic and prognostic frames established by initiators is presented in the next section (5.4).

5.4. Constructing end of life care in Macao

In this section, I present the different prognostic approaches established by initiators in developing the end of life care in Macao. For instance, Sui decided to set up the first hospice service in Macao because the problem she identified to have contributed to the grievance (suffering at the end of life) is the absence of clinical end of life care. Different from Sui, Tao believed that the suffering at the end of life observed in Macao is due to the lack of community end of life care service in addressing the issue of abandonment of the dying, Tao therefore decided to set up a community end of life care service. Influenced by her personal experience, Chu decided to focus her effort on public information-giving about end of life care and on introducing end of life care into the undergraduate nursing module in the institution she worked. This section will present these different approaches established by the three initiators.

5.4.1. Sui – Setting up the first hospice and the concept of end of life care

Presented in section 5.2.1 are the attributions underlying Sui's proposed grievance: the suffering associated with death and dying. A prominent issue (diagnostic frame) that concludes Sui's experience encountering terminally ill individuals in her professional life: Absence of clinical end of life care. Taking into consideration of this diagnostic frame and its contribution to the grievance, the solutions proposed by Sui therefore address this issue directly. The current section is divided into two parts: the first part focuses on the establishment of the inpatient end of life care unit, also referred to as the hospice, in addressing the practical concern Sui has over the care for the terminally ill. In the second part, I explore further the ideological solution Sui developed in targeting the suffering at the end of life observed in Macao.

5.4.1.1. The establishment of the first inpatient end of life care service

Based on Sui's interpretation of her moral obligation to help those who suffer from terminal illnesses, Sui firmly believed that the establishment of an inpatient unit is the key solution for addressing the absence of care for the dying. Specifically Sui suggested the hospice service would provide an alternative option, besides curative therapy, for the terminally ill individual and his or her family. Looking back on the journey of establishing the inpatient end of life care service, Sui recalled the process has been slow, with priority placed on acute emergency care by both the Macao government and the private charity hospital that she worked for.

> *"It showed a real demand for end of life care. So at that time, we reported the demand to the government, to the Health Bureau, hoping that Macao would have this service in the future, because everyone else has it already. So we have suggested many times, we have written formal letters to the government this kind of thing. But as always, as you know, acute emergency matters take priority in Macao, so the starting of the service was not that easy. Eventually, when the new building of the private hospital opened in 1999, there were spaces. The government also wanted end of life care but they didn't want to do it. It is not because they didn't want to do it themselves, but it would not be as a smooth process if the government was to do it themselves. So at that time, the private hospital had emptied out the old building. Once the private hospital started to negotiate with the government, an agreement was set up immediately, in which the government provided the monetary capital. The end of life care service was a relatively special organisation. It is jointly governed by the government, the Health Bureau, the Social Welfare Bureau and the private hospital. It is financially invested by the government but administered by the private hospital. From the government's side, they needed a government sector to monitor the project, so at that time they appointed the Social Welfare Bureau to do it. The administration of the hospice is shared by three sectors." (Sui, Initiator, Hospice)*[5]

To a certain extent, the ideological obstacles resulting from the existing cultural values related to death and dying, are presented as associated with the practical obstacles Sui faced in her early attempts to establish the hospice service in Macao. Firstly, both the government, and the hospital she worked for, prioritised acute emergency care over the need to care for the terminally ill. The rationale behind the priority given to acute emergency care most certainly reflects the epidemiological profile of Macao at the time, as circulatory diseases were and continue to be one of the major causes of death; equally communicable diseases are still prevalent in Macao (Macao Government, 2017). Secondly, as the demographic transition set in, following the advances of medicine and the overall improvement of the society in Macao, the focus on acute emergency care remains. The reason for this focus could be explained by the findings of the current study, in that the format and goal(s) underpinning acute emergency care aptly fits into the cultural value of life preservation adhered to and valued by the people in Macao. By

---

[5] Part of this quote has been used in page 101.

becoming directly involved in the development of end of life care, the Macao government could potentially be recognised as validating values that are against the deeply ingrained traditional cultural values adhered to by Macao's population. For that reason, I propose that the hesitation in adopting and supporting end of life care by the Macao government partly stems from government's unwillingness to appear to violate existing cultural values in end of life situations. Extending my argument further, I tender the idea that the influence of certain cultural values in relation to death and dying in the Chinese society of Macao stretches beyond the systemic level of Macao. It is arguable that the decision and policy makers are themselves restrained by the greater belief system that is agreed, shared and abided by the collective morals of Chinese people in Macao.

Sui's quote shows the prominent influence of filial piety and the desire for life preservation are evident not only in people's perceptions regarding end of life situations but both value sets are also present in people's behaviours towards issues related to end of life situations. With respect to the issue of the existing belief system particularly the desire for life preservation, and its influence on the end of life care movement, I will further address this matter in section 6.3.

The prominence of these cultural values certainly comes across as more profound in Tao's case. As I will explore further, in section 5.4.3, being a foreigner and a cultural outsider, Tao and his organisation have certainly struggled in terms of establishing themselves and their proposed service for end of life care in the predominantly Chinese culture of Macao. Tao and his organisation therefore sought financial support from foreign Christian groups in order to establish and run the community end of life care service in Macao, while Sui continued to seek support from the Macao government.

In spite of the cultural and subsequent systemic obstacles encountered (see section 6.2.1), Sui was able to realise her planned solution and establish the first end of life care unit, aka a hospice, in Macao. The solution has indeed solved the issue that care for the dying was absent and offered a specialist clinical environment to care for the terminally ill, and thereby lessen the burden of the patient's family. However, as reflected by the initiators, as well as the developers in this study, the establishment of the hospice has in fact produced other issues. The idea that modern hospices are places to conceal death and dying from mainstream society is not new; researchers have studied and found that the physical space of hospices has been used to sequester the dying (Hockey, 1990; Lawton, 1998; Mellor, 1993). In the case of Macao, the separation of life and humanness from death as a result of the fear of death is, as raised by Chu, already an existing issue. In fact, the establishment of the hospice has further aggravated this separation by provoking a divide between cure and care. Therefore, the introduction of end of life care has ironically reinforced some of the existing cultural biases that are against the ideologies proposed. In addition to the separation of life and humanness from death, Sui also explained that the establishment of the hospice has provoked a new dilemma between cure and care and is acknowledged as counterframing in the framing perspective (Benford & Snow, 2000). The result of counterframing is the weakening of movement, and is certainly evident in the case of the end of life care of Macao; a conclusion confirmed by the data presented in this study. A detailed discussion on counterframing, with respect to the current study, will be presented in section 7.3.3.

Inherent to the establishment of the inpatient service is the conceptualisation of end of life care. Based on Sui's account, the section below will explore the role of the hospice in the construction of the end of life care concept in Macao.

5.4.1.2. The construction of the end of life concept

In addition to the establishment of the hospice, Sui has placed equal emphasis on the building of the concept of end of life care. Initiator Chu is also found to have highlighted the importance of end of life care concept construction. Not only does the hospice help to address the gap in the provision of clinical care services for the dying, the hospice also serves to promote the concept of end of life care amongst the people in Macao. The purpose of promoting the concept of end of life care is to target the deeper cultural issues impacting end of life situations in Macao. Below is Sui's reflective account on her interpretations on these cultural values and their relationship with death and dying.

> *"In fact, for people with cancer, their mood would probably be 'worry about their personal gains and losses' (患得患失). They will be searching for a cure all the way; even though they accept they are at the terminal stage, they still have hope and expectations (期望). (…) They hope they can be cured. In this type of situation, (patients) in fact will go for cure. So, it is a matter of enabling their acceptance (…)*
>
> *From my perspective, I feel people from the society, whether or not they are patients, relatives, or other people from the society, they are not really, not able to acknowledge the fact. It turns out that, in some situations, people will only think about it when the issue of death and dying is close to them. If my family and I, if none of us has cancer, we will not think about such issue.*
>
> *For some families, once doctors mention to them about the hospice, they would 'worry about their personal gains and losses' (患得患失) - the decision whether to send the patient to the hospice or to treat him/her in the hospital curatively. In many situations, the families will feel that, if they don't treat the patient curatively, are they breaching filial piety? Especially for offspring, to decide whether to treat curatively, or not, contributes to their feeling of whether or not they are following filial piety. Actually, I believe (end of life care) is a form of education."*
>
> *(Sui, Initiator, Hospice)*

Expressed by Sui above is the adherence to hope and expectations by the terminally ill to sustain their lives for as long as possible. In pursuing the wish of life preservation, curative intervention, as observed by Sui, is the only measure within the existing health care system of Macao to allow for such a pursuit.

The denial of death is evident in people's unwillingness to recognise the proximity of death to themselves or their family members. People only acknowledge the reality of impending death when the situation arises in their family; therefore, more often than not, the pursuit of a cure in order to preserve life is the preferred approach in end of life situations. Linked to Chu's personal experiences as illustrated above in section 5.2.2, the Chinese cultural belief that death is the determinant in separating people for eternity, contributes to people's fear of death; particularly the anticipatory fear of one's own death. Reinforced in Sui's quote is the belief system, in which death denial, the fear of death and life preservation are critical values affecting people's views on end of life situations. In addition, moral obligations imposed by the virtue of filial piety are involved in order to ensure the values enshrined within the traditional belief system are being respected. As illustrated by Sui, it is certainly the filial obligation of the family to support the dying to achieve the goal of life preservation. The virtue of filial piety works implicitly as a mechanism to reinforce the cultural values existing within the greater belief system of death and dying in Macao.

As explained by Sui, the decision of choosing end of life care has certainly created a significant moral dilemma, underpinned by the desire for life preservation and the obligation of filial piety in accomplishing such a desire. The values attached to the existing belief system are therefore in direct conflict with the practice of end of life care, for in that care one must acknowledge impending death and forgo the expectation of life preservation. The conflict between the existing cultural values in Macao and the ideologies endorsed by the end of life care movement can be illustrated by the concept of frame misalignment in the framing perspective. In such a misalignment the frames, in this case the ideologies proposed by movement initiators, are not able to resonate with extant cultural values (Snow & Benford, 1988).

Both of Sui's quotes presented above reflect extensive ideological misalignment between end of life care and the existing cultural values on death and dying adhered to by the people of Macao. Her quotes serve to illustrate the emergence of counterframing and constraints in narrative fidelity (see section 4.4.1 for more explanation) (Snow & Benford, 1988). With reference to the framing perspective, both counterframing and frame misalignment are considered as limiting factors, interfering with movement mobilisation. In terms of the end of life care development in Macao and its inhibiting factors, I will present them in Chapter Six.

Nevertheless, the discussion above has presented the solutions articulated by the initiators Sui in targeting the grievance of suffering experienced by individuals in death and dying. Illustrating the framing perspective of social movement, these solutions are known as prognostic frames with which the diagnostic frame is addressed. The next section focuses on Chu and the solutions she developed in addressing the suffering at the end of life.

5.4.2. Chu – The construction of the end of life care concept

Sharing a similar vision with Sui, the solution of Chu is found to be primarily oriented towards the construction of the end of life care concept. According to Chu's interpretation, the separation of life and humanness from death is a key contributor to people's suffering at the end of their lives. Reflected in section 5.2.2, Chu's experience is largely associated with the field of nursing in terms of the manifestation of the separation of life from death. Nevertheless, the analysis of this study has revealed that the divide between life and death is evident in the public domain, underpinned by the well-established cultural fear of death, and the eternal separation from life caused by death (please refer to section 5.2.2). In deliberating over her professional background and ability, in relation to the development of end of life care, Chu decided that the construction of the end of life care concept would be more efficient and fitting if oriented in an academic direction towards the field of nursing education, as well as being shared in information given to the general public. The earliest work that Chu has undertaken, in order to introduce the idea of end of life care in the society of Macao, is to publicly write about it even before the inception of the inpatient hospice.

> *"In terms of the impetus of end of life care, I have done some early work. I have written some articles about my personal experiences. (…) I have brought the idea (end of life care concept) back to Macao and started to write some articles about it. The Nursing Association of Macao has published a book, called Angels of Bitterness and Joy (苦樂天使), and there is a special column, in there I wrote quite a few articles on end of life issues. Also I have written articles on bioethics and organ transplantation. I have organised a group of people to visit the Bradbury Hospice in Hong Kong and wrote more about the experience there too. I have also done some early promotional work publishing on the Journal Va Kio. There was a conference in Oncology Nursing (…) in which I have invited some hospice nurses as speakers. All of the work was done in the early 90's, 91, 92. (…) If Macao has this kind of service (end of life care), it will help to resolve the suffering of a lot of people, particularly in helping the bereaved family to overcome this obstacle. This is, according to my feeling, the most important matter. End of life care is something we need to do. This is my feeling. This is something we need to push forward." (Chu, Initiator, Nurse Education)*

Stemming from her personal experience in relation to end of life situations, Chu decided to introduce and promote the concept of end of life care in the society of Macao, through the channel of information-giving to the public and in the field of nursing education. Evident from Chu's quote is not only her attempt to provide information on end of life care, but also her active attempts at exposing others to the practice of end of life care. With the understanding that end of life care was a completely new concept, Chu attempted to integrate it with the existing belief system where end of life issues were raised amongst discussions on bioethics, organ transplantation and oncology. Not only did Chu recognise the problem of suffering in death and dying, and try to address it by introducing end of life care, at the same time, she also acknowledged the underlying influences of the existing culture and thereby devised a solution that would fit into, and therefore complement, the existing cultural environment. The purpose of Chu, in offering information on the concept of end of life care to both nurses and the public, is to enable them to recognise that there could be an alternative approach to end of life situations, other than the one they were accustomed to. Continuing her reflection, Chu recounted the ongoing challenges encountered in promoting the concept of end of life care, as a result of the existing cultural elements.

> *"Not accepting. Last year, I have invited Professor X (an end of life care expert) to promote this matter. Despite the professor was highly spirited, there were only a small amount of people responded. For example, we have organised seminars for the public, focusing on middle school, primary school teachers and counsellors, the nursing field, the medical field and the field of nursing and medical education. For people from different fields, we have organised different seminars and workshops, but the response was not enthusiastic. Perhaps people think there are more important things than death and dying. (…) "When will we talk about life and death? It is nothing to do with me" Or "Death is so far away from me"." (Chu, Initiator, Nurse Education)*

Above, Chu again emphasises the Chinese focus on the detachment of life and humanness from death. In spite of her enthusiasm in sharing the topic of death and dying with the society of Macao, it is evident that people are still in denial in relation to death. As observed by Chu, the people in Macao continue to distance themselves from the topic of death, denying the proximity and even possibility of such an event as death. The solution Chu adopted in addressing the problem of suffering in death and dying, is shown to be hindered by people's denial and rejection regarding death. This finding is consistent with the discussions above, in which the separation of life from death is identified as a salient belief in the Chinese culture of Macao; a belief affecting people's overall perception on topics related to end of life, death and dying. Focusing on the discussion on the conflict between the existing belief system in Macao and the concept of end of life care, Chapter Six will develop the argument further with reference to the framing perspective of social movement.

In addition, Chu's initiating effort also involved constructing an independent module on end of life care in the undergraduate nursing programme.

> *"In 2002, we established a module called end of life nursing. We felt every module tutor should have a complete concept and assimilate the whole-person concept in their individual modules, in order to see the person as a complete whole. (…) So we had the module for a couple of years but very soon afterwards, it was discontinued. The idea of end of life care was eventually integrated back into the whole programme."*
> *(Chu, Initiator, Nurse Education)*

Chu has noted similar responses with respect to the conceptualisation of end of life care in nursing education. On reflection, Chu acknowledged that the emphasis of the programme continues to be placed on technical skills. The emotional aspect of care, for the dying patient or even the family, is not recognised as an important aspect in nursing care.

> *"On the other hand, from the nursing college point of view (…) the teaching in this area offered from our course is not obvious. This is because there are many things they need to know, like giving injections, many technical skills that are perhaps more urgent. (…) And of course, one can say that not knowing how to deal with death and dying won't do any harm, since the person is already dead and the family members are fine. They will probably cry, even though I don't know how to deal with it, I can support them or put my hand on their shoulder, nothing will happen to them and they will walk out of here again. But the permanent hurt and pain (傷痛) is something we cannot assess. And the effect on them from (death) and the effect of (death) on the next generation without our following up, could result in more problems."*
> *(Chu, Initiator, Nurse Education)*

The quote above essentially reinforces one of the attributes of the problem suggested earlier by Chu, in that the strong technical focus of corpse care is a clear indication of the separation of life from death. Nursing education's focus on technicality begins from the process of care delivery, even before patients' terminal stage, until end of life stage and the individual’s eventual death. Explained by Chu, the existing perception towards the process of dying and death is oriented towards medical treatments and cures, with little acknowledgement of any other needs of the family, i.e. specific emotional needs resulting from bereavement.

Despite Chu’s introduction of end of life care in the nursing programme, it is found that the external environment, for instance the sole focus on medicalisation, continues to have an overarching influence on the orientation of the nursing education programme; thereby inhibiting the consolidation of end of life care education. The ultimate goal of Chu, in focusing on the nursing realm, is to allow nurses to be able to recognise their responsibility in caring for the terminally ill throughout their dying process. Furthermore, reinforcing the idea that life and death are inseparable during care provision, Chu intended to expand such influence from the patient level to the public level.

Despite there being a clear coherence between the problems identified and the prognostic frame articulated, ambiguities in the prognostic framing process were experienced by Chu. Having carried out the plan proposed in her prognostic frame, Chu was confronted with two conflicts. The internal conflict stemmed from the incompatibility between the solution and the ideology of Chu’s organisation. Explained by Chu, teaching end of life nursing as an individual module, independent from other subjects, was not in accordance with the concept of the whole-person, as proposed by her organisation. The second conflict was external: the additional module of end of life nursing had put the nursing programme under scrutiny by the external validators. Despite establishing the end of life nursing module was a viable solution in addressing the suffering at the end of life, taking into consideration the two conflicts, Chu and her organisation had decided, upon review, to discontinue the module.

Based on Chu’s professional background therefore, the most effective way to address the suffering at the end of life was to introduce end of life care in nursing education. By doing so, nurses are then able to address the suffering of dying patient and family subsequently influence the public’s perception of end of life care.

Even though the possibility of death is acknowledged, Chu’s quote shows that some people in Macao had detached themselves from death because of the perceived experiential remoteness of it happening to them.

The process of all core framing is fluid, contextually and temporally variable; being subjected to change during social movement activities (Snow et al, 1986). Reflecting on Chu's case above, the internal and external conflicts have evidently contested the original prognostic frame. The dynamic nature of the framing process means Chu was then able to react to those conflicts, resulting in the creation of a different plan. Despite Chu's initial plan being disputed, a new plan was able to support the prognostic frame identified. Nevertheless, in accordance with the framing perspective of social movement, the two conflicts encountered by Chu can be identified as contextual constraints with respect to the end of life care movement (Snow & Benford, 1988). Discussion on contextual constraints and facilitations impacting on the end of life care movement in Macao is presented in section 6.2.

5.4.3. Tao – The establishment of the community home visiting service

In regards to Tao's prognostic frames within the end of life care movement, there are two key analytical outcomes. The first outcome focuses on the establishment of the home visiting service for the terminally ill; the second prognostic frame involves a broader cultural, religious, political and organisation agenda. Different from the other movement's initiators, as discussed in section 5.2.3, Tao's interpretation was underpinned by his contentious view on the existing Asian culture he experienced in Macao. Despite the grievance from Tao being conceptually consistent with other initiators, his prognostic framing process had taken a different path, mainly aiming at the integration of Judeo-Christian values that he and his organisation adhere to. To begin, the section below presents the prognostic frame constructed with respect to the provision of a home visiting service to the terminally ill. Looking deeper regarding Tao's goal in assimilating the Judeo-Christian ideology in Macao, the second section analyses the impact of such belief in the process of prognostic framing.

5.4.3.1. The establishment of the first home visiting service

Consistent with other initiators, Tao has also identified suffering in death and dying as the grievance. Particularly, he attributed the grievance to the absence of care services which was reinforced by the lack of institutional focus on death and dying in the community (the diagnostic frame). In view of this, Tao decided to start a home care service that specifically targeted the dying; this home care concept became the approach proposed to solve the problem he identified. In addressing the absence of such a community end of life care service, Tao decided to redirect the existing community service in his clinic to focus on the terminally ill in Macao.

> *"As I mentioned, one of the reasons for going specifically into terminal care ministry was that it was something that particularly the government health services had not yet focused on. And so this was the recommendation of our nurses, whereas previously they were providing more general community nurse service. Compared to the population it was a very small amount of people we were able to reach but the model was established and then, when the government also adopted this model as a part of their healthcare provisions, then we, our nurses recommended we focused more on terminal illness at that time." (Tao, Initiator, Community end of life care)*

Tao and his clinic conceived the idea of terminal care in the community because they had witnessed a need for such care. At the same time, the government's health service was just starting their community nurse programme. The absence of a home care service, and focus on community care in death and dying, had encouraged Tao and his team to start their community end of life care service.

Despite the establishment of the home visiting service being the main approach articulated in the prognostic frame, analysis of the data has revealed an extended purpose in which the focus of the prognostic frame was in fact placed in a broader institutional and religious agenda. Observed by Tao, the purpose of starting the community service also served to encourage change at the institutional level.

5.4.3.2. Changing institutional attitudes towards death and dying

Grounded in his experience, combined with his contentious views on the Asian culture in Macao, Tao suggested that setting up independent services would not only help to address the suffering of people at the end of their lives in Macao, the introduction of an independent service was also aimed to shame the Macao government and provoke a reaction.

> *"So, we've adopted a more of a grassroots, ground up approach, which is to create small you know functioning units, such as community nursing and then you know, terminal care, palliative care, creating small functioning units, which then raise the priority of these compassionate care needs and bring them more to the awareness of the culture in the government.*
>
> *Basically use the culture which is culture of shame, so if we do a good job, we can then shame the government into saying "Why aren't we doing this?" The small group of individuals become vocal enough that that we have helped and shown a different way, and then they go to Hong Kong and see "Oh, it's this way in Hong Kong" "Why can't it be over here?". So basically, you have to shame the system into changing and creating- trying to create something, that would meet the, you know, standard, the need, that is here." (Tao, Initiator, Community end of life care)*

Adhering to the grievance, Tao had addressed the problem quite differently from the other two initiators. For Tao, the purpose in setting up a service was not only to offer a practical solution to solve the imminent problem of the absence of home care service, it had a more extensive gaol in trying to influence the attitude and behaviour of the government and to raise awareness with respect to the issue of death and dying.

The grassroots, ground up approach suggested by Tao has had some value in promoting certain issues. For instance, in view of the lack of community care, Tao started the general community nursing service; 10 years later the Macao government commenced their own community nurse programme. Identifying 'shaming' as a successful tactic Tao, as illustrated above, adopted the same approach for the end of life care movement. As part of grassroots health campaign, it is often the case that the campaign is targeting a wider systemic problem and it is hoped that the campaign can call for changes on the macro, or even universal, level (Hoffman, 2008). Similar to the case of the end of life care in Macao, Tao hoped to use the grassroots approach to call for changes in the care for the dying, thereby resolving the problem of sufferings in death and dying. However, the use of the grassroots approach adopted by Tao was not evident in the behaviour of the other two initiators. In fact, Tao was the only initiator who had proposed this tactic as part of his prognostic solution. Tao's interpretation of experience highlighted the phenomenon of organisational segregation; particularly, the isolation experienced by his organisation (see section 5.2.3 and 6.2.2.3). In addition to this isolation, Tao received no support from the government of Macao.

> *"So the support was very limited initially. (…) However that you know, being aware of the other priorities that the government had at that time, the government was focusing on establishing basic government community health centres and so they were more focused again, on maternal and children's care and public health, immunisations those type of things. So it was you know, not until the late 90's that those community centres were established and could begin and branch out to focus on other areas. So help was extremely limited." (Tao, Initiator, Community end of life care)*

As a result of organisational segregation and the limited government support, Tao and his organisation had to find other ways to build care services that could serve to fill the gap they identified. On the contrary Sui, in building the inpatient service, received government support, as presented in section 5.4.1.1. The difference between Sui and Tao can be considered as a contextual constraint that targets individual initiators and their organisations; a circumstance that has impacted on the overall end of life care development in Macao (see section 6.2.1). Further discussion of constraints influencing the development of end of life care in Macao is presented in section 6.2.

5.5. Conclusion

This chapter has presented and examined the journeys of the three initiators: Sui, Tao and Chu, in establishing end of life care in Macao. Also, in this chapter I have integrated the framing perspective of social movement to inform the analysis of data. The different cultural and professional backgrounds guiding each of these three initiators formed the basis of the interpretations for their experiences in relation to death and dying. Despite the different backgrounds from which their interpretations stemmed, the study's findings show that the three initiators have conceptualised that the suffering of people as experienced at the end of their lives is the one predominant issue that needs to be addressed.

When viewed through the framing perspective, this issue of suffering is conceptualised as '*the grievance'*. Based on the shared grievance identified, findings of the study then show that the attributions for the grievance - the diagnostic frames - closely mirror, and are informed by, the three initiators' respective backgrounds. The diversity of these attributions has led to the construction of various solutions, in the form of prognostic frames, and the development of various approaches, to target the diagnostic frames identified. As a consequence of these solutions the end of life care development in Macao, as data from this study show, is being driven in different developmental directions. Having explored ‘why’ and ‘how’ end of life care has emerged in the context of Macao, Chapter Six now examines the factors that have influenced the development of end of life care in Macao.

6. Chapter Six: Factors that influence the development of end of life care in the context of Macao

6.1. Introduction

In Chapter Six, I discuss the contextual and conceptual factors which, through the process of analysis, are found to have substantial effects on the initiation and the subsequent development of end of life care. In analysing the interview data of both initiators and developers, the growth of end of life care is shown to be influenced by systemic control exerted by the government of Macao. According to the analysis, the systemic control imposed by the government of Macao includes limited resource allocation for the development of end of life care, and the dominance of the government over the general development of end of life care. Within the end of life care movement, the developmental strategies established by the three end of life care initiators are also found to have contextual influences on the overall development of end of life care in Macao. I have grouped the influence from the government and the development strategies as contextual factors and will discuss their impact on the development of end of life care in section 6.2.

The conceptualisation of end of life care and the meaning embedded in end of life care are found, in this study, to have impacted on the development of end of life care in Macao. The meaning and practice of end of life care are found to be in direct contrast with the existing cultural values relating to death, and cultural expectations relating to the maintenance of life, within Chinese culture. As a result, negative connotations have emerged and impacted on the establishment and overall development of end of life care services in Macao. In section 6.3, I consider the factors that have influenced the conceptualisation of end of life care and their impact on the development of end of life care in Macao.

Adhering to the presentation style employed in Chapter Five, in Chapter Six the analytical discussions are presented with reference to the theoretical considerations of the framing perspective. As clarified in Chapter Five, the study of social movement in the framing perspective is primarily the examination of the meaning (frame) constructed for the proposed movement (Snow et al, 1986). The process of constructing meaning is otherwise known as framing; framing in social movements is generally directed towards generating frames that contrast or even challenge existing shared meanings (Benford &

Snow, 2000; Snow & Benford, 1988). Supported by Benford & Snow (2000), the process of framing in social movements is subjected to contextual and ideological constraints. These constraints not only have influence on the constructions of the proposed movements, to a certain extent they also affect the progression of the overall movement (Benford & Snow, 2000). Discussions on the contextual and conceptual factors identified in sections 6.2 and 6.3 are therefore conducted with reference to the framing perspective, particularly the contextual and conceptual constraints, in order to develop a theoretical structure to suitably illustrate the development of end of life care in Macao.

6.2. Contextual factors and their impact on the development of end of life care in Macao

This section is organised into two segments, section 6.2.1 presents the contextual factors concerning the systemic control exercised by the government of Macao, which includes limited resources allocation for the development of end of life care, and the dominance of Macao government over end of life care. In section 6.2.2, I examine the contextual factors informing the individual organisations in relation to their strategies in developing the end of life care in Macao. With respect to the theoretical discussions concerning the contextual factors that have emerged from the study data, I examine the influence contextual factors have on the overall development of end of life care, through the lens of the framing perspective of social movement suggested by Snow and colleagues (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986).

6.2.1. Systemic control – The dominance of the government of Macao over the context of end of life care

The study analysis suggests that the government of Macao has exercised its dominance over the development of end of life care by imposing limitations on the following three aspects: i) limitations on relevant resources allocation, ii) legislative limitations on controlled drugs and iii) limitations on inpatient end of life care provision. The current sections offer evidence from the research data in substantiating the analytical argument that the government of Macao has overall dominance so enabling it to influence the development of end of life care in Macao.

The following section 6.2.1.1 discusses the limited resource allocation provided by the government of Macao for the development of end of life care. A salient subtheme to emerge from analysis of the research data is the initiators' and developers' views that both the hospice and the community service consistently reported inadequate and inconsistent allocation of resources for the development of end of life care in their respective organisations. Consequently, the data support the argument that the issue of limited resources has negatively impacted the overall development of end of life care in Macao.

Analysis of the current section is mainly drawn from the interview accounts of the initiators and developers from the hospice and the community service, for they have consistently and collectively reported the impact of the limited resources on their respective organisations. The research data suggests the focus of initiators and developers, from the realm of nursing education, was mainly concerned with the conceptual aspect of end of life care, which is presented in section 6.3.

6.2.1.1. Limitations on resources allocation for end of life care

In the current section, I argue the theme that inadequate and inconsistent resources allocation for end of life care development is an intentional manoeuvre by the Macao government in order to enforce systemic control over the individual organisations involved in the work of providing Macao's citizens with end of life care.

In the analysis I found systemic control of limited resources is executed in the disparity of government funding between the hospice and the community service. This limitation has directly led to the development of diverse strategies in delivering end of life care amongst the individual organisations, during the development of their respective end of life care services. Findings of the study suggest that the incoherent strategies developed by individual organisations are one of the key factors preventing the overall advancement of the end of life care in Macao. Discussions relating to this specific topic are developed in section 6.2.2.

The hospice is the only end of life care service that is fully government funded; the funding from the government to the hospice being provided through the private hospital. Whilst the Macao government is the sole funder of the hospice, the entire operation and administration of the hospice is managed by the private hospital, through which all government funded care takes place.

> *"The government wanted to do it, but they didn't want to do it themselves...Not that they didn't want to do it themselves, but if they were to do it, the situation might not be as smooth. The private hospital had an empty er… the old inpatient building, so when we started to talk to the government, everything just fell into place. The government would invest, so the hospice has a relatively unique management structure. The hospice is co-managed by the government: Serviços de Saúde (The Health Department), Instituto de Acção Social (The Social Department), and the private hospital. It is because the government is financially investing into the hospice, but the administrative execution is from the private hospital, so the government needs to assign a unit to…take charge of this project. So that the time, they have assigned the Instituto de Acção Social."(Sui, Initiator, Hospice)*

As a result of the opportunity the government has helped to establish a cost free service, using the facilities of a private hospital. It is notable that the government of Macao acknowledged the provision of some end of life care to be important. The private hospital provides the facility, the equipment and human resources to enable the operation of the hospice care service to people able to access the private hospital, whilst the Macao government funds and oversees the operation through the Instituto de Acção Social.

> *"The intervention we provided was okay, we could stop pain, stop nausea, those types of discomfort, and breathlessness. Occasionally, for people who had very swollen legs, we bought some machines for the purpose of providing physiotherapy for them." (Tam, developer, Hospice)*

With the government funding through the private hospital, and the administration of the private hospital, the hospice has become the only facility offering cost-free inpatient care for the terminally ill in Macao. In addition to the management of physical symptoms, psychological care for patients and families is also an important part of inpatient care delivered within the hospice environment.

> *"End of life care is not just about giving out injections, but the most important aspect is to care for the psychological state of the patient, and the problems between the patient and the family, whether we can help to resolve them." (Sui, Initiator, Hospice)*

The focus of the hospice service is primarily inpatient care, addressing physical symptoms as well as offering psychological care for patients and their families; services limited to the inpatient setting within the premises of the private hospital.

In contrast to the funding stream to the hospice within the private hospital, the community end of life care service did not receive any funding or any form of support from the government of Macao. The funding for the community end of life care service was predominantly via charitable donations from outside Macao. In relation to the theme of limited resources allocation, the primary concern for the community service initiator (Tao) and developers (Ng and Lo), is the absence of government funding for their service.

> *"In terms of nursing care at the beginning, we would help patients to change their wound dressing if they have wounds. Simple things. It is because there were already a lot of resources available in the communities; the government community health centres already exist. So it turns out that, if we saw some unmet demands, we would work on meeting those demands. Demands that were not met by the Serviços de Saúde (The Health Department), we would do some. It is because our resource was limited. All our funding was donations from enthusiastic people, specifically from the USA, a church there helped us to raise the fund, yes. The beginning of the clinic was funded by a church in USA, they have raised this fund. My employment (to work for end of life care) was also paid from that fund. It was not a local resource." (Ng, Developer, Community end of life care)*

The lack of resource allocation for this independent end of life care organisation from the government of Macao reflected the status of end of life care in Macao. More specifically, the cure-focused Macao government did not consider end of life care as part of the dominant care system because of the conflicting ideologies between the two care models.

The indirect involvement of the Macao government in the development of end of life care (also discussed in section 5.4.1.1), and the limitations on resources allocation for end of life care could be attributed to the government's desire to dominate the field of end of life care. The desire to dominate, as suggested in this study, could be related to the reluctance of the cure-oriented government to be recognised as validating values (death acceptance) that are against the deep-seated Chinese cultural pursuit of longevity and life preservation. The cure-focused attitude adhered by the Macao government within the Chinese cultural context of Macao is found in this study to have also contributed to the negative conceptualisation (counterframing) of end of life care, hence limiting its subsequent development. Discussions on the negative conceptualisation (counterframing) of end of life care are presented in section 6.3.

The absent government funding to support the community service meant that developers of the service had to adapt to the financial limitation they experienced and devise approaches suitable for them to continue with their developmental work on end of life care. According to Ng, the limited resources available for the community service led to the development and adjustment of approaches that focus primarily on end of life care demands that were not addressed by the government resourced community health care services.

> *"The work is not only to care for the patients through their body; the caring is physical, psychological, social and spiritual. Our service carries this meaning, this concept – whole-person treatment, whole-person nursing care, this idea. (…) So in the year 2000, I became part of the team and began the work of end of life care, as in the end of life care service. The idea is to deliver home visits, this line of work." (Lo, Developer, Community end of life care)*

The approaches devised by the community end of life care service are unique to them with respect to the circumstances in which they are situated. For instance, in addition to nursing care for wounds, the community service is specifically focused on the delivery of spiritual care and psychological care, in the form of community home visits for the patients as well as their family. The consequence of the disparity in funding is evident from the limitation the community service experienced in developing care strategies, and the different care approaches developed between the two organisations. The unfair funding system has, I contend, underpinned the divide between the hospice and the community end of life care service. This divide, as I further argue, is a form of systemic control imposed intentionally by the government of Macao. The disparity between these end of life care organisations has hindered the coordinated development of end of life care in Macao, which I will further discuss in section 6.2.2. The intention of such systemic control can be illustrated by the framing perspective, in that the systemic control is a form of contextual constraint imposed by the government of Macao to maintain their *status quo*, thereby influencing the newly emerged end of life care movement in Macao.

In the following section, I further deliberate over the Macao government's intention to limit the development of end of life care, through legislative limitations on the prescription and dispensing of controlled drugs.

6.2.1.2. Legislative limitations on controlled drugs

Identified in the previous section, the community end of life care service has not received any support from the Macao government. In addition, analysis of the study data found that the government has reinforced legislative restrictions regarding the prescription and dispensing of controlled drugs, predominantly relating to the community end of life care service. These limitations have prevented the community service from becoming involved in providing symptom control for the terminally ill in their own home. As a consequence of this situation some aspects of treatment had to stop and the service’s focus was shifted towards a more psychological and less physical care by the community end of life service.

> *“During the year 2002, I believe Dr.Tao wanted to contact the government hospital, hoping there would be a continuity, from home (…) Hoping that there would be an integration from the hospital. In order for patients who have been discharged to have continuing service at home. So Dr. Tao tried to contact the department of haematological oncology at the government hospital: the head doctors and the director doctors, hoping to establish a holistic, a more holistic care. But then, at that time because the clinic was not permitted to administer morphine to patients, so we couldn't provide medication. It is because from the perspective of the hospital, they couldn't let the clinic to do these things. In relation to medications for pain (…) Medication control. Yes! So at the end, it was decided that, within the home environment, we are focusing on the care of physical, psychological, social and spiritual care. Mostly caring for the patients’ psychological care; also to support them in terms of resources, to help these patients and their relatives.” (Ng, Developer, Community end of life care)*

Imposed by the government of Macao on the community end of life care service is a macro level of dominance, with the power being exercised in two facets. First of all, the proposal suggested by Tao to establish collaboration between the community end of life service and the government hospital, in order to provide a continual end of life care clinical service in the community, was rejected by the government hospital. The second facet is the legislative limitations, preventing the community service from prescribing and dispensing controlled medications, which is linked to the rejection of the collaboration proposal in the first place. As a result, the community end of life care service has resorted to developing other more psychosocial approaches to care, which are within the legal and practical capacity of the organisation, so allowing the development of the community end of life care service to continue. According to the study's findings, the restrictions applied to the community end of life care service, as identified above are, I suggest, a demonstration of government dominance over the service, due to government's hesitation in supporting individual private organisations.

> *"You know the government opposition to private initiatives and so, again, even in the colonial government, there was very much an "us and them" kind of attitude in that government resources, you know, were to be used only for the government. Ideas from outside of that system were really not welcomed and actually to be to be discouraged and to be opposed and isolated. It's still the same and that again fits right into this culture, you know the separation into interest groups. And so we still have not overcome that. So there is still no significant official formal cooperation between the clinic and private organisations like ours, which would be private NGOs or humanitarian organisations in the UK sense. There is still no sense of that, the cooperation is still basically impossible, between the government and our organisation, at least officially." (Tao, Initiator, Community end of life care)*

The absence of government support to private initiatives, both financially and systemically, is prominently experienced by the community end of life care service. The restriction, as explained by Tao, stems from long-standing cultural conflicts between Macao based private initiatives and the government of Macao. Further, the attitude of isolation demonstrated by the government has enforced a divide between the hospice and these private individual organisations. These divisions, I contend, have prevented the development of a coherent plan for joint strategies amongst different organisations and inhibited the overall development of Macao's end of life care services.

The above quote from Tao raises questions regarding his claim about the government's segregation of private initiatives. As identified in Chapter Five, the government has in fact supported the establishment and operation of the hospice through the provision of funding to the private hospital. Whilst this support decision may indicate the government's favouritism for the private hospital, further analysis reveals that, in advocating the establishment of the hospice via the private hospital, the government has, at the same time, inflicted other forms of dominance over the private hospital and the hospice. Discussion of this issue is presented in the section below.

6.2.1.3. Limitations on inpatient end of life care provision

Since its establishment the hospice has remained the only inpatient, as well as end of life care, service receiving funding from the Macao government; whilst the administration of the hospice is managed by the private hospital. Nevertheless, the government of Macao has maintained its role in overseeing the operation of the hospice via the private hospital (see section 6.2.1.1). This systemic control, I suggest, serves to monopolise the inpatient end of life care service, in order to further enforce dominance over the development of end of life care in Macao.

> *"In fact, on some occasions, the government hospital and some patients will ask about us (the hospice), and we will say to them "It's okay, you can come visit us and take a look first". If after taking a look at our environment and you still feel you cannot bear it…with no alternative (無可奈何), you still ought to come here. It is because the government hospital will not accept you, isn't it? But if you do not have any financial difficulties, you can still stay in first class hospital bed, or other class at the private hospital. This is the freedom of choice. We are not saying that all terminal cancer patients must stay in the hospice. If you feel you want a comfortable environment, or if you wish to continue with curative treatments… active interventions, in fact, you can stay in the second class, first class (more superior) beds in the private hospital, that is equally acceptable." (Sui, Initiator, Hospice)*

The quote from Sui provides a clear indication that the hospice is a) the only cost-free and b) the only inpatient end of life care option available for the terminally ill in Macao. The limited care option is firstly due to the partial funding from the government in supporting the establishment of only one inpatient end of life care service in Macao. Secondly, the limitation is due to the refusal of the government hospital to accept terminally ill patients into their cost-free, curatively oriented inpatient service. The combination of the two conditions has determined the hospice to be the only, and the inevitable, care option for the dying who would require inpatient care services. There is, nevertheless, an opportunity to deviate from this situation. As explained by Sui, for people who have financial capability, the option of the cost-bound, cure-focused inpatient service at the private hospital is available to them. In contradiction to the 'freedom of choice' suggested by Sui, I argue that the 'freedom' only realistically applies to the people who can afford the cost-bound service at the private hospital. For those who do not have the financial power, the inpatient end of life care option is not an alternative; rather, it is an inevitable option at the end of their lives. Consequently, access to inpatient end of life care is not a free choice, but an unavoidable decision imposed on the dying by the system.

According to the description offered by Sui, the stages of hospital admission for a terminally ill patient prior to the introduction of inpatient end of life care services are outlined in Figure 3 below. I therefore argue that the monopolisation of inpatient end of life care is deliberately instigated by the government of Macao, for the unvarying purpose of imposing systemic dominance over the overall advancement of end of life care services.

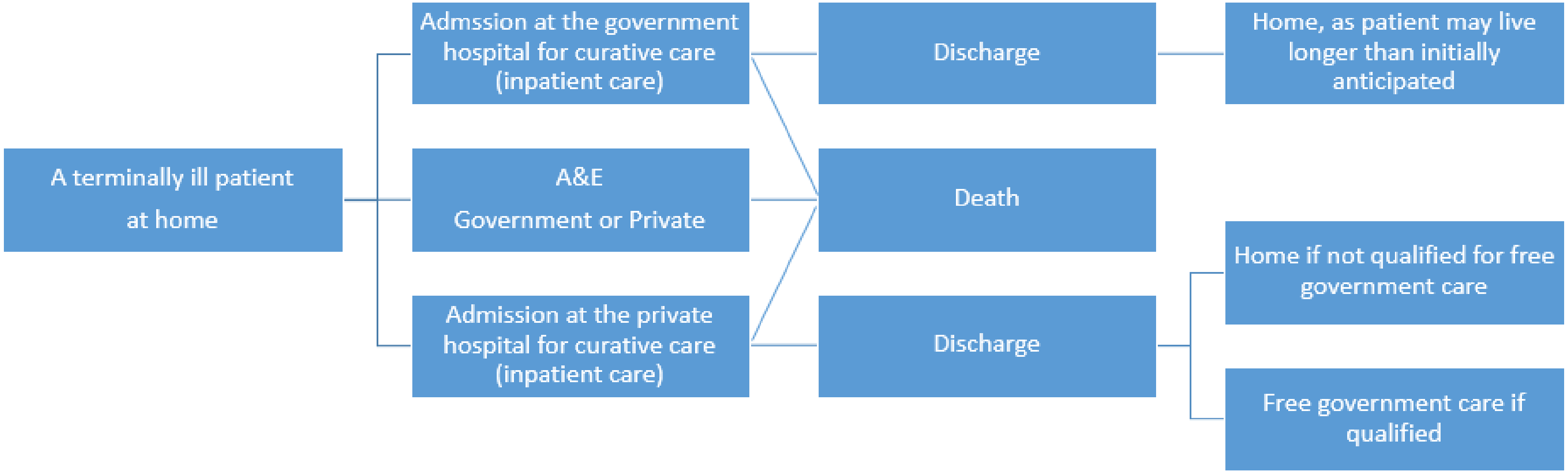
Found in this study, the monopoly of inpatient end of life care service, i.e. the hospice, is found to have significantly influenced the conceptualisation of the meaning of end of life care in Macao, which will be examined in section 6.3. Prior to that discussion, I want to explore further the findings that are related to the government's monopolising dominance of the inpatient end of life care services.

> *"… Once the patients entered terminal stage, if they needed to stay in the private hospital, they had to pay for the second class bed and they couldn't stay in the cheapest class. So, during terminal stage, a lot of patients had suffered a lot before being admitted to the hospital. This was before the hospice service. And also, a lot of the time, many patients had used all their money on curative treatment and had become poor (醫窮醫窟), so at the end of their lives in fact, they were in pain and suffering (痛苦). They had to find places for health care, they had to find a place that could deal with the patient's condition. At that time, this type of terminal patients really suffered (辛苦). At that time, according to the system of the private hospital, the cheapest third class beds were charity beds, so according to the policy, patients with no acute emergency care needs could not be allocated with those beds. In the government hospital, they would accept those patients, but often times, patients were treated in A&E and once treated, they would be sent home. Many patients were carried in and out of the hospital all the time." (Sui, Initiator, Hospice)*

Repeated in the extract above are the three findings examined previously. First of all, curative care was the only available care option for the terminally ill prior to the establishment of end of life care services. Secondly, the hospice is being monopolised as the only cost-free inpatient end of life care service available for the dying. Lastly, the hospice is not an option but an unavoidable, systemically enforced destination imposed on people who cannot afford the cost-bound service offered by the private hospital;

people who are simultaneously denied the free curative service offered by the government hospital. In addition to the aforementioned findings, highlighted in Sui's excerpt above, is the cultural desire to preserve life by pursuing a cure at all costs. The preservation of life, as observed in this study, not only stems from the individual's desire to continue living, but also the cultural expectation to keep alive and ward off death at all costs. These findings resonate with existing research in that amongst the cultural Chinese population, the desire to keep alive when one is terminally ill is frequently observed as a coping strategy that fosters hope for the dying and their relatives (Chen et al, 2014). In a study involving 146 patients with advanced cancer, nearly half of the participants continued to recognise life preservation as their chief care goal (Bai et al, 2010). With respect to the current study, in the context of Macao, the 'cure only' option, prior to the establishment of the hospice, has facilitated and very much reinforced adherence to the deep-seated cultural yearning and expectation for life preservation. The dominance of government in monopolising the inpatient end of life care service and imposing such service to those who cannot afford to pay for curative therapy are found in this study to have inadvertently led to the emergence of various misconceptions of end of life care. I will expand this discuss further in section 6.3. In the next section, I examine the different strategies developed by the end of life care organisations and its overall impact on the development of end of life care in Macao.

Figure 3 Stages of hospital admissions for a terminally ill patient in Macao



6.2.2. Incoherent strategies in the development of end of life care in Macao

In Chapter Five, I explored the different approaches established by the three initiators in developing end of life care in Macao, despite the three initiators sharing the same grievance: the suffering of people as experienced at the end of their lives. As examined in section 6.2.1 (above), I suggest the deliberate systemic segregation of the end of life care organisations by way of funding disparity and dominance imposed by the Macao government have contributed to incoherent strategies being developed in the process of establishing the end of life care in Macao. In this section, I consider how the different approaches developed by the three initiators and their organisations are used to address the problem of end of life suffering. With reference to the framing perspective, the discussion of this section focuses on illustrating the theoretical understanding of frame disputes, which are conflicts with respect to specific organisational approaches used to accomplish movement objective; frame disputes are commonly seen as a result of multiple organisations involved in one social movement (Benford, 1993).

This section is divided into four parts; the first three parts concern the approaches established by the three organisations: i) the hospice, ii) the nursing education institution and iii) the community end of life care service. Particularly, my discussion aims to compare and contrast these different approaches in addressing the suffering at the end of life. In the final section, I consider the relevance of this discussion with respect to the framing perspective in social movement.

6.2.2.1. The hospice

As discussed in Chapter Five, the absence of care for the dying has motivated initiator Sui to devote her pioneering efforts to setting up a clinical end of life care service in Macao. The provision of clinical support for the dying is primarily there to address the problem of suffering at the end of life. After the establishment of the hospice, developers observed that the lack of education about end of life care was contributing to the public's rejection of end of life care, as well as the negative conceptualisation of end of life care. In response to the rise of these new problems, developers of the hospice decided to introduce an additional solution, that of information-giving about end of life care in an effort to increase their knowledge and help them understand the end of life care services.

> *"In Macao in fact, there has been no education about life and death in all these years, it only started in the last 2 years. (…) Some friends and people I encounter, they really resist end of life care. They said to me: "What!? Why are you doing this? Why don't you resuscitate? This is inhumane!" These people think end of life care is inhumane. But in fact, I really want to tell them, if a person really is dying, by forcing tubes down the person, this really is inhumane. This really is our conceptual difference. Of course, I cannot directly argue with them because their concept has not changed, and they don't know about end of life care; you just cannot argue with them because we are not on the same page. So, in relation to the citizens in Macao, this impedes our development. It is because the background culture of our city, the education about life and death is inadequate. (Chung, Developer, Hospice)*

In addressing the lack of education about life and death, Chung not only highlighted the result of rejection of end of life care, but also raised the concern that end of life care is being labelled as inhumane. This perception, with its overtly critical connotation, is because end of life care implying the acceptance of death, is against the existing culture of Macao; the emphasis is firmly on the preservation and extension of the individual's life. Such a mindset resonates with the existing understanding that the preservation of physical life and the attainment of longevity are highly desirable and greatly valued in Chinese culture (Birnbaum, 1985). The contrasting ideology between end of life care services and the cultural desire to preserve and extend life has impacted on the conceptualisation of such services, leading to the emergence of misconceptions about the intentions of end of life care. A discussion focused on the rise of those misconceptions of end of life care is presented in section 6.3.2. Having identified that the lack education relating to the issues of life and death has contributed to the rejection of end of life care, the Macao hospice developers therefore decided that information-giving about end of life care is a feasible way to facilitate the acceptance of such a sensitive topic, thereby helping the development of end of life care, as indicated by Chung's quote below.

> *“We also hope for more people to know about our service. (…) So we have, at some point in the past, collaborated with some social organisations, for example, the Women's Federation and the Federation of Workers (…) we have organised some seminars for the citizens of Macao.” (Chung, Developer, Hospice)*

Examined in this section are the two solutions for the suffering at the end of life developed by the hospice. First, the provision of clinical end of life care service is to target the problem of suffering at the end of life; second, information-giving is to address issues of misconception about end of life care. Whilst the provision of an end of life care service was intended to address the suffering at the end of life (the grievance), the provision of public information-giving on end of life care was articulated as a response to the rise of misconceptions about the intentions of end of life care, after the hospice was established.

Findings of the study indicate the provision of information on end of life care by all three of the end of life care organisations. However, the circumstances informing the implementation of the solution vary from organisation to organisation. Equally, the information-giving was found to be incongruent amongst organisations.

In section 6.2.2.2, I consider the approaches to promote the concept of end of life proposed in the field of nursing education.

6.2.2.2. Nursing education

In Chapter Five, I considered the key motives that have underpinned Chu’s pioneering work in establishing end of life care in Macao. The practical focus on corpse care has attributed to Chu’s interpretation that nursing care, relating to death and dying, is a separation of life and humanness from death. This separation, along with Chu’s personal experience in relation to end of life suffering, have subsequently motivated her to work on constructing the concept of end of life care in the public sphere, as well as in nursing education. In the context of Macao, in particular, the philosophical understanding that life is valuable is proffered by Chu as a key notion within the concept of end of life care. In view of the construction of the concept of end of life care, Chu has engaged in the work of information-giving for the people in Macao. For instance, she has published articles on the topic of end of life care in public journals, and has also been involved in organising seminars designed to introduce the concept of end of life care to the public of Macao. The efforts focused on public information-giving have been extensively discussed in section 5.4.2 above; therefore, in this section I consider the approaches manifested in nursing education that were designed to accomplish the goal of constructing the concept of end of life care, in the hope of addressing the suffering experienced by individuals at the end of lives.

> *"The subject that I taught in relation to death and dying, was relatively too isolated. It is because it was very much just a focus on the operation, as in how to care for a corpse. For students to learn, when a patient is not here, how we help nurses to do the last cleaning, treating the body and grooming them tidy before they leave." (Zhu, Developer, Nurse Education)*

Similar to the understanding suggested by Chu (see section 5.4.2), Zhu's quote above reflects that the only nursing care related to death and dying, corpse care, was an isolated form of care that focuses only on the processing of the dead body; such a 'mechanically' prescribed process reinforces the idea that life is being separated from death. In view of the detachment of life from death in nursing care in the events of death and dying, developers have therefore decided to focus the strategy of information-giving on integrating the understanding that life is valuable into the undergraduate nursing programme.

> *"Our teaching concept is, from personhood to benevolence. (…)So I think, if we persevere with this teaching concept in promoting end of life care, we will enable people to pay more attention to enhance their characters, and thereby valuing other people's lives more, their own lives more, and further reflect the meaning of being a nurse." (Chu, Initiator, Nurse Education)*

Explained by Chu, the goal of information-giving on end of life care is to enhance student nurses' character and thereby enabling them to realise the value of life. With such information-giving, developers of nurse education aimed to address the issue of the detachment of life from death in the existing model relevant to dealing with death and dying. Such a focus will thereby fulfil the goal of constructing the concept of end of life care.

The strategy articulated by the initiator and developers of nurse education adheres to the idea of information-giving, to the public as well as in nursing studies. Despite the hospice founder and nurse educators identifying information-giving as a key strategy in targeting the master problem of suffering at the end of life, their approaches are rooted in different aspects, during different periods. Whilst initiator Chu has committed some of her problem solving efforts to the public sphere, the strategy of information-giving in nursing education is largely contained within the undergraduate nursing programme. Such a location serves the purpose of embedding the value of life in the building of the end of life care concept. The hospice management, on the other hand, has primarily focused their information-giving efforts on the public domain, during the development of their end of life care initiative. Again, Sui's and Chu's campaign were not coordinated by an overall aim. So it wasn't a two pronged approach to one problem, rather two approaches to two apparently different issues.

In section 6.2.2.3, I consider the approaches developed by the community end of life care service in addressing the issue of end of life suffering.

6.2.2.3. Community end of life care service

The provision of home visits for the terminally ill is the approach developed by the community organisation as its solution to the problem of alleviating the suffering of the dying. In section 6.2 I have examined a number of factors found to have limited the delivery of home visits to focus only on the provision of psychological care. At the outset, the community organisation is found to be adhering to a different approach from the hospice and nurse education, in solving the problem of end of life suffering. Data from the study indicate developers of the community organisation recognised the importance of 'information-giving' relating to the concept of life and death. However, based on the research data, it is evident the community organisation has continued to focus its efforts on home visits.

> *"The service will continue with the care visits, and continue with attention to the physical, psychological, social and spiritual care needs. But perhaps the service will further explore the education of the concept of life and death." (Lo, Developer, Community end of life care)*

Reinforced in this section is the perception of the incoherent strategies proposed by all three of the end of life care initiators, as they established, developed and promoted end of life care in Macao. In spite of their shared goal to alleviate the suffering of the dying, findings of the study indicate that these initiators have never liaised or cooperated in relation to the strategies they designed and implemented in order to establish end of life care in Macao.

Building on this finding, in section 6.2.2.4, I discuss how these incoherent strategies can be illustrated by the theoretical understanding of frame disputes in the framing perspective.

6.2.2.4. Incoherent strategies and their relevance to the framing perspective

In this section, I consider the segregation of the developmental strategies amongst the three end of life care organisations, and how such a model impacted on the establishment of end of life care in Macao.

Prognostic frames, as explained in the Chapter Four, are the articulation of solutions in addressing the problems (diagnostic frames) identified in social movements (Benford & Snow, 2000). As suggested in some literature on the framing perspective, the diagnostic frames identified are commonly found to correspond with the proposed prognostic frames (Asah et al, 2012; Benford, 1987; Ragnhild, 2014; Snow & Benford, 1988). In other words, the articulation of prognostic frames is dependent on how a particular problem is being interpreted. Discussed in Chapter Five, in spite of the different personal experiences in relation to death and dying, initiators of the end of life care in Macao have developed a shared interpretation of the grievance: the suffering of people as experienced at the end of their lives. As the discussion in the previous sections presented, despite the shared interpretation of the grievance, initiators and developers of the three organisations are found to have articulated different approaches in targeting the same concern. The disparity concerning the approaches proposed in solving the shared problem illustrates the notion of frame disputes with reference to the framing perspective. The conflicts identified from the data of the current study are informed by the strategies designed to resolve the identified problems, which are otherwise known as disputes of prognostic frames (Klandermans, 1984). Explained by Benford (1993), the involvement of multiple organisations in one social movement makes the movement more susceptible to solution conflicts. Even if organisations may all be driving towards a unified goal, conflicts often exist with respect to the specific organisational objectives and strategies used to accomplish the shared goals (Benford, 1993).

With respect to the current study, the involvement of three organisations with diverse backgrounds, has contributed to the articulation of different strategies in addressing the shared grievance. As considered in section 6.2, there are also infrastructural factors which, in the case of Macao's end of life care, have constrained the formation of problem solving tactics, and coerced the three organisations into developing organisational-specific prognostic frames, which are different from one another.

In social movements it is expected that the sharing of the same frame, either the problems or the solutions to the problems, may not be immediately achievable or may actually be impossible to achieve (Goffman, 1974). Nevertheless, the dispute process is also one that allows various organisations to ‘negotiate’ a more agreeable reality (Benford, 1993). Nevertheless, prognostic frame disputes amongst organisations are often found to persist throughout the development of movements, without reaching a joint solution; an outcome which reflects the case of Macao. Insofar as the collected data indicate, the ‘negotiation’ of a joint solution relating to the end of life services in Macao has never been attained. As I have discussed in the last three sections, the analysis of the data has reinforced the perception that the hospice, the community end of life care service and the field of nursing education, have remained incongruent in terms of their solutions proposed in targeting the problem of end of life suffering in people. In addition to considering the prognostic frames composed at the establishment of end of life care, I have further examined the solutions articulated in response to the rise of new problems in the process of developing end of life care. For instance, the rise of misconceptions about end of life care (detailed in section 6.3.2) make up a new problem that was identified by developers of the hospice. In targeting this problem, hospice developers have proposed public information-giving as an additional solution; as the data of the study indicated, this new prognostic frame has remained as the strategy adopted within the hospice. The community end of life care service and nurse education have continued working on their own approaches.

In the case of Macao, the findings of this study suggest that the three end of life care organisations have developed various strategies in order to address the same grievance, that is, the suffering of people as experienced at the end of their lives. As a result, these three organisations are found to have no overall clarity in the strategy of end of life care development in Macao. Further, the dispute of prognostic frames is found in this study, to be an important contextual factor impacting on the establishment and development of end of life care.

6.3. Conceptual factors and their impact on the development of end of life care in Macao

In this section, the focus of discussion is primarily on the conceptualisation of end of life care, and the impact of the conceptualised understandings on the overall development of the end of life care in Macao.

Developed into two parts, section 6.3.1 examines the factors identified in the study which are found to have impacted on the process of the conceptualisation of end of life care. Specifically, I discuss the Chinese cultural desire and expectation regarding life preservation by way of cure and life sustaining measures. Secondly, I consider the lack of understanding of end of life care noted in the study; an equally significant factor influencing the meaning construction of end of life care in Macao. During section 6.3.1, the development of misconceptions of end of life care is considered, mainly within the context of the cultural attitudes identified above. An extended discussion on the misconceptulisation of end of life care, and its impact on the development of end of life care in Macao, is further presented in section 6.3.2.

Findings relevant to the current section draw on data involving both initiators and developers, across all three areas of concern relating to the end of life care in the case of Macao. Furthermore, in this section, discussions on the findings are considered in parallel with the theoretical framework of the framing perspective of social movement. Specifically, the phenomenological issues of frame alignment are discussed in relation to the conceptual factors identified to have influenced the conceptualisation of the end of life care in Macao. I will seek to demonstrate the areas of integration, as well as deviation, between the findings and the theoretical framework of the framing perspective of social movement.

6.3.1. Factors influencing the conceptualisation of the end of life care in Macao

In this section, I examine factors that are found to have influenced the conceptualisation of end of life care in Macao. Within the context of the present study, I consider the conceptualisation of end of life care as the process wherein the meanings of end of life care are established, together with how these meanings are conceived.

In the analysis, a number of factors are identified to have influenced the establishment of the meanings of end of life care. Most prominently observed, in the current study, is the cultural attitude towards life preservation by way of curative therapy. Identified in section 6.2.1.1 is the emergence of misconceptions about end of life care, as a result of the affiliation between the cultural desire to preserve life and the existing cure oriented culture in Macao. In the first part of this section, I examine the cultural attitudes towards life preservation revealed by the respondents in this study. The orientation towards curative therapy, aligned with life preservation, will then be examined and the impact of that orientation on the conceptualisation of end of life care will be considered.

The second factor found via data analysis, is the experience of suffering. Identified in chapter Five, the experience of suffering was recognised as the main problem amongst the terminally ill; a condition from which the end of life care movement of Macao was instigated. The end of life care movement in Macao was essentially introduced in order to address the problem of suffering amongst the dying. In spite of the establishment of end of life care, findings from the study indicate the experience of suffering continues to be a problem, primarily because the suffering within the curative care context continues to be accepted, whilst end of life care is being rejected. The effect of the reinforcement of curative care is found to have influenced the establishment of the meaning of end of life care in Macao. Further discussion focusing on this issue occurs in section 6.3.2.

6.3.1.1. Life preservation and cure orientation

In this section, I substantiate my claim that cure oriented attitudes are strengthened by the existing cultural attitudes and deeply held desire of Macao residents to preserve their lives. In the analysis, the connection between these two attitudes is reported by initiators and developers across all three of the organisations to have impacted on the meanings established for the end of life care in Macao. Findings of the study show that the reinforced connection between the cultural desire and expectation for life preservation and cure orientation has affected the establishment of the meaning of end of life care in a negative way.

> *"… They feel that no resuscitation equals giving up on life. Yes, so when the patient is not for resuscitation, relatives will feel they are sending the patient to a place with no medical treatment. Relatives will find it very difficult to see past their obligations. They have not really understood the service of palliative care. So their thoughts are normal."*
> *(Wong, Developer, Hospice)*

Illustrated in Wong's quote are three areas of concerns that are addressed in the current section: a) the first factor is the cultural beliefs wherein life preservation is a desire and expectation, fulfilled by curative measures, b) the second factor is the emergence of misconception of end of life care, and c) the third factor illustrated is the lack of understanding of end of life care amongst the people in Macao, as observed by developer Wong.

Evident in Wong's quote is a clear correlation between the cultural expectations of sustaining life through resuscitation. Within the context of end of life care, a link has been established between the idea of no treatment and no resuscitation; as a result, end of life care is being conceptualised (framed) and generally perceived as a way of abandoning the dying relatives. These findings lend support to existing research on decision making regarding resuscitation, or a lack of it, in end of life situations (Wang et al, 2016; Zhang et al, 2015). Amongst Chinese patients and families, making a decision for the complete withdrawal of resuscitative measures was deemed unacceptable, due to the existing filial obligations; as a result, basic life support medications were still commonly given regardless of resuscitation status (Wen et al, 2013).

The quote from Wong (above) substantiates my argument that people's cultural expectations to preserve life have played a part, influencing the meaning formation of end of life care in Macao. End of life care is being conceptualised / perceived as a form of abandonment of the dying; an issue which is further examined in section 6.3.2. The conceptualisation of end of life care as a form of abandonment of the dying illustrates narrative fidelity, one of the issues of frame alignment, in the framing perspective. Adopted by Snow and Benford (1988) from Fisher (1984), narrative fidelity concerns the congruity between the meanings (framings) conceptualised within a social movement and the existing cultural narrations (Snow & Benford, 1988). Culture is not only about shared understandings, but also the practices that are based on those understandings (Napier et al, 2014). Cultural narrations are therefore the shared stories, myths and folk tales that over centuries have formed the basis of one's cultural heritage, which subsequently informs the experiences one encounters (Snow & Benford, 1988). The more compatibility that exists between the proffered meanings (frames) of a social movement and the existing cultural narrations, the more acceptable and popular the movement becomes, thereby demonstrating a level of narrative fidelity (Hunt et al., 1994).

In the case of end of life care in Macao, the existing cultural narratives, as discussed above, are manifested in the form of cultural expectations to preserve life, stemming from filial obligations. The connection of end of life care and no resuscitation is therefore unable to align with the existing cultural expectations of life preservation. Such dissonance illustrates that the proposed movement to provide end of life care in Macao has failed to attain narrative fidelity, thereby inhibiting the advance of end of life care services in Macao. In studies of social movement, it is well established that one of the biggest challenges for movement initiators and developers is to promote the meanings (frames) established within a social movement that are often in conflict with the dominant culture, in which the movement is embedded (d'Anjou & Van Male, 1998). In this case study, I argue that complete alignment between existing cultural narrations, and ideas proffered by the end of life care movement, could not be achieved due to the divergence between and within those cultural values and the ideas proffered by the end of life care movement.

Besides the issue with narrative fidelity discussed above, Wong's excerpt has also indicated the conceptualisation of a negative meaning of end of life care; that is, end of life care does not offer any treatment(s) but is a way to abandon the dying. The emergence of this misconception illustrates the phenomenon of counterframing. As a consequence of introducing new ideologies, counterframing is essentially the opposing framing effort created to restrict proposed movement ideologies in order to stop or prevent changes (Benford, 1987). I see the emergence of misconceptions of end of life care as the process of counterframing which, as I discuss further in section 6.3.2, is found to be a negative influence on the general development of end of life care in Macao. In addition to the emergence of misconceptions about end of life care, the lack of understandings of end of life care plays a significant part in influencing the conceptualisation of end of life care in Macao. In the analysis process, the lack of understandings of end of life care is repeatedly observed and noted by initiators and developers to be an important inhibiting influence on the conceptualisation of end of life care; an issue discussed in section 6.3.1.2.

From the perspectives of community end of life care and nursing education, initiators and developers have observed the impact of cultural expectations to preserve life on individuals' meaning construction of end of life care. Ma's extract below is another illustration of the connectedness amongst a range of issues: a) the cultural desire to preserve life through active, life sustaining measures, b) the emergence of misconceptions, and c) the lack of understanding of end of life care amongst the people in Macao.

> *"The thing that people cannot accept the most is that, they fear once they enter the hospice, they will not come out… So in the old days, when people first heard about the hospice, they resisted the service, they didn't want to go. They felt that once they went in there, they would certainly die without a doubt.*
>
> *But also perhaps patients still have a desire (渴望), hoping that in the hospital ward, doctors are there to cure; and in the hospice, they will do nothing, do nothing to cure. Patients are there to suffer (捱), suffer until their time is up. This is their belief." (Ma, Developer, Nursing educator)*

According to Ma, end of life care, particularly the inpatient end of life care, is conceptualised as a place where death is certain, and where suffering is conceived to be the direct result of a lack of active treatment. Active care embodies the qualities of sustaining people's desire to preserve life, to save lives through the unremitting commitment to be 'doing something' for the terminally ill. This misconception of end of life care entails the opposite meaning of end of life care originally proposed by initiators and developers, thereby demonstrating the phenomenon of counterframing. However, I argue that neither the counterframing observed here, nor in Wong's excerpt cited earlier, is intentional; rather, the counterframing is an unintentional by-product of the combination effect of systemic control and the existing cultural attitudes towards death and dying in Macao. This is one of the key findings of this study and will be extensively discussed in Chapter Seven: Discussion.

I contemplate that the conceptualisation of end of life care misunderstandings is strongly associated with the incongruence between the proposed frames from end of life care and the existing Chinese cultural values in the context of Macao. The strong phenomenological alignment between Chinese cultural attitude of life preservation and the life sustaining quality of curative care is informed by Ng's extract below.

> *“Yes, there is nothing much you can do to help them at home. It is also difficult for them to go to A&E all the time. Firstly, it is not that easy practically because the patients are already suffering a lot. Even after they have been to A&E and have their sufferings relieved, they need to leave immediately. For the relatives and also the patients, it's a torture for the patients, and it’s a torture for the relatives. When we explain to patients, they should just go to the hospice, the hospice can palliate their pain, and the hospice is only temporary, after they have achieved palliation, they can go home. It is just incomprehensible that the concept they have is that: once they enter the hospice; it is a dead end and they will not be able to come out again. They have such a concept. A portion of patients will frequent A&E, a portion of patients, when in their worst phase, will go to A&E.” (Ng, Developer, Community end of life care)*

Reflected on the limitations imposed by the Macao government on the availability of end of life care in Macao (see section 6.2.1), I proposed these limitations have led to the emergence of misconceptions about end of life care. As presented in Ng’s extract above, being the only end of life care option, the hospice is often refused by the dying as they insisted on life sustaining measures offered by A&E. At the same time, the hospice is being conceptualised as a place where death is certain, illustrating the notion of counterframing. Here, a close link between the emergence of a misconceptions about end of life care, as well as a lack of understanding of end of life care, is apparent. The misconception of end of life care as a ‘dead end’ and the lack of understanding of the potential benefits of end of life care, as suggested in this study, create a mutually reinforcing situation in which negative perceptions of end of life care are reinforced by the lack of understanding of end of life care and vice versa.

I have examined the impact of the Chinese cultural attitudes of life preservation which encourage individuals to pursue curative measures, on the conceptualisation of end of life care in Macao. I have explored how this affiliation has facilitated the development of some similar misconceptions of end of life care. I have touched on the issue of a general lack of understanding of the end of life care and its connection with the misconceptions about end of life care. During this section, I have also illustrated issues which arose from the findings within the realm of the framing perspective; issues including the emergence of counterframing and the issue of narrative fidelity.

In section 6.3.1.2, the impact on the conceptualisation of end of life care as a result of the lack of understandings of end of life care amongst the people in Macao, will be explored and discussed from the perspective of the initiators and developers associated with the three end of life care organisations.

6.3.1.2. The lack of understanding of end of life care

Findings from the study show the understanding of end of life care found to be lacking amongst the people in Macao, is primarily related to, and informed by, the understanding of the moral obligations of end of life care. With the absence of knowledge regarding the moral liabilities specific to end of life care, the practice of end of life care is found to be measured against the moral obligations belonging to curative care. Such a choice thereby elicits conceptual conflicts between curative and end of life care, subsequently affecting the conceptualisation of end of life care.

> *"…for financial resources, the hospice needed to be supported by others. If we require patients to pay for a palliative care service, if they need to pay to be admitted to the service, I can honestly tell you, if I was a relative or a patient, if I have to pay to be in a normal curative ward, and I also have to pay to be in the hospice, if I have not understood the palliative care service, I will choose the normal curative ward." (Wong, Developer, Hospice)*

Demonstrated in Wong's quote is the adherence to curative measures if the patient's financial condition was not a consideration. Without adequate understanding of the palliative care offered by the hospice, the people in Macao would be inclined to adhere to a desire to receive curative therapy. The inclination for curative care is not only because of the adherence to cultural attitudes towards life preservation, but also the attachment to the moral obligation of curative care, which is to cure. As Wong further explains:

> *"It is difficult to say that the doctors are…it is very difficult to accuse them of lacking in knowledge about end of life care. In fact, they are only human. It is because being a health care professional, your goal is to want to cure the patient for them to recover and leave the hospital. However, in the hospice, the patient you face, they won't be cured and won't leave." (Wong, Developer, Hospice)*

What Wong was reflecting, is simply the deontological root of medicine and health care, in that all health care professionals are ethically obliged to prevent, relieve or cure a person's suffering (Harris, 1929). The moral principle of end of life care is essentially being measured against the moral obligation of curative care, which correlates highly with the cultural desire and expectation of the patients in this research to preserve life in Macao. The second element of moral obligation identified with curative care is that of being humane.

> *“In addition, the existing concept has always been that the outside wards (wards in the private hospital) are active wards, they feel they have to use all medical interventions to help the case and to try their best until the last second. If they try their best until the last second, this then can be qualified as humane. I even have doctors who came and told me that our service is not humane. They are not normal citizens but doctors. From the mouth of doctors and call our service inhumane. 'What!? Your service in fact is really inhumane', 'You are just going to let these people be like that? You are not going to give them nutrient IV? You are not going save them?' Those doctors feel (the hospice) is inhumane.” (Chung, Developer, Hospice)*

Here, Chung identifies that the moral obligation of curative care is not only to cure, but also by way of exhausting all medical interventions to cure, humanity is maintained. These two moral liabilities identified as central to a patient being cured are certainly in agreement with Chinese cultural attitudes towards life preservation. Chung then reflected on the moral comparison between curative and end of life care, where end of life care was being labelled as inhumane by medical doctors. The issue informing this negative conceptualisation of end of life care is the absence of moral obligations specific to end of life care. As a consequence, the moral obligation of end of life care was being interpreted to be in opposition to that of curative care; namely, hospice based end of life care is inhumane.

In this section, I have examined the issue of the lack of understanding of end of life care, in the context of Macao. I have identified the lack of understanding of end of life care is informed by the absence of knowledge of the moral endeavour of end of life care. Under such circumstances, end of life care is consistently being measured against the existing moral obligations of curative care, leading to the emergence of misconceptions about end of life care, as presented in the current section.

Continuing the discussion on misconception of end of life care, in section 6.3.2, I explore the various misconceptions about end of life care noted in this study, and their impact on the development of the end of life care movement in Macao.

6.3.2. The emergence of misconceptions about end of life care

In this section, I focus my exploration on the misconceptions about end of life care. I have already discussed the conceptual factors that are found to have affected the conceptualisation of end of life care. I have also identified that the moral obligations of end of life care were interpreted based on curative care, due to the absence of knowledge in the end of life care area. Besides the concept of moral obligations, findings of the study show that the meaning of end of life care is largely built upon the existing definition of curative care; however, by then adopting the opposite values of to those of curative care. The emergence of misconceptions about end of life care illustrates counterframing of the framing perspective and I further integrate the discussion of counterframing and its impact on the development of end of life care in this section.

To begin, I explore the misconceptions of end of life care in relation to the opposite understanding of curative care, in the Macao context.

6.3.2.1. End of life care as the opposite as curative care

I have previously examined the absence of moral obligations specific to end of life care; a deficit which has led to end of life care being conceived as inhumane. The formation of this misconception is, as seen through the prism of moral liability, essentially embracing the opposite values to those of curative care. Findings of the current study show that most end of life care misconceptions stemming from the opposite values of curative care, are related to the context of inpatient end of life care.

> *"Also, they didn't want to feel as if they have now come to the end and have to go to (the hospice) at the last moment of their lives. So, for them, they would perhaps choose to go to the hospital ward. Some people have asked to be transferred back to the hospital ward after coming into the hospice." (Ma, Developer, Nurse Educator)*

As Ma's extract suggests, end of life care is conceptualised as a place where death is certain, whereas curative care is the more hopeful alternative; therefore, some people may choose to go back to curative care. The concept that the inpatient end of life care is a place of death is observed by initiators and developers from all three organisations.

> *"It only just happened that in the past 2 days, there were 2 patients and they obviously rejected the hospice. They would rather go back and forth to the acute and emergency department, than to go into the hospice. If that's what they would prefer, we can only respect that. We have already explained and if they are unwilling to accept, we can only respect their wishes. We will continue to work on explaining to them, but if at the end they are still unwilling, we can only respect. We hope…we really don't want to see that, we don't want to see that they have a bad, a bad end of life stage (…) they reject (the hospice). As I said before. They see that by going into the hospice, it symbolises failure. Complete utter failure and by that it means accepting death."*
> *(Lo, Developer, Community end of life care)*

The extract from Lo above reinforces my argument that end of life care is being perceived in accordance with the opposite value of active curative care. The rejection of end of life care primarily stems from the idea that the acceptance of end of life care symbolises the acceptance of death. Complementing the misconception discussed above, end of life care is conceived as a place of death. Further, the inability to fulfil the cultural desire and expectation to sustain one's life would seem a cultural and moral failure; an added characteristic of end of life care that appears contrary to curative care. The misconceptions of end of life care identified thus far, not only oppose the values of curative care, but also they are associated in the minds of the terminally ill with the absence of the intention and action to cure. The absence of cure and the absence of the intent to cure mean that end of life care does not align with the Chinese cultural desire and expectation of life preservation. I suggest that this misalignment contributes to the emergence of misinterpreting end of life care; thereby inhibiting the public acceptance of the concept, as well as the practice of end of life care, during its developmental process. With respect to the framing perspective, the development of the misconceptions identified above, illustrates counterframing where the purpose was to reject the proposed end of life care by introducing opposing ideas. As reflected in Lo's quote, and the accounts of other developers and initiators, the opposing counterframing effort had evidently led to the rejection of end of life care amongst the people in Macao. Further, the misalignment between end of life care and existing cultural attitudes informing life preservation also means that end of life care fails to achieve narrative fidelity towards the external cultural beliefs. The attainment of narrative fidelity of end of life care is crucial in order for any proposed movement to achieve public resonance and acceptance (Snow et al, 1986).

Findings of this study show that the proposed end of life care in Macao was predisposed to both intrinsic and extrinsic contradiction from the moment it was first introduced. Intrinsically, the end of life care principle of 'not striving for a cure at any cost' is evidently incompatible with a culture that insists on life preservation; a conflict which has led to the development of misinterpretations. The resulting misinterpretations of end of life care, and their strong association with the certainty of death, have further reinforced the misalignment between end of life care and the existing cultural context, which has further inhibited the growth and acceptance of end of life care services in Macao. However, in the process of analysis, the intrinsic contradiction between end of life care and the existing cultural attitudes regarding life preservation through curative measures had already been recognised by the initiators at the early stage when end of life care was first introduced. The fact that end of life care is not able to offer life sustaining measures makes it intrinsically difficult to align with Macao's existing cultural values. As display in Sui's quote below, the introduction of end of life care was hindered by this internal contradiction between end of life care and the extant cultural values of sustaining life, which then contributed to systemic inhibition imposed directly on the development of end of life care in Macao, as was discussed in section 6.2.

> *"We felt there was a real demand for end of life care. So, at that time, we had communicated the demand to the government and the Serviços de Saúde (The Health Department). We hoped Macao could have this service in the future because other places already had this service. So we had suggested many times, we wrote letters, this kind of thing. But as you know, acute matters needed to be attended first, so it wasn't easy to start end of life care." (Sui, Initiator, Hospice)*

The priority has always been placed on life sustaining measures, a situation initiators were well aware of; they certainly understood this as a challenge in introducing end of life care. In spite of such a challenge, initiators persisted with their beliefs and pioneered end of life care in their individual areas (despite they did not work together). However, as the study's findings suggest, the problem of the misalignment between end of life care and the existing culture regarding life preservation, has persisted. The findings of the study also show that initiators and developers of the different organisations did not work together to change the public perception or enhance public understanding of end of life care in Macao. This misalignment subsequently became a major inhibitor of the development of end of life care, as I have presented in section 6.3.1 and the current section 6.3.2.

I have examined issues that are primarily related to the conceptualisation of end of life care and their impact on the overall development of end of life care in Macao. In the analysis, the understanding of suffering within the context of curative care is found to be another conceptual influencer, exerting an opposing effect on the end of life care movement. Detailed discussion focusing on this conceptual barrier is presented in section 6.3.3 below.

6.3.3. The understanding of suffering in curative care

In Chapter Five, I discussed the point that the suffering of people as experienced at the end of their lives particularly within the cure oriented environment, was identified by initiators as the grievance which had prompted them to establish the provision of end of life care services by their respective organisations.

In the process of analysis, I found that the understanding of suffering between the people in Macao and the initiators and developers of end of life care in Macao, was different. This difference has in fact become more apparent after the introduction of end of life care. In this section, I examine how this difference in the understanding of suffering has become a conceptual issue in the development of end of life care; particularly its contribution to the emergence of the misinterpretations and misunderstandings of end of life care and its services. With respect to the theoretical understanding of the framing perspective, the understanding of suffering in the context of curative care illustrates the counterframing effort, opposing the advancement and growth of end of life care services. Findings indicate that the people of Macao hold a more accepting attitude towards the suffering generated under the curative environment, especially when compared to the context of end of life care.

> *"Actually I think, there are many people still holding onto the concept that once they enter the hospice, it will be the end. So if they can endure the suffering (捱) for one more day, they will not go into the hospice. This attitude is because they don't have enough understanding of the concept of our service. So, in fact, they don't know that once they enter our service, we will make them more comfortable, and you don't have to suffer. It is better not to suffer, why do they want to suffer? Our service is here because we don't want you to suffer and we want you to feel comfortable. So in fact, this is a concept that's not accepted by many people." (Sui, Initiator, Hospice)*

Reinforced by Sui's quote are the previous presented arguments that end of life care is being interpreted as literally 'the dead end', and along with this interpretation is the rejection of end of life care. Crucially, Sui's quote highlighted not only the lack of understanding of end of life care, but also that the people in Macao are willing to stick with curative measures and endure the suffering that comes with that decision. This willingness to endure suffering in curative care is further reinforced by Sui below.

> *"We already knew it was terminal cancer. But if you ask the question: whether or not to cure? Normally for patients, they want to be treated, they have expectations. They hope they can suffer (捱) as many years as they can." (Sui, Initiator, Hospice)*

As I have previously suggested, the misconception of end of life care is grounded in potential clients' perception of 'no cure'. The absence of curatively intended interventions, hence the absence of moral obligations in sustaining life, contributes to the rejection of end of life care, thereby justifying the suffering in curative care. The type of suffering denoted by Sui above mainly implies physical suffering. The endurance of suffering, particularly physical pain, amongst Chinese patients has long been a research interest. Studies have found that Chinese patients were more inclined to endure pain and sufferings, because of their belief that the ability to tolerate discomfort enables them to strengthen their moral character in times of difficulties (Ho et al, 2013). Further, the ability to endure suffering and pain is viewed as a virtue from Buddhist and Confucian perspectives.

Physical pain and suffering are closely associated with the idea of trial and sacrifice; therefore, more often than not, patients choose to endure their suffering because they see the experience as a necessary process in enriching the spiritual dimension of their lives (Chen et al, 2008; Tung & Li, 2015). The idea that moral character can be strengthened through the endurance of suffering is also supported by Lo's observation that many people see accepting end of life care as a failure; therefore they refuse to accept end of life care, as discussed in section 6.3.2.1.

> *"They reject the hospice and what it has to offer. As I said before, they see that by going into the hospice, it symbolises failure. Complete utter failure and by that it means accepting death." (Lo, Developer, Community end of life care)*

The discussion presented above further supports the proposed connection between Chinese Macao's existing cultural values and curative care; a connection which subsequently leads to the misconception of end of life care, as well as reinforcing the rejection of end of life care. With respect to the framing perspective of social movement, similar to narrative fidelity as discussed earlier, experiential commensurability (Snow & Benford, 1988) denotes the compatibility between the meanings proposed by movements and the everyday lives and experiences of the public. In other words, the problems identified by the movements need to be in parallel with the situations experienced by the intended audiences. Levels of attitudinal compatibility reflect the degree of public acceptance of the proposed ideas from the movement.

As examined in Chapter Five, the problem of suffering at the end of life was identified by initiators as one of the main grievance that had motivated the establishment of end of life care services. However, findings of the study show the understanding of suffering of end of life care between the initiators and developers of end of life care, when compared to the understanding exhibited by the people of Macao, is completely the opposite. Such a divided understanding of the proposed grievance (suffering at the end of life), between the initiators and developers of end of life care and the public of Macao, clearly indicates that the proposed grievance has failed to harmonise with the experiences of the people in Macao. As a result of this lack of cohesion, the advancement of end of life care was hindered by the emergence of misconceptions detracting from potential clients positively valuing end of life care services, as presented in this section.

In this section, I have discussed the conceptual misalignment between the understanding of suffering between the people and the initiators and developers of end of life care in

Macao; an example illustrating the concept of experiential commensurability of the framing perspective. As a result of this conceptual misalignment, misinterpretation of end of life care developed and has been further reinforced, which has led not only to the rejection but also the inhibition of the development of end of life care, as suggested by the findings of the current study.

6.4. Conclusion

This chapter has examined the contextual and conceptual factors that this research found to have impacted the overall development of the end of life care in Macao. The dominance of the Macao government was able to impose a great deal of systemic control over private health care organisations; specifically i) the community end of life care service and ii) the hospice via the private hospital. This control was achieved by means of financial and legislative restrictions relating to aspects of end of life care. As a result, the dominance of the Macao government is found to have elicited and facilitated the misconceptions of end of life care, which then inhibited the overall development of end of life care in Macao; an outcome evident in this study.

In terms of conceptual issues, factors that this research found to have impacted on the development of end of life care in Macao include: i) the close connection between the existing Chinese cultural attitudes towards life preservation and curative care, ii) the conceptual comparison between curative care and end of life care, iii) the absence of defined moral obligations applicable to end of life care, and iv) the understanding of suffering within the context of curative care. I argue that all these factors have contributed to the rising levels of misinterpretation and misunderstanding of end of life care, which then negatively affected the overall development of end of life care and its services in Macao.

7. Chapter Seven: Discussion

7.1. Introduction

The aim of this thesis was to understand how end of life care was introduced, established and developed in the context of Macao. Adopting the qualitative case study approach proposed by Stake (1995), the case for this thesis was determined to be the end of life care in Macao. The use of Stake's qualitative case study approach provided me with a flexible, yet bounded infrastructure to perform a focused and intensive examination of the end of life care in that specific socio-cultural location. In the initial stage of this research the infrastructure of the case study model has granted this project the flexibility to extensively explore the subject of end of life care taking place within one specific location: that of Macao. The case study method provided me with the means to gather considerable amounts of data from the three initiators who pioneered Macao's end of life care. The three initiators had individually contributed to the establishment of end of life care in three different aspects: i) an inpatient end of life care service, ii) a community end of life care visiting service, and iii) introducing end of life care to undergraduate nursing education and public information-giving on end of life care. I was also able to include eight individuals from these three settings who were involved in the subsequent development of end of life care. The contextually rich data I collected allowed me to build the thematic analysis, in order to address the research questions raised in this study.

1. Why and how did end of life care emerge in Macao?
2. What factors have influenced the subsequent development of end of life care in the context of Macao?

I have made the decision to utilise the framing perspective propounded by (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986) to interpret the study findings, in respect of how end of life has been initiated and developed in the context of Macao. The development of end of life care in Macao reflected certain processes of social movement formation suggested in the framing perspective, which is a useful template to help understand and theorise the establishment and development of end of life care in Macao. In the preceding findings chapters (Chapters Five and Six), I have analysed the emergence of end of life care predominantly from the accounts of the three initiators. I discovered that despite these three individuals having different personal and professional experiences related to end of life situations, they had identified the same problem (the grievance). Specifically that problem was the suffering of people as experienced at the end of their lives, and what could be done about it, which was the target of their end of care movement efforts. Developed from the findings in Chapter Five, Chapter Six presented the two key findings of the present study: i) the incoherent strategies developed by initiators in establishing end of life care (the lack of internal frame cohesion), and ii) the variety of contextual and conceptual constraints that influenced the subsequent development of end of life care (the lack of external frame cohesion). In this chapter, I centre my discussion on the framing perspective, interpreting and theorising these two core findings. My aim is to demonstrate how this theoretical understandings of the findings can answer the research questions posed and address the aim of the study.

The discussion of the two key findings, the lack of internal and external cohesion are located in section 7.2 and 7.3 respectively.

7.2. The lack of internal frame cohesion within the end of life care in Macao

Upon analysis, the problem, that of ‘ the suffering of people as experienced at the end of their lives’, was shown to have underpinned the inception of end of life care in Macao; a state conceptualised as ‘grievance’ in the framing perspective (Snow et al, 1986). Grievance is essentially the discontent people have interpreted from their experiences or events, specifically in the context of social movement (Snow et al, 1986). Whilst ‘grievance’ indicates the problem social movement initiators have identified and wish to address, ‘frames’ are interpretations articulated by initiators attempting "to locate, perceive, identify, and label" the various experiences they encountered (Goffman, 1974). Frames not only function to organise and give meanings to experiences, but they also serve to guide individual or collective actions in social movements (Snow et al, 1986).

In the case of end of life care in Macao, findings suggested that whilst the articulation of frames, by end of life care initiators, was based on the shared grievance, the meanings rendered to those frames were diverse. This diversity was particularly visible amongst the diagnostic and prognostic frames, thereby contributing to the incoherence of internal frames. (Please see Chapter Four for a detailed discussion of the categories and meanings of frames proffered in the framing perspective).

Table 6 below presents the various diagnostic and prognostic frames conceptualised by the three end of life initiators in Macao.

Table 6 Diagnostic and prognostic frames conceptualised by initiators

	Diagnostic Frames	Prognostic Frames	Prognostic Approaches
Sui (Hospice Initiator)	Absence of clinical EoLC	To alleviate suffering at the end of life	Establishing the first hospice
Tao (Community EoLC Initiator)	Abandonment of the dying Absence of community EoLC to address abandonment of the dying	To alleviate suffering at the end of life To promote acceptance of death	Establishing the first EoLC home visit service
Chu (Nursing Education Initiator)	Personal encounter of EoL experience Separation of life from death in nursing education	To promote acceptance of death	Constructing the EoLC concept in the nursing field and public sphere

As shown in Table 6, the diagnostic frames conceptualised by the three initiators reflect their individual interpretations of the grievance. The prognostic frames conceptualised, though appearing to be both overlapping and synchronised, yielded significantly different approaches. Since the purpose of the approaches were identified with the prognostic frames addressing the diagnostic frames, I therefore, categorised them as prognostic approaches. In section 6.2.2.4, I already presented details of the incoherent strategies developed by the three initiators. In the current section, my goal is to interpret the frame incoherence observed within end of life care, with reference to the framing perspective. In particular, I intend to understand the issue of ‘frame disputes’ and how it impacts on addressing the research question.

7.2.1. Intra-movement frame disputes

Emphasised by Snow & Benford (1988), the process of framing involves an ongoing negotiation between the values proffered by social movements and the values existing in the context where these movements are situated. The process of constant negotiation is necessary in order for social movements to garner support from potential participants, thereby enhancing consensus mobilisation. The framing perspective is essentially a theoretical construct entailing the frame alignment processes suggested by Snow et al (1986) when explaining social movements.

Contrary to the concept of the framing perspective, the present study found the articulation of frames for end of life care in Macao did not follow the dynamic framing processes. The data suggested that movement frames were articulated exclusively according to the individual interpretations of the personal and professional experiences of the three end of life care initiators. It was suggested that this particular frame formation circumstance contributed to the two key findings of this study: i) the lack of internal frame cohesion and also ii) the lack of external frame cohesion in the end of life care movement in Macao.

The separate articulation of frames by movement initiators in Macao resulted in the cultivation of frames that carried different meanings and served different purposes. As presented in Table 6, the diagnostic and prognostic frames proposed by the initiators were diverse, and therefore led to the development of incoherent strategies. The diversity of these movement frames reflected intra-movement frame disputes regarding the framing perspective; a diversity that was the main cause of the lack of internal frame cohesion.

An intra-movement frame dispute is, as emphasised by Benford (1993), a universal and common feature of social movements. However, there is a study arguing that the theoretical perspective of frame disputes, perceived from the framing perspective, is not comprehensive enough to explore the intra-movement frame disputes; the reason for such a deficit being mainly because the focus of a framing perspective is largely on the facilitation of frame alignment (Payerhin & Ernesto Zirakzadeh, 2006). In their study the authors raised questions about how participants of a social movement come to agree on goals and strategies. Focusing on the First National Congress of Poland's 'Solidarity movement' in 1981, the authors observed one of the unforeseeable outcomes was the conflicts amongst the Congress attendees, in relation to the aim of the Congress. Underpinned by the different understandings of democracy and democratic accountability, Congress attendees held different views in terms of the long-term goals of the Solidarity movement, and how these goals should be achieved. Based on their observations, the authors noted that as well as frame alignment, the framing perspective should also address one particular issue. The specific concern was that of *'intra-movement conflict'* as the fragmentation of goals and/or strategies amongst different individuals/ groups, within one movement, would eventually limit movement mobilisation (Payerhin & Ernesto Zirakzadeh, 2006).

In the case of end of life care in Macao, whilst initiators shared a unified vision of the grievance: *'the suffering of people as experienced at the end of their lives'*, their framing efforts in terms of the problems (diagnostic frames) contributed to this grievance differed. As a result of this issue the solutions for these prognostic frame problems remained segregated from one another (see Table 6 above for more details). The diverse approaches (prognostic approaches) developed as a result can be theorised as intra-movement frame disputes according to the framing perspective.

Despite possible structural differences, social movements should have "cohesion and continuity over time" (Johnston, 2014, p.24) . In the case of end of life care in Macao, the framing perspective has illuminated a fundamental issue: the lack of collectiveness informed by the absence of joint action amongst the initiators and developers in the development of end of life care. This lack of collectiveness - the lack of internal frame cohesion - implies that the end of life care in Macao is not a full social movement, as that concept was defined above. Further, the framing perspective has served to illuminate the issue of the lack of internal frame cohesion in the development of end of life care in Macao. As suggested in this thesis, the lack of internal frame cohesion is considered to be one of the main contributors to the lack of advances in, or development of, end of life care in Macao.

The framing perspective has: i) enabled the theorisation of intra-movement frame disputes, which had contributed to the understanding of the limited development of the end of life care in Macao, and ii) explained why the end of life care in Macao failed to meet the criteria of being cohesive and collective in a social movement. Both of these significant points indicate that end of life care in Macao is not a full social movement and further reinforced its limited degree of development.

However, reflecting upon the critique by Payerhin & Ernesto Zirakzadeh (2006) cited above, the framing perspective was unable to fully facilitate the investigation of the emergence of frame disputes in the case of end of life care in Macao. In particular problems remain regarding: a) how initiators came to devise incoherent strategies and b) how the diversity has continued without any observable collaboration between initiators and developers. Nevertheless, the focus on frame alignment within the framing perspective has aided this research in explaining and theorising the lack of external frame cohesion, as discussed in the section below.

7.3. The lack of external cohesion between the end of life care movement and the context of Macao

The second key finding of this study is the lack of external frame cohesion impeding the development of end of life care. Conceptual constraint is the main contributor to the lack of external frame cohesion. The conceptual constraint identified in this study primarily concerns the limitations stemming from the phenomenological interaction between the establishment of end of life care and the cultural context of Macao, and the limitations resulting from that interaction. The frames proposed by end of life care initiators were found to be in conflict with the extant cultural belief of life preservation. To a great extent, the conflicting nature between end of life care and the extant cultural element of life preservation has challenged the introduction of end of life care from the start, mainly because the ideologies framed by initiators of end of life care were in complete contrast with the cultural beliefs held by Macao residents.

The current section of this chapter consists of three parts: the first discussion demonstrates the theoretical corroboration of the framing perspective on the misalignment of frames (lack of external cohesion) between the end of life care initiators and the context of Macao. Nonetheless, this study found that the demonstration of interpretations only offered a partial understanding of the formation of frame misalignment. In section 7.3.2, I elaborate further on the multidimensional and cyclical processes involved in the formation of frames concerning the end of life care movement. With reference to the framing perspective, I aim to highlight the limitation this theoretical structure imposes on the interpretations of the research findings. Section 7.3.3 explores the emergence of counterframing as part of the interpretation offered by the framing perspective.

7.3.1. Frame misalignment – the lack of external cohesion

In the data analysis I found there had been a pervading cultural norm in Macao to maintain life at all cost, and that this particular belief was in contradiction to the ethos of end of life care proposed by the three initiators. Interpreting through the framing perspective, this contradiction of values demonstrates the difference between the prognostic frames proffered to address the suffering at the end of life in Macao, and the cultural insistence in Macao of sustaining a person's life, regardless of quality; this contradiction is known as 'frame misalignment'. The current section therefore, focuses on discussing the emergence of frame misalignment in the development of end of life care in Macao.

Suggested by initiators and developers, the pursuit of life preservation is the customary option when it comes to end of life situations within the Chinese cultural context of Macao. The Chinese cultural desire and expectation to preserve life, has been shown to impact attitudes towards end of life care and that impact has been widely studied (Bai et al, 2010; Bowman & Singer, 2001; Kwok et al, 2007; Lam et al, 2015; Wang et al, 2016; Weng et al, 2011; Zhang et al, 2015). Much debate has been focused on the persistence of life sustaining treatments in end of life situations (Kwok et al, 2007; Wang et al, 2016; Wen et al, 2013; Zhang et al, 2015). In a study based in Shanghai, China, researchers collected sociodemographic information, clinical information, and information related to unexpected medical problems preceding the deaths of 314 patients, as well as information relating to the patients' main caregivers (Zhang et al, 2015). The research aimed to explore ethical and cultural considerations for cardiopulmonary resuscitation (CPR) in Chinese patients with cancer at the end of life. The study found none of the recruited patients had used advance directives for the stipulation of their medical care. Furthermore, almost half (49.36%) of the patients had received CPR before they died. That number includes patients who received CPR due to unexpected medical problems as well as those who did not have such problems (Zhang et al, 2015). On discussing their findings the research team drew connections between the pursuit of life-sustaining treatments and Chinese cultural traditions. In particular, the researchers agreed with existing evidence that filial piety had a significant role to play in encouraging patients and their offspring to sustain life by all means and at all cost (Cong, 1998; Weng et al, 2011). Consistent with existing literature, initiators and developers in the current Macao based study suggested that filial obligation imposed on family members had contributed to the desire and expectation to preserve life of Macao residents. Therefore, the connection between end of life care and no resuscitation was unable to align with the cultural expectations to preserve life; thereby substantiating the concept of frame misalignment.

The issue of frame misalignment is pervasive in the end of life care development in Macao. The findings regarding the misalignment of ideologies between end of life care, and the Chinese cultural beliefs relating death and dying, is consistent with previous studies. In a 2010 study by Bai et al (2010) (also mentioned in Chapter Two, see p. 31) the authors conducted a cross-sectional survey in the city of Henan in China. The study set out to examine Chinese people's attitudes towards palliative care by using two sets of self-developed, 17 item questionnaires, for two groups of participants. The first group consisted of 146 patients with advanced cancer, and the second group was a health care professional group made up of 66 doctors and 106 nurses. The study of Bai et al (2010) suggested over 60% of the patient respondents accepted death and dying as natural life events; 56% of the same group recognised the goal of palliative care is to provide comfort care and pain management. However, amongst the patient respondents, 43% of them asserted life preservation as the primary care goal at the end of life phase. The study by Bai et al (2010) revealed a conflicting relationship between the acceptance of death as a natural life event and the pursuit to sustain life. Adding complexity to this conflict was the recognition of the ethos of palliative care amongst patient respondents. In contrast to the study by Bai et al. (2010), the pursuit of life preservation in the context of Macao was found to have prevented the acceptance of end of life care; an outcome which served to impede the development of such care. To be specific, the acceptance of end of life care in the Chinese context of Macao symbolised the acceptance of death; on the other hand, the acceptance of death was found to be recognised as a concept against the cultural status quo of life preservation. The 2010 study by Bai et al. proposed a more fluid dynamic informing the acceptance of death, the pursuit of life sustainment and the recognition of palliative care. However, the present study identified a relatively linear relationship between the pursuit of life sustainment and the rejection of end of life care that was primarily due to the conflict between the ideologies proposed by end of life care and the long established cultural norms in Macao.

Snow & Benford (1988) suggested the success of social movement mobilisation is subjected to the success of consensus and action mobilisation. Consensus mobilisation is achieved when the ideologies put forward by social movement organisations are agreed and accepted by target audiences. Action mobilisation is a step up from consensus mobilisation, in that it is the process in which audiences have not only accepted the frames proposed by social movement organisations, but also the members of those audiences are motivated to take action and become involved in the social movement themselves (Snow & Benford, 1988). The connection wherein movement audiences have agreed with the ideologies proposed by social movement organisations is known as 'frame alignment', and the alignment of frames is subjected to a number of constraints (Snow et al, 1986). For instance, phenomenological constraints where the process of framing is contingent on the level of phenomenological relatedness between the proffered framings and target audiences (Snow & Benford, 1988) (Details of these constraints have been presented in Chapter Six).

With respect to the current study, the findings strongly suggest the existence of a substantial gap between the frames proffered by end of life care and the cultural values in Macao, a situation attributed to the one of the three phenomenological constraints: narrative fidelity. Narrative fidelity primarily concerns frame resonance between the constructed by movement organisations and the external cultural context where movement activities are embedded (Holland, 2014; Snow & Benford, 1988). Rooted in the rejection of death, the insistence of preserving one's life through curative means at all cost fundamentally conflicts with the frame to promote the acceptance of death as proffered by end of life care initiators. It is not uncommon for social movement organisations to initiate or promote events that may not, ideologically, resonate with their target audiences; some frames proposed may even, as Snow et al (1986) suggested, appear to be antithetical to existing values. Under these circumstances, Snow et al (1986) would predict social movement organisations adopting a number of frame alignment processes in trying to establish a connection with their target audiences. These frame alignment processes are categorised into four different processes: i) frame bridging, ii) frame amplification, iii) frame extension and iv) frame transformation (Snow et al, 1986). In a literature review of the framing perspective, Benford & Snow (2000) refined their previous studies and suggested that the frame alignment processes mentioned above are strategic by nature. Frame alignment processes help social movement organisations to negotiate frames, in order to garner agreement from potential supporters, these processes are also shown to be involved strategically, as social movement organisations begin to establish their frames, and potentially enhance their movement efficacy from the start. This new refinement on framing processes, as proposed by Benford & Snow (2000) is, to an extent, more appropriate in theoretically illustrating the dynamic and interactive framing processes.

Despite being grounded in a different field, the study by Xia (2016) on the anti-express-rail-link movement in Hong Kong (HK) can help to us to understand the impact of the lack of cultural resonance on social movement progression, by highlighting instances when the articulation of initial frames did not involve any strategic frame alignment processes. In Xia (2016) study, the anti-express-rail-link movement failed to attract much mainstream attention, or support from the wider society in HK, when it was first introduced; there were two main attributions for the initial failure according to Xia's analysis. The first issue was the lack of information dissemination around the potential problems that the express rail development might bring; the second was that the collective action frames proposed were marginal values primarily appealing to a small group of local residents. Thus the movement was unable to resonate sufficiently with the wider population in HK in order to instigate their participation. On the contrary, the study by Berbrier (1998) on the legitimisation of the new white separatist movement in the United States showed the success of the movement was primarily due to the cultural considerations given in constructing the 'new racist' rhetoric during the formative stage of the movement. Berbrier (1998) found the white separatist movement had strategically constructed their new movement frames in accord with the cultural and sentimental values within the cultural context it embraced. The 'new racist' rhetoric had deliberately made this move in order to seek cultural resonance and reinforce the legitimation of their newly proposed rhetoric (Berbrier, 1998). The studies by Berbrier (1998) and Xia (2016) demonstrate that the success of social movements is heavily dependent upon the alignment of frames, particularly in relation to their associated cultural aspects.

In view of the lack of external frame cohesion, despite being aware of the prevalent cultural insistence on life preservation in Macao, the current study found that initiators had not considered any processes in aiding the resonance of the initiative's frames. Supported by the collected data, initiators of end of life care Macao were found not to have considered any possible issues relating to cultural resonance during the process of frame articulation. In the studies of social movements, it is well established that one of the biggest challenges for social movement initiators is the promotion of frames, that are often established in contradiction to the dominant culture, in which the movement is embedded (d'Anjou & Van Male, 1998). In the case of end of life care in Macao, I argue that complete alignment between extant cultural values, and frames proffered by end of life care, could be difficult to achieve due to the substantial cultural divergence between the two variables. Nevertheless, I suggest the issue of frame misalignment is, in one way or another, attributed and heightened by the negligence of initiators to take into account this cultural divergence, when in the beginning stage of frame articulation for the end of life care in the case of Macao.

Continuing the discussion on frame misalignment by way of the framing perspective, in section 7.3.2, I have further elaborated on the influence of the chain effect on the issue of a lack of external frame cohesion. This deficit results from the lack of consideration initiators had paid to the cultural divergence between the end of life care they proposed and the existing cultural context of Macao.

7.3.2. The lack of consideration of external frame alignment

In the social movement promoting end of life care in Macao, the issue with the lack of consideration of the cultural component of life sustainment during the stage of frame articulation by initiators is, I argue, a significant contributor to the problem of frame misalignment.

In the previous section, I discussed how this lack of cultural consideration during the stage of frame articulation for the end of life care movement has contributed to the subsequent frame misalignment between the end of life care movement and Macao's cultural context. However, I found the framing perspective offered little consideration of the cultural component in frame articulation, and how this may potentially affect the development of social movements. In this section therefore, I intend to contribute to the discussion involving the limitation of the framing perspective in respect to the conceptualisation of frames at the time of the inception of end of life care in Macao.

Put forward by Benford & Snow (2000), there are three categories of processes in understanding frame development, generation and elaboration. These categories are: a) discursive, b) strategic and c) contested processes. These three categories of processes overlap with one another, and are intended to provide better clarity in understanding the generation and development of frames for social movements. In discursive processes, frames are primarily articulated through alignment of events and experiences, by way of conversations and communication during social movement activities. However, according to the suggestion from Benford & Snow (2000), discursive processes concern frame reconstitution during ‘the course of interaction that occurs in the context of movement gatherings and campaigns’ (Benford & Snow, 2000, p. 623). In the initiation of the end of life care movement in Macao, discursive processes were not evident from the gathered data during the stage of frame development.

Strategic processes entail four subcategories: i) frame bridging, ii) frame amplification, iii) frame extension and iv) frame transformation. These processes are, as clarified by Benford & Snow (2000) “deliberative, utilitarian, and goal directed” (Benford & Snow, 2000, p. 624). Social movement frames articulated by way of these processes are generally developed to fulfil a particular goal, such as promoting movement participation from public audiences, mobilising adherents, or the acquisition of resources (Benford & Snow, 2000). Initially conceptualised as frame alignment processes, the focus of these processes was found to concentrate more on the development of social movements. Benford & Snow (2000) later refined and conceptualised strategic processes by encompassing the four processes specified above. The authors had also expanded their interpretive focus on strategic processes to include the beginning stage of frame articulation, prior to the initiation of social movements. With respect to the initiation of end of life care in Macao, findings suggested that initiators had not involved any of the strategic processes in generating frames at the beginning stage of the initiative. However, findings did reveal the implementation of some strategic processes during the developmental stage of the movement, as a way to encourage subsequent movement participation, as well as addressing the issue of counterframing. A detailed discussion on counterframing, highlighting its impact on the frame misalignment in respect to the end of life care movement, is presented in section 7.3.3.

Frame bridging is observed by (Benford & Snow, 2000; Snow et al, 1986) as the most commonly used frame alignment strategy in social movements. Frame bridging specifies the process wherein two “ideologically congruent but structurally unconnected frames regarding a particular grievance” (Snow et al, 1986, p. 467) are being connected. Between social movement organisations and individuals, frame bridging implies the linkage between individuals who share common grievances with social movement organisations (ideologically congruent); however, such individuals are lacking organisational bases (and are therefore structurally unconnected) from which they can deliberate on and elaborate their dissatisfactions. Frame bridging is essentially the establishment of structural connections between social movement organisations and individuals, who are already ideologically connected in the first place.

Frame bridging was not evident in the case of end of life care in Macao, particularly at the initiation stage. This situation was mainly because findings of the study indicate that the grievance (suffering at the end of life) identified by initiators was not aligned with the dominant cultural value of life preservation; thereby implying that these two entities were not ideologically congruent in the first place to build a structural connection.

Frame amplification focuses on the ideological resonance of frames proposed by social movements, as well as on the existing cultural values or beliefs of potential recruits. Given that the success of frame resonance is heavily dependent on the pertinence between the proffered frames and existing cultural values, frame amplification therefore seeks to amplify existing beliefs and values in order to garner support from potential constituents. In the analysis by Xia (2016), HK's anti-express-rail-link movement demonstrated frame amplification by emphasising the value of belonging and the attachment of individuals to the community, in attempting to garner support from members of the public. However, the demonstration of frame amplification was only present after the anti-express-rail-link movement had been introduced, and it was not a framing process considered prior to the introduction of that movement. On interpreting Macao's end of life care movement, frame amplification was not evident mainly because initiators did not appear to have considered the inherent cultural value of life preservation when articulating frames for the movement. Particularly, the two prognostic frames developed by initiators: i) to alleviate suffering at the end of life and ii) to promote acceptance of death, were evidently in contrast to the concept of life preservation firmly grounded in the cultural belief that death should not be accepted; a belief and view suggested by data from the study as well as in available literature on the topic (Bai et al, 2010; Kwok et al, 2007; Lam et al, 2015). The interpretive strand of frame amplification helps to demonstrate the lack of attempts from initiators in trying to align values between the end of life care movement and the value of life preservation when the movement was initially introduced. A consequence of this effort omission was the lack of external frame cohesion informing Macao's end of life care development. However, it can also be argued that the process of frame amplification could only be of restricted use here, due to the gap between the proposed frames and the existing cultural values being too diverse to result in any shared values. Further to frame bridging, there was no evidence of amplification in the frame development stage of the end of life care in Macao.

Frame extension refers to the process wherein social movement organisations extend their primary ideological scope to include problems that are presumably important to potential participants, in an attempt to encourage consensus participation. Frame transformation, on the other hand, refers to the change of old meanings of proposed frames and/or to the generation of new frames with new meanings. Essentially, both frame extension and frame transformation are identified with changes of meaning, from the original versions of meanings proposed by initiators to the new adjusted versions; alterations made in order to attract more participants (Benford & Snow, 2000; Snow et al, 1986). The beginning stage of the end of life care in Macao did not involve either frame extension or frame transformation. In fact, as stated in the discussion presented above, initiators did not employ any of the strategic processes needed to develop the initial frames of the end of life care movement.

Lastly, the contested processes suggested by Benford & Snow (2000) highlight the challenges involved in the development of social movements; that is a) counterframing imposed by parties who oppose to proposed movements, b) disputes of frames within movements, and c) conflicts between frames and events.

Reflecting on the current study, there has been evidence showing counterframing and frame disputes contributing to both the lack of external and internal frame cohesion. In the next section, I considered in some detail the counterframing associated with the end of life care in Macao and how counterframing contributed to the discussion relating to the lack of external cohesion. The discussion of frame disputes in regards to the current study is presented in 7.2.1.

Interpreting from the perspective of frame alignment processes, I conclude from the study's findings that the frames which underpinned the initiation of end of life care were predominantly grounded in the three initiators' interpretations of the degree of a person's suffering experienced at the end of life. As findings of the study demonstrated, initiators did not contemplate the extant cultural element, the desire and expectation to preserve life, when developing the initial frames for the end of life care movement.

This form of initiation wherein social movement was based exclusively on the initiators' ideologies in targeting a specific problem, also identified by the initiators, was not specifically discussed in the frame alignment processes. However, as asserted by Benford (1993) in his study on frame disputes in the nuclear disarmament movement, for most cases of social movements there are usually challenges inhibiting movement initiators to construct and impose a particular version of reality. It is unlikely that the framing processes would not have encountered any form of challenges on social movement introduction. In contrast to Benford's (1993) assertion, in the case of Macao's end of life care was discovered to have been framed exclusively on and informed by the three initiators' version of reality; in summary, they believed the suffering at the end of life should be alleviated through the means of end of life care. As findings of the research show, the development of the end of life care in Macao was subsequently hindered by a number of factors that emerged from the misalignment between the frames introduced by the end of life care movement and the belief in life preservation existing in the cultural context of Macao.

The end of life care in the case of Macao epitomises a type of social movement that is different from the types suggested by Snow et al. (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986), in that the current structure of framing processes informed by framing perspective only offers a limited understanding of social movements that are developed via frames that are exclusively based on the version of reality in accordance with their initiators' interpretations.

The various framing processes suggested by Benford & Snow (2000), Snow et al. (2014) and Snow et al. (1986) as discussed in the current section, do not apply in the case of Macao, as cited. I contend that for the end of life care movement, the consideration of framing processes upon movement initiation is not appropriate, mainly because the ideologies supported by the end of life care initiative are substantially different from the existing cultural values associated with life preservation. To consider integrating the life preserving belief into end of life care might appear to be both unrealistic, and also unattainable, in the case of end of life care in Macao. Therefore, initiators of end of life care in Macao perhaps had no other way to introduce the movement except by disregarding the extant cultural values.

Interpreting the initial framing processes that emerged following the introduction of the end of life care in Macao, by way of the framing processes proposed by this section has further reinforced the perception of the lack of external frame cohesion between end of life care and the Chinese cultural context of Macao. In trying to understand the end of life care in Macao through the framing processes proposed by Snow et al (2014), I discovered that the framing processes is not sufficient to allow an examination of the end of life care development of Macao, in that the process of development was found not to have engaged in any of the framing processes upon its initiation; end of life care was developed exclusively based on the interpretations of the three initiators. Given the example of the end of life care movement in Macao, I argue that the understanding of this type of movement is important. My position is informed by the fact there are social movements, like the end of life care movement in the case of Macao, where not only are the proposed frames opposed to certain mainstream values, but the integration of proposed frames with the mainstream values is impossible. Findings of the study indicated the involvement of framing processes after the introduction of end of life care movement, primarily as a response to the challenge of counterframing (see section 7.3.3). As a result of the lack of framing considerations, I suggest the form of social movement, like end of life care movement, is predisposed to issues of frame misalignment; a development that will subsequently encourage the emergence of counterframing. Having identified these pre-conditions will enhance our current understanding of the concept of social movement.

Having identified the insufficiency of framing processes in explaining the end of life care movement in Macao, in the next section I examine the emergence of counterframing and how it has affected the development of Macao's end of life care movement.

7.3.3. The emergence of counterframing

In this section, I consider the connection between the rise of counterframing and the lack of external frame cohesion in the end of life care movement of Macao. Analysed in Chapter Six, the occurrence of counterframing was seen from the collected data to be a prevalent force in opposing Macao's end of life care movement. The emergence of counterframing in the end of life care movement was presented in the form of the misconceptulisation of the ideologies of end of life care. For instance, the acceptance of end of life care symbolised the acceptance of death; end of life care was found to have been counterframed as a process closely associated with death; end of life care was counterframed to encourage physical suffering at the end of life. By reinforcing the existing cultural desire and expectation to preserve life at all cost, these interpretations were framed to oppose end of life care in Macao.

From the study's findings, I suggest that the emergence of counterframing was primarily grounded in the conceptual gap between the ideologies proposed by end of life care and the existing cultural value of life preservation adhered to in Macao. Counterframing was encouraged by the absence of the consideration of traditionally held values taken upon the movement's initiation in Macao.

Counterframing is framing efforts made in opposing new ideologies introduced by social movements; the purpose being to stop or prevent changes that may affect the *status quo* (Benford, 1987). For the end of life care movement in Macao, the absence of conceptual consideration in the initial framing processes reinforced the substantial ideological difference between the social movement and the cultural insistence on preserving life at all cost. This ideological difference was the main catalyst of counterframing against the end of life care movement.

Nevertheless, it is not uncommon for social movement organisations to adjust existing frames in the hope of rectifying counterframing, thereby enabling frame alignments to occur (Snow & Benford, 1988). The shifting and readjusting of frames in social movements are common procedures and can be achieved by the various framing alignment processes categorised by (Snow et al, 1986). These frame alignment processes overlap with the framing processes suggested for movement initiation, including frame bridging, frame amplification, frame extension and frame transformation. The definitions and contexts involved in these processes have already been mentioned in section 7.3.2 (above).

Many social movements have undertaken re-framing processes in order to enhance alignment of the frames they proposed. In the example of Xia's study of the anti-express-rail-link movement in Hong Kong, the author discovered that the eventual success of the campaign was due to movement activists being able to strategically change the original frames in accordance with the external cultural context; thereby, integrating the marginal values suggested by movement activists into mainstream values (Xia, 2016). In some cases, counterframing can exert a positive impact on social movements. Like Xia's case cited above, counterframing has triggered movement activists to reframe their proposed movement, thereby, improving their movement efficacy, which ended with mobilisation success. However, in the case of Macao, the counterframing effort encountered by the end of life care movement was too impairing, particularly because the counterframing effort was built upon the lack of frame negotiation between the proposed movement and the existing cultural belief in the importance of life preservation held by the residents of Macao. Further, initiators and developers did not commit to reframing via frame alignment processes. With the existing constraints too much from counterframing, initiators and developers struggled to mobilise the end of life care movement subsequently, and further contributed to the lack of external frame cohesion.

In this section, I elaborated on the counterframing efforts evident in the end life care movement in Macao. According to Snow et al (1986), the framing perspective illustrates the emergence of counterframing in the end of life care movement in Macao. This development was predominantly due to the absence of any consideration relating to the cultural aspect of life preservation; an omission which then led to the misalignment of frames and encouraged counterframing. I have also highlighted the weaknesses in the framing perspective in explaining the end of life care movement in the case of Macao. The framing perspective does not offer a good background to understand social movement, like the end of life care movement wherein the initial frames are primarily constructed from the isolated interpretations of initiators, with limited considerations of the external cultural environment wherein the movement is situated.

7.4. Conclusion

This research has built on, and developed further, the current knowledge and theoretical understanding of the development of end of life care in the specific socio-cultural context of Macao. While research relating to the development of the modern hospice movement is plentiful, research of this nature is limited and unavailable in the Chinese context of Macao. Besides, there is very limited empirical evidence of end of life care development, both international and in a Chinese context, being examined by way of a social movement perspective; even though the modern hospice movement itself is recognised as a social movement. The journey in establishing end of life care in the Chinese context of Macao is unique, and faces challenges that are different to those experienced in other cultural environments. The findings offered in this thesis are therefore a substantial contribution to the body of knowledge relating to the end of life care development in Macao, and a valuable addition to the body of end-of- life-care-related knowledge. The accumulated knowledge coming from this investigation resulted from specifically examining end of life care's development through the theoretical lens of the framing perspective of social movement (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986).

By interpreting my study's findings by way of the framing perspective, this chapter has presented two key theoretical contributions to the understanding of the end of life care development in the context of Chinese Macao.

The first contribution is the identification of the lack of internal frame cohesion in the development of end of life care in Macao. The findings of this study suggest that this frame incoherence results from the diagnostic and prognostic frame disputes proposed by the three pioneering initiators and later endorsed by the various developers. These intra-movement frame disputes, as initially proposed by Benford (1993), illuminate an underlying conflict of reality construction amongst these pioneers. More specifically, whilst these initiators had agreed upon a common grievance topic: *'suffering at the end of life'*, they struggled to come together in constructing a shared "alternate reality" (Benford, 1993, p.679), where suffering at the end of life would be alleviated through end of life care. This current study does not argue that the construction of this 'alternate reality' is impossible; in fact, this reality has already been constructed as is evident from the establishment of both the hospice and the community end of life care services in Macao. The findings of intra-movement frame disputes, and the subsequent lack of internal frame cohesion caused, demonstrate how these factors have impacted the end of life care development in Macao, and are thereby contributing to the theoretical understanding of such care model's developmental process. Furthermore, intra-movement frame disputes reflected the lack of collectiveness amongst pioneers, illuminating that the end of life care in Macao is not a successful, or even cohesive, social movement, which goes towards explaining its stagnant development.

The second theoretical contribution made by this research is the conceptualisation of the lack of external frame cohesion influencing the development of end of life care in Macao. Revealed in the findings is that the lack of external frame cohesion is primarily underpinned by the issue of frame misalignment between the prognostic frames proffered to address the grievance topic: *'suffering at the end of life'* and the cultural insistence of the Chinese in Macao, to sustain a person's life regardless of its quality. The connection between end of life care and 'no resuscitation' was unable to align with the cultural expectation and desire to preserve life at any and all costs; thereby substantiating frame misalignment. In view of the lack of external frame cohesion instigated by frame misalignment, the study findings suggest that despite being aware of the prevalent cultural insistence on life preservation in Macao, initiators had not considered any of the framing processes that may have been of use in aiding frame alignment. The phenomenon of counterframing was the result, an outcome which further contributed to the stagnant development of end of life care in Macao.

To conclude, the findings of this study suggest that the initiation of end of life care in Macao is completely dependent on, and isolated by, the interpretations of the three pioneering initiators. The three individuals did not acknowledge the external socio-cultural value placed upon longevity in particular when introducing the concept of end of life care in Chinese Macao, nor did they act jointly together when developing end of life care. The omission of the dominant Chinese cultural belief in, and value of, life preservation contributed to the shortcoming of this development. The lack of external cohesion between end of life care and the Chinese context of Macao, together with the absence of joint co-operative action by the pioneers, contributed to the lack of internal cohesion within the end of life care in the context of Macao.

The aim of this thesis is to establish a theoretical understanding of the development of end of life care in the context of Chinese Macao. The key findings discussed in this chapter have addressed the research aim, as well as contributing to the body of knowledge regarding the end of life care development in Macao. Based on these findings, the next chapter will discuss implications and recommendations for policy, education and further research.

8. Chapter 8: Conclusion

8.1. Introduction

This chapter concludes the thesis. I begin by reflecting on my personal journey through the research process, along with a summary of the study. Implications of the research findings for policy, education and further research are examined and finally recommendations for further initiatives are offered.

8.2. Summary and reflection on the research

End of life care in Macao is a topic that is very close to my heart. The desire to conduct this research was mainly driven by the death of my grandmother, who died in suffering in the hospice in Macao in 2002. Since that event I have continued to observe the development of end of life care in Macao. According to my observations through the years, it appeared that there was very limited development of end of life care in Macao after the introduction of the cancer patient support group in 1996 and the establishment of the hospice in 2000. My observations led to my particular interest in understanding the overall development of end of life care in the specific environment of Macao. In preparation for my first year review in my doctoral study at the University of Edinburgh, I began by reviewing the literature in relation to the end of life care in Macao, from which I discovered that there was generally very limited evidence examining the issue of end of life care in that specific context. I expanded my literature review to the wider context of end of life care development in other Chinese environments, including Mainland China, Taiwan and Hong Kong. Again, I was obliged to conclude there were only minimal empirical examinations of the same subject.

In the international context, there were plenty of studies looking into the developmental trajectory of end of life care; particularly the emergence of the modern hospice movement which started in the 1960’s in the United Kingdom. This initiative had attracted ample research interest, looking into how the modern hospice had both gradually advanced and contributed to the formation of palliative care as a medical specialty; a dimension of that specialist care initiative being its relative integration into the mainstream health care system(s) (Clark, 1998; 2007; Clark & Graham, 2011). Nevertheless, I noticed that despite the modern hospice being implicitly recognised as a social movement, there was little empirical evidence examining the mobilisation of the modern hospice movement from any theoretical perspective of social movement. Very little is known, from a theoretical social movement perspective, about the elements that have facilitated / inhibited the mobilisation of the modern hospice movement. Equally, there was no research which examined the development of end of life care by adopting the perspective of social movement in any of the socio-cultural Chinese cultural environments examined in this research.

At the end of the literature review process, during the initial stage of my doctoral study, I determined that the aim of this research was *'to understand the development of end of life care, and how this service has been facilitated and limited within the specific socio-cultural context of Macao'*. Under the direction of this broad aim, I began the research process with an open mind; the research questions were subsequently consolidated during the process of data analysis. The research questions developed were:

1. Why and how did end of life care emerge in Macao?
2. What factors have influenced the subsequent development of end of life care in the context of Macao?

A qualitative case study methodology was selected for this research; specifically, Stake's (1995) case study design was adopted and 'end of life care in Macao' was defined as 'the case' for this research. Taking into consideration that the issue of end of life care in Macao was under-explored, Stake's (1995) case study design, and its methods, offered depth to the exploration. Underpinned by interpretive and constructionist infrastructure, the qualitative case study model has enabled me to systemically and intrinsically examine the development of end of life care in the context of Macao.

My fieldwork was conducted in Macao from November 2012 to August 2013. In seeking to develop an in-depth understanding of the development of end of life care in Macao, there was one key consideration informing participant recruitment. I needed to identify individuals who could provide insights, so enabling the construction of an in-depth understanding of the processes from which end of life care emerged in Macao. In this case study, initiators and developers of end of life care were considered to be the most appropriate personnel for providing personal experiences of introducing end of life care in Macao. I was in an advantageous position because I was aware of the existence of two groups of initiators through professional connection prior to this research: i) three nurse educators who were involved in introducing end of life care education, and ii) a hospice developer. Using purposive sampling, I recruited a total of eleven participants, including three initiators and eight developers of end of life care in Macao. Being able to recruit the pioneers and key developers in Macao's end of life care, in a study where the aim was to understand the development of end of life care, was particularly useful for the valuable insights provided for this unique study.

Data was collected through semi-structured in-depth interviews with all eleven participants. While listening to my participants' accounts of the development of end of life care in Macao, I was made very aware of my own position, as the researcher, in this study. Not only was I aware of my belonging to the socio-cultural context of Macao and my personal interest in understanding the end of life care in Macao, but also I recognised how my position had impacted on my research practice. Section 3.6 detailed how I considered my reflexivity in undertaking this research.

Data analysis began as soon as I started my transcription. I found that being involved in the transcription process was helpful, in that it allowed me to be fully immersed in the data and therefore facilitated the building of my understanding of the data (Bryman, 2015; Hepburn, 2017). The data analysis process was informed by the thematic analysis principles suggested by Braun & Clarke (2006).

Through thematic analysis, the emergence of end of life care in Macao could be understood, to some extent, to have developed through a social movement formation. Furthermore, reflecting on the lack of empirical investigation on the development of end of life care and the lack of any theoretical exploration through the lens of social movement, I decided to adopt the framing perspective (Snow & Benford, 1988; Snow et al, 2014; Snow et al, 1986). This theoretical framework aided the interpretation of the research findings, as well as theorising the understanding of the 'end of life care' case in Macao. Underpinning this study with the framing perspective offered a unique and innovative way to approach an investigation into the establishment of end of life care, thereby generating new knowledge on the development of end of life care in the context of Macao.

Following the principles of thematic analysis, underpinned by the framing perspective, I identified three key conceptual perspectives elucidating the process of establishment of end of life care in Macao; also identified were factors contributing to the growth and stagnation of end of life care. These three conceptual perspectives were:

- The conceptualisation of the problem with dying: the suffering of people as experienced at the end of their lives (the grievance in the context of the framing perspective)
- The incoherent strategies developed by initiators in establishing end of life care (the lack of internal frame cohesion)
- The variety of contextual and conceptual constraints that influenced the subsequent development, and then stagnation, of end of life care (the lack of external frame cohesion) within the context of Macao

Prior to undertaking this research, I did not have much awareness in terms of ‘why’ and ‘how’ end of life care in Macao was started, or of the factors that had impacted on that care model’s development. Entering this research with an open mind, I discovered that even though initiators came from different professional backgrounds, they had identified and conceptualised the same grievance: the suffering of people as experienced at the end of their lives. The initiators involved in this study expressed clearly that they had conceptualised the grievance based on their individual experiences, with respect to the issue of death and dying in the context of Macao. Building on the individual interpretations of the grievance, even though the grievance identified was the same, initiators were found to have remained segregated and had each devised approaches within their own realms of professional capacity to address the grievance. As critiqued in section 7.2, the strategic incoherence in developing the end of life care in Macao indicated the issue of intra-movement frame disputes in the framing perspective, illuminating that the end of life care in Macao was not a full social movement which partly explained its limited development found in this study. While the framing perspective had offered an innovative way interpreting the development of end of life care in Macao, it was unable to fully examine the emergence of intra-movement frame disputes, i.e. how initiators had come to devise incoherent strategies and the lack of observable collaboration between initiators (see also section 7.2).

Nevertheless, the focus on alignment of the framing perspective was able to illustrate the misalignment of values between those proposed by end of life care and those existing in the society of Macao. In particular, the conceptual conflict between the pursuit of life preservation ‘at all cost’ in the existing environment of Macao and the acceptance of death promoted by end of life care, was one of the main contributors for frame misalignment found in this study. Also identified in this study was the omission of considerations involving the cultural aspects of life preservation in the development of end of life care in Macao; another factor which contributed to frame misalignment. Acknowledging the issue of frame misalignment, the framing perspective has proposed a number of compensatory processes a social movement could adopt to negotiate between the different values in order to reach for frame agreement. The four main processes are: i) frame bridging, ii) frame amplification, iii) frame extension and iv) frame transformation (Snow et al, 1986). However, findings of this study revealed that the end of life care in Macao failed to employ any of the framing processes. For example, the grievance (suffering at the end of life) identified by initiators during the introduction of end of life care in Macao was found to be in conflict with the dominant cultural value of life preservation. Despite this ideological incoherence, initiators and developers did not engage in any of the framing processes mentioned to promote frame alignment (see section 7.3.2). As a result, the lack of frame negotiation served to deepen the misalignment of the frames, thereby encouraging the emergence of counterframing. Emerging from frame misalignment was the issue of counterframing, which is the opposing framing effort made to inhibit movement mobilisation (Benford, 1987; Benford & Snow, 2000). In the case of end of life care in Macao, counterframing was manifested by way of misconception of the ideologies of end of life care. For instance, the acceptance of death advocated by end of life care was being counterframed as the encouragement of physical suffering at the end of life; a perspective which was subsequently found to have contributed to the impeded development of the end of life care in Macao.

The lack of internal and external frame cohesion found in the development of end of life care in Macao illustrated that the initiation and development of such end of life care was completely dependent on, and isolated by, the interpretations of the three groups of initiators and developers. The lack of internal frame cohesion was a result of initiators limiting their pioneering efforts in developing end of life care to their individual professional realms, with no observable or evident collaboration between one another, even after the individual services were established. The lack of external frame cohesion, on the other hand, was a result of initiators neglecting the inhibiting impact of the value Chinese culture placed on the desire for and pursuit of life preservation, while those pioneers were developing end of life care in Macao.

This study has addressed the existing gap of knowledge relating to the lack of understanding of the development of end of life care in the context of Macao. By adopting the framing perspective, this study has offered a new and innovative way of exploring and examining the establishment of end of life care. It is informed by a theoretical perspective of social movement for the examination of end of life care. This study identified the shared grievance by initiators, as well as how these initiators had continued to construct end of life care with diverse strategies; thereby leading to the incoherent internal developments within Macao. Further, the understanding of the development of end of life care extended to the misalignment between values proposed by the end of life care initiatives, and the existing cultural values of Macao. Such a dissonance subsequently impacted on the overall growth of the Macao-based end of life care programmes. In the section below, the implications of the key findings in this research, relating to aspects of policy, education and future investigations, are considered.

8.3. Implications and recommendations resulting from this research

This study has identified three key conceptual perspectives illustrating the developmental trajectory of, and factors contributing to, the growth and then stagnation of end of life care within the specific socio-cultural environment of Macao. The findings from this study have not only contributed to the body of knowledge about the development and understanding of end of life care in Macao, but have also added knowledge by examining the development of end of life care through the theoretical perspective of social movement. I now consider this unique contribution from three perspectives; the implications for: a) policy, b) education and c) future research.

8.3.1. Implications and recommendations for policy

Since the introduction of end of life care in Macao 18 years ago, there continues to be no legislation or any official policy in relation to end of life care, or any end of life related issues, in Macao. Taking into consideration the other Chinese regions of Taiwan, Hong Kong and Mainland China discussed in this thesis, Taiwan is the only place with topic-relevant established legislations. However, Hong Kong has implemented official recommendations for setting up advance directives. Despite Mainland China having no official strategies relating to end of life issues, it has made broad statements regarding the importance of end of life care in a number of national health care policies. Reflecting on the development of end of life care in both Taiwan and Hong Kong, wherein legislative support is present, there is evidence of professional advances, collaboration and engagement in the field of end of life care (Chan, 2002; Cheng et al, 2001; Hospital

Authority, 2017; Law Reform Commission of Hong Kong, 2006; The Patient Autonomy Act, 2015; Tse, 2018). Presented in this thesis is the limitation imposed on the development of end of life care in Macao as a result of the diverse strategies, seen in the lack of internal frame cohesion, employed amongst the different but involved organisations (see section 6.2.2). A contribution to this diverse strategic development was found to be the unequal funding from the government of Macao to the different end of life care organisations. For instance, the hospice service is fully funded by the government of Macao, while the community end of life care service receives no financial support from the government. Such a discrepancy of funding between the different organisations was found, in this study, to have contributed to those organisations' different strategic approaches to the development and implementation of end of life care in Macao. In addition, as discussed in section 6.2.1.2, the government primary care system has limited the type of service the community end of life care service could offer. The impact the decision making power of the government hospital has on assessing a patient's eligibility for hospice admission, despite the administrative responsibility fully lying with the private hospital, is a good example of that limitation. The findings of this study therefore informed the inconsistency of the government of Macao in facilitating the development of end of life care. To this end, these findings suggest that policy makers from the government should consider establishing an infrastructure of resourcing to ensure a more balanced and fair distribution of government resources to aid the building of comprehensive end of life care in Macao. An equal distribution of resources will also encourage collaboration amongst the existing end of life care organisations in further promoting the overall advancement of end of life care in Macao.

In terms of legislations relevant to end of life care, there is still much work that has to be done to raise awareness amongst Macao's policy makers to include end of life care as part of mainstream health care development. Learning from the cases of Taiwan and Hong Kong, we understand that having legislations in the field of end of life care can enhance and protect professional development, as well as the overall development of the professional services. Therefore, this study has highlighted the importance of raising awareness amongst Macao's policymakers regarding legislation informing end of life issues. Examples of these challenging and complex issues are: i) do-not-attempt resuscitation, ii) a patient's best interest, iii) advanced directives, iv) the impact of this policy on the development of this professional field and v) collaboration between individual organisations. These are the central issues that need to be addressed in

Macao (and elsewhere) in order to ensure the continued improvement of the quality of death, together with the provision of high-quality palliative end of life care (Economist Intelligence Unit, 2015).

8.3.2. Implications and recommendations for education

There are several implications for education that emerge from this study. The findings of this research have illustrated that the misconception of end of life care is primarily the result of the pervasive desire and pursuit of life preservation existing for millennia in the Chinese culture, which has inhibited the growth and spread of the end of life care in Macao. By way of the framing perspective, the rise of that misconception is an opposing effort emerged from within the society of Macao, successfully impeding the concept and practice of end of life care. Despite initiators and developers were found to have engaged in public information-giving and nursing education, end of life care was still being misconceptualised. Informed by these findings therefore, is the importance in strengthening the Macao public's education regarding the concept of end of life care, together with the moral principles that end of life care adheres to, in order to assert a more informed attitude towards end of life care. In addition to public information-giving, professional education in medicine, nursing and other allied health professions should also be considered as an integral part in facilitating the development of end of life care. Reflecting on two studies examining the understandings of nurses and nursing students towards hospice care in Macao, both of the studies identified their participants as having inadequate knowledge about the concept of end of life care, mainly because participants felt that the topic of end of life care did not apply in their clinical practice (Leong et al, 2007; Wong et al, 2002). Specifically, in the study by Wong et al (2002), some participants were found to believe end of life care nursing was not challenging because of the absence of resuscitation. Although these are the only studies examining health care professionals' understanding about end of life care in Macao, limited by small sample sizes, they are to an extent able to show the negative impact of the limited understanding on the practice of end of life care.

Considering the extensive impact of the misunderstanding or plain lack of understanding of the 'end of life care' concept on the development of end of life care in Macao found in this study, educational programmes should be set up to counter the lack of relevant information. Existing end of life care organisations should strengthen their efforts at information-giving about end of life care for the people in Macao, as well as implementing structured education programmes or workshops to cater for health care professionals. Further, I suggest that existing end of life care organisations should make it a priority to address the established misunderstandings of end of life care, by way of public information-giving and structured education initiatives.

8.3.3. Implications and recommendations for research

The aim of this study is to understand how end of life care was introduced, established and developed in Macao, and to examine the factors that had shaped the end of life care services in Macao. In this study, I did not include employees of the end of life care organisations who had played no part in their organisation's establishment and development process, because I was only focusing on 'why' and 'how' the end of life care in Macao was established. Therefore, these employees would not be able to provide me with the relevant information needed to answer my research questions, and hence were excluded. Another consideration was the time and resources available to conduct this research. Nonetheless, the experiences of these employees who were working for the established end of life care services would be useful in furthering the understanding of the development of end of life care in Macao. Nor, in this study, did I consider service users' perspectives for similar reasons to those mentioned above. As discussed in the methodology limitations section (3.8), it was uncertain whether there would be robust ethical frameworks in the three end of life care services to protect the service users. To prioritise the protection of the service users, I excluded them from this research. However, it would be interesting to explore 'why' service users would choose to accept an end of life care service, considering the findings of this study had identified the culturally valued Chinese resistance towards end of life care as a result of the strong long-established desire for, and pursuit of, life preservation.

Despite the modern hospice movement that was initiated in the United Kingdom always being known as a social movement, there is only limited evidence examining the modern hospice movement from such a theoretical perspective. Focusing on the end of life care in Macao, this study has provided a new way to examine the development of end of life care by way of a social movement theory: the framing perspective. The findings of this study have broadened the understanding of the development of end of life care in Macao in the social movement sense. In particular, the framing perspective has theorised the suffering of people as experienced at the end of their lives as the grievance, and the different diagnostic frames and prognostic approaches (see Table 6 Diagnostic and prognostic frames conceptualised by initiators in p. 128 for more details).

Whilst the framing perspective informed the consequential relationship between the diverse strategies in developing end of life care and their negative impact on end of life care, the framing perspective was unable to fully explain the phenomenon wherein the end of life care in Macao was developed upon the versions of reality in accordance with initiator’s individual interpretations of the grievance. Further, the framing perspective was unable to explore how initiators had come to devise incoherent strategies in establishing end of life care, and how the diversity had continued, with no observable collaboration between initiators and developers.

Being the first of its kind, this study has offered a novel insight into the development of end of life care in Macao from the framing perspective. However, the use of the framing perspective has to an extent limited the understanding of the development of end of life care if and when perceived from a social movement perspective. This limitation again provides an opportunity for future research to consider other social movement theories in exploring the development of end of life care, not merely in Macao but also in other cultural contexts.

8.4. Concluding comments

The journey to conduct this study stemmed from my personal desire to understand why end of life care in Macao has seen only very limited development, even though it was introduced almost two decades ago. In this journey, I needed to ask the questions ‘why’ and ‘how’ end of life care in Macao was originally established, and ‘what were the factors that had shaped its development?’ In addition to the limited progress of end of life care development, there is also only very limited empirical evidence examining end of life care in Macao. Equally, there is a dearth of evidence examining the development of the modern hospice concept by way of a social movement perspective, as identified in Chapter Two: Literature Review. Taking these knowledge gaps into consideration, I conducted this research to examine and clarify the reasons and processes associated with the establishment of end of life care, including the related services, in Macao. Further, I have identified several contextual, as well as conceptual, factors that are found to have contributed to the stagnant development of end of life care in Macao. In the process of analysis, I adopted the framing perspective to establish the conceptual perspectives identifying the developmental trajectory and factors contributing to the growth and then stagnation of end of life care in Macao. The three conceptual perspectives grew from the conceptualisation of the problem with dying: i) the suffering of people as experienced at the end of their lives, ii) the lack of internal frame cohesion as a result of the incoherent developmental strategies established by initiators, and iii) the lack of external frame cohesion informed by the contextual and conceptual constraints that influenced the subsequent development and then stagnation of end of life care available in Macao. My hope is that the findings of this study will raise awareness of the stagnant state of end of life care development in Macao and thereby motivate stakeholders and policymakers to significantly change the current situation.

References

Abma, T. A. & Stake, R. E. (2014) Science of the Particular: An Advocacy of Naturalistic Case Study in Health Research. *Qualitative Health Research*, 24(8), 1150.

Aranda, S. (1999) Global Perspectives on Palliative Care. *Cancer Nursing*, 22(1), 33-39.

Asah, S., Bengston, D., Wendt, K. & DeVaney, L. (2012) Prognostic Framing of Stakeholders' Subjectivities: A Case of All-Terrain Vehicle Management on State Public Lands. *Environmental Management*, 49(1), 192-206.

Avis, M. (2005) Is there an epistemology for qualitative research?, in Holloway, I. (ed), *Qualitative Research in Health Care* Open University Press, 3-16.

Ayscough, F. W. (1938) *Chinese women, yesterday & to-day*. London: J.Cape.

Bai, Q., Zhang, Z., Lu, X., Shi, Y., Liu, X. & Chan, H. (2010) Attitudes towards Palliative Care among Patients and Health Professionals in Henan, China. *Progress in Palliative Care*, 18(6), 341-345.

Bartunek, J. M. (2008) Insider/outsider team research: The development of the approach and its meanings, in Shani, A. B., Mohrman, S. A., Pasmore, W. A., Stymne, B. & Adler, N. (eds), *Handbook of Collaborative Management Research* [eBook]. Thousand Oaks: SAGE, 73-92.

Beijing Songtang care hospital (2018) *Introduction: Songtang.* Available online: http://www.stghyy.com/yyjs.html [Accessed 22.07.2018].

Benford, R. (1987) *Framing Activity, Meaning, and Social Movement Participation: The Nuclear Disarmament Movement*. PhD University of Texas.

Benford, R. (1993) Frame Disputes within the Nuclear Disarmament Movement. *Social Forces*, 71(3), 677.

Benford, R. D. & Snow, D. A. (2000) Framing Processes and Social Movements: An Overview and Assessment. *Annual Review of Sociology*, 26(1), 611-639.

Berbrier, M. (1998) Half the battle: Cultural Resonance, Framing Processes, and Ethnic Affectations in Contemporary White Separatist Rhetoric. *Social Problems*, 45(4), 431-450.

Berger, P. L. & Luckmann, T. (1991) *The social construction of reality: A treatise in the sociology of knowledge*. UK: Penguin.

Bingley, A. & Clark, D. (2009) A Comparative Review of Palliative Care Development in Six Countries Represented by the Middle East Cancer Consortium (MECC). *Journal of Pain and Symptom Management*, 37(3), 287-296.

Birnbaum, R. (1985) Seeking Longevity in Chinese Buddhism: Long Life Deities and Their Symbolism. *Journal of Chinese Religions*, 13(1), 143-176.

Blinderman, C. D. & Cherny, N. I. (2005) Existential Issues Do Not Necessarily Result in Existential Suffering: Lessons from Cancer Patients in Israel. *Palliative Medicine*, 19(5), 371-380.

Block, S. D. (2000) Assessing and Managing Depression in the Terminally Ill Patient. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians - American Society of Internal Medicine. *Annals of Internal Medicine*, 132(3), 209.

Blum, C. A. (2006) ‘Til Death Do Us Part?’The Nurse’s Role in the Care of the Dead: A Historical Perspective: 1850–2004. *Geriatric Nursing*, 27(1), 58-63.

Bodek, H. (2013) Facilitating the Provision of Quality Spiritual Care in Palliative Care. *OMEGA*, 67(1-2), 37-41.

Bonner, A. & Tolhurst, G. (2002) Insider-Outsider Perspectives of Participant Observation. *Nurse Researcher*, 9(4), 7.

Boston, P., Bruce, A. & Schreiber, R. (2011) Existential Suffering in the Palliative Care Setting: An Integrated Literature Review. *Journal of Pain and Symptom Management*, 41(3), 604-618.

Bowman, K. W. & Singer, P. A. (2001) Chinese Seniors’ Perspectives on End-of-Life Decisions. *Social Science & Medicine*, 53(4), 455-464.

Braun, V. & Clarke, V. (2006) Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Brown, P. & Flores, R. (2011) Making Normative Structures Visible: The British National Health Service and the Hospice Movement as Signifiers of Compassion and Hope. *Acta Sociologica*, 54(1), 53-65.

Bryman, A. (2015) *Social research methods*, 5th edition. Oxford: Oxford University Press.

Buck, J. (2009) ‘I am willing to take the risk’: Politics, Policy and the Translation of the Hospice Ideal. *Journal of Clinical Nursing*, 18(19), 2700-2709.

Casarett, D. (2005) Ethical Considerations in End-of-Life Care and Research. *Journal of Palliative Medicine*, 8(Supplement 1), s148-s160.

Chan, C. (2009) The Chinese death taboo, in Bryant, C. D. & Peck, D. L. (eds), *Encyclopedia of Death and the Human Experience*, 1st edition SAGE, 190-192.

Chan, C. K. L. & Yau, M. K. (2009) Death Preparation among the Ethnic Chinese Well-Elderly in Singapore: an Exploratory Study. *OMEGA*, 60(3), 225-239.

Chan, C. L. W. & Chow, A. Y. M. (2006) *Death, dying and bereavement: a Hong Kong Chinese experience*. Hong Kong: Hong Kong University Press.

Chan, C. W. H. & Chang, A. M. (2000) Experience of Palliative Home Care According to Caregivers' and Patients' Ages in Hong Kong Chinese People. *Oncology Nursing Forum*, 27, 1601-1605.

Chan, K. S. (2002) Two Decades of Palliative Care. *Hong Kong Medical Journal*, 8(6), 465-466.

Chan, N. C. (2007) Assessment of Demands for Hospice Care of Cancer Patients in Macau and Strategic Planning for Future Hospice Care. *Health Science Journal of Macao*, 7(4), 251-254.

Chan, T. H. Y., Chan, F. M. Y., Tin, A. F., Chow, A. Y. M. & Chan, C. L. W. (2006) Death Preparation and Anxiety: A Survey in Hong Kong. *Omega*, 54(1), 67-78.

Chan, W. C. H. & Epstein, I. (2011) Researching "Good Death" in a Hong Kong Palliative Care Program: A Clinical Data-Mining Study. *OMEGA*, 64(3), 203-222.

Chao, C. C. S. (2002) Physicians’ Attitudes Toward DNR of Terminally Ill Cancer Patients in Taiwan. *Journal of Nursing Research*, 10(3), 161-167.

Chen, H., Komaromy, C. & Valentine, C. (2014) From Hope to Hope: The Experience of Older Chinese People with Advanced Cancer. *Health*, 19(2), 154-171.

Chen, L.M., Miaskowski, C., Dodd, M. & Pantilat, S. (2008) Concepts within the Chinese Culture that Influence the Cancer Pain Experience. *Cancer Nursing*, 31(2), 103-108.

Chen, P. J., Liang, F. W., Ho, C. H., Cheng, S. Y., Chen, Y. C., Chen, Y. H. & Chen, Y. C. (2018) Association between Palliative Care and Life-Sustaining Treatments for Patients with Dementia: A nationwide 5-year Cohort Study. *Palliative Medicine*, 32(3), 622-630.

Chen, Y. H., Ho, C. H., Huang, C. C., Hsu, Y. W., Chen, Y. C., Chen, P. J., Chen, G. T. & Wang, J. J. (2017) Comparison of Healthcare Utilization and Life-Sustaining Interventions Between Elderly Patients with Dementia and Those with Cancer Near the End of Life: A Nationwide, Population-Based Study in Taiwan. *Geriatrics & Gerontology International*, 17(12), 2545-2551.

Cheng, R. C., Chung, D. C. H., Lai, E. Y. L. & Chao, C. C. S. (2001) The Development of Hospice Palliative Care in Taiwan. *Taiwan Journal of Hospice Palliative Care*, 6(1), 2-13.

Cheng, S. Y., Chen, C. Y. & Chiu, T. Y. (2016a) Advances of Hospice Palliative Care in Taiwan. *Korean Journal of Hospice and Palliative Care*, 19(4), 292.

Cheng, S. Y., Hu, W. Y., Liu, W. J., Yao, C. A., Chen, C. Y. & Chiu, T. Y. (2008) Good Death Study of Elderly Patients with Terminal Cancer in Taiwan. *Palliative Medicine*, 22(5), 626-32.

Cheng, S. Y., Lin, W. Y., Cheng, Y. H., Huang, C. H., Chen, C. Y., Hwang, S. J., Tsai, S. T. & Chiu, T. Y. (2016b) Cancer Patient Autonomy and Quality of Dying: A Prospective Nationwide Survey in Taiwan. *Psycho-Oncology*, 25(2), 179-186.

Chou, R. J. A. (2011) Filial Piety by Contract? The Emergence, Implementation, and Implications of the Family Support Agreement in China. *Gerontologist*, 51(1), 3-16.

Chow, A. Y. M., Chan, C. L. W. & Ho, S. M. Y. (2007) Social Sharing of Bereavement Experience by Chinese Bereaved Persons in Hong Kong. *Death Studies*, 31(7), 601-618.

Chung, B., Leung, D., Leung, S. & Loke, A. (2018) Beyond Death and Dying: How Chinese Spouses Navigate the Final Days with Their Loved Ones Suffering from Terminal Cancer. *Supportive Care in Cancer*, 26(1), 261-267.

Clark, D. (1998) Originating a Movement: Cicely Saunders and the Development of St Christopher's Hospice, 1957-1967. *Mortality*, 3(1), 43-63.

Clark, D. (1999) 'Total pain', Disciplinary Power and the Body in the Work of Cicely Saunders, 1958-1967. *Social science & Medicine*, 49(6), 727.

Clark, D. (2001a) Religion, Medicine, and Community in the Early Origins of St. Christopher's Hospice. *Journal of Palliative Medicine*, 4(3), 353-360.

Clark, D. (2001b) A Special Relationship: Cicely Saunders, the United States, and the Early Foundations of the Modern Hospice Movement. *Illness, Crisis & Loss*, 9(1), 15-30.

Clark, D. (2007) From Margins to Centre: A Review of the History of Palliative Care in Cancer. *Lancet Oncology*, 8(5), 430-438.

Clark, D. & Graham, F. (2011) Evolution and Change in Palliative Care around the World. *Medicine*, 39(11), 636-638.

Clark, D. & Wright, M. (2007) The International Observatory on End of Life Care: A Global View of Palliative Care Development. *Journal of Pain and Symptom Management*, 33(5), 542-546.

Cong, Y. (1998) Ethical Challenges in Critical Care Medicine: A Chinese Perspective. *The Journal of Medicine and Philosophy*, 23(6), 581.

Corr, C. A. & Corr, D. M. (1983) *Hospice care: principles and practice*. London: Faber.

Creel, H. G. (1937) *The birth of China: A study of the formative period of Chinese civilization*. New York: Ungar Publishing Company.

Creswell, J. W. (2018) *Qualitative inquiry & research design: choosing among five approaches*, 4th edition. Los Angeles: SAGE.

Crotty, M. (1998) The foundation of social research. *NSW Australia: Allen and Unwin*.

d'Anjou, L. & Van Male, J. (1998) Between Old and New: Social Movements and Cultural Change. *Mobilization: An International Quarterly*, 3(2), 207-226.

De Guzman, A. B., Lacorte, J. C., Lacsamana, A. K. G., Lagac, M. L. M., Laguador, J. M., Lapid, J. J. R. & Lee, L. M. C. (2012) Who Says there is No Life After Abandonment? A Grounded Theory on the Coping of Abandoned Filipino Elderly in Nursing Homes. *Educational Gerontology*, 38(12), 890-901.

Denzin, N. K. & Lincoln, Y. S. (2017) *The Sage handbook of qualitative research*, 5th edition. Los Angeles: SAGE.

Department of Health (2008) *End of Life Strategy- promoting high quality care for all adults at the end of life.* London: Department of Health.

Diani, M. (1992) The Concept of Social Movement. *The Sociological Review*, 40(1), 1-25.

Dickson-Swift, V., James, E. L. & Liamputtong, P. (eds) (2008) *Undertaking sensitive research in the health and social sciences: managing boundaries, emotions and risks*. Cambridge: Cambridge University Press.

Documentation and Information Centre of the Statistics and Census Service (2008) *Macao Resident Population Projections 2007-2031.* Macao: DSEC.

Documentation and Information Centre of the Statistics and Census Service (2017a) *Demographic Statistics.* Macao Available online: http://www.dsec.gov.mo/Statistic.aspx?lang=en-US&NodeGuid=7bb8808e-8fd3-4d6b-904a-34fe4b302883 [Accessed 13.05.2018].

Documentation and Information Centre of the Statistics and Census Service (2017b) *Tourism Statistics.* Macao SAR: Documentation and Information Centre of the Statistics and Census Service. Available online: https://www.dsec.gov.mo/Statistic.aspx?NodeGuid=7b23463a-d253-4750-bd12-958030df5ccb [Accessed 13.05.2018].

Dong, F., Zheng, R., Chen, X., Wang, Y., Zhou, H. & Sun, R. (2016) Caring for Dying Cancer Patients in the Chinese Cultural Context: A Qualitative Study from the Perspectives of Physicians and Nurses. *European Journal of Oncology Nursing*, 21, 189-196.

Economist Intelligence Unit (2015) *The 2015 Quality of Death Index: Ranking palliative care across the world*.London.

Enguidanos, S., Yonashiro-Cho, J. & Cote, S. (2013) Knowledge and Perceptions of Hospice Care of Chinese Older Adults. *Journal of the American Geriatrics Society*, 61(6), 993-998.

Esposito, N. (2001) From Meaning to Meaning: The Influence of Translation Techniques on Non-English Focus Group Research. *Qualitative Health Research*, 11(4), 568-579.

Evans, A. A., Cohen, C., Huang, P., Qian, L., London, W. T., Block, J. M. & Chen, G. (2015) Prevention of Perinatal Hepatitis B Transmission in Haimen City, China: Results of a Community Public Health Initiative. *Vaccine*, 33(26), 3010-3015.

Fisher, W. R. (1984) Narration as a Human Communication Paradigm: The Case of Public Moral Argument. *Communications Monographs*, 51(1), 1-22.

Flyvbjerg, B. (2006) Five Misunderstandings about Case-Study Research. *Qualitative Inquiry*, 12(2), 219-245.

Food and Health Bureau (2009) *Introduction of the Concept of Advance Directives in Hong Kong Consultation Paper*.Hong Kong.

Forster, E. M. & Windsor, C. (2014) Speaking to the Deceased Child: Australian Health Professional Perspectives in Paediatric End-of-Life Care. *International Journal of Palliative Nursing*, 20(10), 502-508.

Fung, C. S. C. & Mercer, S. W. (2009) A Qualitative Study of Patients' Views on Quality of Primary Care Consultations in Hong Kong and Comparison with the UK CARE Measure. *BMC Family Practice*, 10, 10-10.

Gamson, W. A. & Modigliani, A. (1989) Media Discourse and Public Opinion on Nuclear Power: A Constructionist Approach. *American Journal of Sociology*, 95(1), 1-37.

Gary, D., Yuilya, Y. & Cynthia, P. R. (2015) Using Social Media and Targeted Snowball Sampling to Survey a Hard-to-reach Population: A Case Study. *International Journal of Doctoral Studies*, 10, 279-299.

General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*.London.

Gerring, J. (2007) *Case study research: principles and practices* New York: Cambridge University Press.

Gilbert, G. N. & Stoneman, P. (2016) *Researching social life*, 4th edition. Los Angeles: SAGE.

Gillis, J., Lai, C. T., Lin, M. L. & Lee, S. Y. (2008) Connecting Palliative Care and Intensive Care in Taiwan. *International Journal of Gerontology*, 2(2), 33-34.

Glass, A. P., Chen, L. K., Hwang, E., Ono, Y. & Nahapetyan, L. (2010) A Cross-Cultural Comparison of Hospice Development in Japan, South Korea, and Taiwan. *Journal of Cross-Cultural Gerontology*, 25(1), 1-19.

Goffman, E. (1974) *Frame analysis: An essay on the organization of experience*. Cambridge: Harvard University Press.

Goldin, G. (1981) A Protohospice at the Turn of the Century: St Luke's House London, from 1893 to 1921. *Journal of the Social History of Medicine and Allied Sciences*, 3, 383-413.

Gu, X. & Cheng, W. (2016) Chinese Oncologists' Knowledge, Attitudes and Practice towards Palliative Care and End of Life Issues. *BMC Medical Education*, 16(1), 149.

Hadders, H. (2007) Dealing with the Dead Patient at the Intensive Care Unit. *Mortality*, 12(3), 207-222.

Harris, M. L. (1929) Deontology, or the Moral Obligation of Medicine: President's address. *Journal of the American Medical Association*, 93(2), 85-89.

Haven of Hope Hospital (2006) *Haven of Hope Hospital* Hong Kong: Haven of Hope Hospital.

Henoch, I. & Danielson, E. (2009) Existential Concerns among Patients with Cancer and Interventions to Meet Them: An Integrative Literature Review. *Psycho-Oncology*, 18(3), 225-236.

Henry, B. & Scales, D. C. (2012) Ethical Challenges in Conducting Research on Dying Patients and Those at High Risk of Dying. *Accountability in Research*, 19(1), 1-12.

Henwood, K. L. (1996) Qualitative inquiry: Perspectives, methods and psychology, in Richardson, J. T. E. (ed), *Handbook of qualitative research methods for psychology and the social sciences*. Leicester: Leicester : British Psychological Society, 25-42.

Hepburn, A. (2017) *Transcribing for social research*. Los Angeles: SAGE.

Hesse-Biber, S. N. (2014) Feminist research: exploring, interrogating, and transforming the interconnections of epistemology, methodology, and method, in Hesse-Biber, S. N. (ed), *Handbook of Feminist Research : Theory and Praxis*, 2nd edition. London: Sage.

Ho, A. H. Y., Chan, C. L. W., Leung, P. P. Y., Chochinov, H. M., Neimeyer, R. A., Pang, S. M. C. & Tse, D. M. W. (2013) Living and Dying with Dignity in Chinese Society: Perspectives of Older Palliative Care Patients in Hong Kong. *Age and Ageing*, 42(4), 455-461.

Ho, S. W. & Sanders, G. F. (2015) Preferences on End-Of-Life Decisions Among Older Chinese in Macau. *Journal of Transcultural Nursing*, 26(2), 157-163.

Hockey, J. L. (1990) *Experiences of death: an anthropological account*. Edinburgh: Edinburgh University Press.

Hoffman, B. (2008) Health Care Reform and Social Movements in the United States. *American Journal of Public Health*, 98(9 Suppl), S69.

Holland, J. J. (2014) Narrative Fidelity to the Little Red Book in the Framing Efforts of the Red Guard Movement: A Theoretical Model for Foundational Documents. *Discourse & Society: An International Journal for the Study of Discourse and Communication in Their Social, Political and Cultural Contexts*, 25(3), 383-401.

Holliday, A. (2007) *Doing and writing qualitative research*, 2nd edition. London: SAGE.

Hospice Foundation of Taiwan (2018) *Hospice and palliative care in Taiwan.* Available online: http://www.hospice.org.tw/2009/english/about.php [Accessed 20.07.2018].

Hospital Authority (2017) *Strategic Service Framework for Palliative Care.* Hong Kong: Strategy and Planning Division.

Hsu, C. Y., O'Connor, M. & Lee, S. (2009) Understandings of Death and Dying for People of Chinese Origin. *Death Studies*, 33(2), 153-174.

Hu, K. & Feng, D. (2016) Barriers in Palliative Care in China. *The Lancet*, 387(10025), 1272.

Huang, H., Hsieh, J., Hsieh, C. J. & Wang, Y. (2017) Do Cancer Patients with Dementia Receive Less Aggressive Treatment in End-of-Life Care? A Nationwide Population-Based Cohort Study. *Oncotarget*, 8(38), 63596-63604.

Huang, X. Y., Chang, J. Y., Sun, F. K. & Ma, W. F. (2010) Nursing Students' Experiences of Their First Encounter with Death During Clinical Practice in Taiwan. *Journal of Clinical Nursing*, 19(15-16), 2280-2290.

Huggins, C. (2014) *Arranging and conducting elite interviews : practical considerations*. London: SAGE.

Hunt, S. A. & Benford, R. D. (1994) Identity Talk in the Peace and Justice Movement. *Journal of Contemporary Ethnography*, 22(4), 488-517.

Hurd, I. (2010) Constructivism, in Reus-Smit, C. & Snidal, D. (eds), *The Oxford Handbook of International Relations*Oxford University Press.

Johnston, H. (2014) *What is a social movement?* Cambridge: Polity Press.

Jones, J. M., Cohen, S. R., Zimmermann, C. & Rodin, G. (2010) Quality of Life and Symptom Burden in Cancer Patients Admitted to an Acute Palliative Care Unit. *Journal of Palliative Care*, 26(2), 94.

Kagawa Singer, M., Dressler, W. & George, S. (2016) Culture: The Missing Link in Health Research. *Social Science & Medicine*, 170, 237-246.

Kan, S. P., U, W. I., Cheong, L. P., Tam, S. F. & Jiang, Y. F. (2003) To Investigate the Impact of Death on Nurses of KWH. *Macau Journal of Nursing*, 2(1), 34-37.

Kavanaugh, K. L. & Campbell, M. L. (2014) Conducting End-of-Life Research. *Nursing Science Quarterly*, 27(1), 14-19.

Kerr, D. (1993) Lin Zhong Guan Huai: Terminal care in China. *The American Journal of Hospice & Palliative Care*, 10(4), 18-26.

Klandermans, B. (1984) Mobilization and Participation: Social-Psychological Expansions of Resource Mobilization Theory. *American Sociological Review*, 49(5), 583-600.

Kleeman, T. F. (2003) Taoism, in Kastenbaum, R. & Leaman, O. (eds), *Macmillan Encyclopedia of Death and Dying*. New York: Macmillan 873-875.

Krongyuth, P., Campbell, C. L. & Silpasuwan, P. (2014) Palliative Care in Thailand. *International Journal of Palliative Nursing*, 20(12), 600-607.

Kubiak, A. E. & Suriková, M. (2010) The Hospice Movement: The Example of Conflict Between the Process of Personalized and Rationalized Institutionalization. *Slovak Sociological Review*, 42(3), 237-254.

Kwok, T., Twinn, S. & Yan, E. (2007) The Attitudes of Chinese Family Caregivers of Older People with Dementia Towards Life Sustaining Treatments. *Journal of Advanced Nursing*, 58(3), 256-262.

Lai, C. T. (2006) Making peace with the unknown: A reflection on Daoism funerary, in Chan, C. & Chow, A. (eds), *Death, Dying and Bereavement: A Hong Kong Chinese Experience*. Hong Kong Hong Kong University Press, 87-92.

Lai, Y. L. & Su, W. H. (1997) Palliative Medicine and the Hospice Movement in Taiwan. *Supportive Care in Cancer*, 5(5), 348-350.

Lam, K. W., Yeung, K. W. A., Lai, K. Y. & Cheng, F. (2015) Changes in the Attitude and Practice Toward End-of-Life Care:Perspective of Chinese Physicians in Medical Department. *American Journal of Hospice and Palliative Medicine®*, 32(5), 549-554.

Lancaster, K. (2016) Confidentiality, Anonymity and Power Relations in Elite Interviewing: Conducting Qualitative Policy Research in a Politicised Domain. *International Journal of Social Research Methodology*, 1-11.

Law Reform Commission of Hong Kong (2006) *Substitute decision-making and advance directives in relation to medical treatment: report.* Law Reform Commission of Hong Kong.

Lawton, J. (1998) Contemporary Hospice Care: The Sequestration of the Unbounded Body and 'Dirty Dying'. *Sociology of Health & Illness*, 20(2), 121.

Leong, R. L. B. (2003) Palliative Care in Malaysia: A Decade of Progress and Going Strong. *Journal of Pain & Palliative Care Pharmacotherapy*, 17(3-4), 77.

Leong, S. F., Chan, P. N., Chio, I. P., Lo, L. C. & Lei, S. P. (2007) Student Nurses' Attitude and Cognition towards Hospice Care in Macau. *Macau Journal of Nursing*, 6(2), 20-22.

Leung, K. K., Liu, W. K., Cheng, S. Y., Chiu, T. Y. & Chen, C. Y. (2009) What Do Laypersons Consider as a Good Death. *Supportive Care In Cancer*, 17(6), 691-699.

Li, J., Davis, M. & Gamier, P. (2011) Palliative Medicine: Barriers and Developments in Mainland China. *Current Oncology Reports*, 13(4), 290-294.

Li Ka Shing Foundation (2018) *"Heart of Gold" National Hospice Service Program: About Us.* Available online: http://www.hospice.com.cn/en/#A1 [Accessed 22.07.2018].

Lin, A. & Huang, H.M. (2003) Factors Related to Attitudes Toward Death among American and Chinese Older Adults. *OMEGA*, 47(1), 3-23.

Lincoln, Y. S. & Guba, E. G. (1985) *Naturalistic inquiry*. London: SAGE.

Liu, G., Dupre, M. E., Gu, D., Mair, C. A. & Chen, F. (2012) Psychological Well-Being of the Institutionalized and Community-Residing Oldest Old in China: The Role of Children. *Social Science & Medicine*, 75(10), 1874-1882.

Lo, S. H. (2002) The Experience of Developing the Hospice Service in Hospital. *Macau Journal of Nursing*, 1(1), 33-35.

Lo, S. H. (2005) *An investigation and analysis of the spiritual requirement of the terminal cancer patient in Macau*. MSc South China Normal University.

Luczak, J. & Hunter, G. P. (2000) Hospice Care in Eastern Europe. *The Lancet*, 356, S23.

Luk, J. K. H., Chan, W. K., Ng, W. C., Chiu, P. K. C., Ho, C., Chan, T. C. & Chan, F. H. W. (2013) Mortality and Health Services Utilisation Among Older People with Advanced Cognitive Impairment Living in Residential Care Homes. *Hong Kong Medical Journal*, 19(6), 518.

Macao Government (2017) *Health Statistics: 1990-2016.* Macao Documentation and Information Centre of the Statistics and Census Service.23 October 2017].

Macao Information Bureau (2002) *Macao Yearbook 2002.* Macao SAR: Macao Special Administrative Region.

Macao Information Bureau (2010) *Macao Yearbook 2010.* Macao SAR: Macao Special Administrative Region.

Macao Information Bureau (2017) *Macao Yearbook 2017.* Macao SAR: Macao Special Administrative Region.

Mak, M. H. J. (2011) Chinese Secondary Students' Knowledge of, and Attitudes Toward, Death, Dying, and Life Education: A Qualitative Study. *Illness, Crisis & Loss*, 19(4), 309-327.

Maruyama, T. C. (1999) *Hopsice care and culture*. Aldershot: Ashgate Publishing Company.

Mason, J. (2002) *Qualitative researching*, 2nd edition. London: SAGE.

Mason, J. (2018) *Qualitative researching*, 3rd edition. Los Angeles: SAGE.

McAdam, D. (1999) *Political process and the development of Black insurgency, 1930-1970*, 2nd edition. Chicago: University of Chicago Press.

Mellor, P. (1993) Death in high modernity: the contemporary presence and absence of death, in Clark, D. (ed), *The Sociology of Death: Theory, Culture, Practice* Oxford: Blackwell Publishers.

Miles, M. B. & Huberman, A. M. (1994) *Qualitative data analysis: an expanded sourcebook*, 2nd edition. Thousand Oaks: SAGE.

Milićević, N. (2002) The Hospice Movement: History and Current Worldwide Situation. *Archive of Oncology*, 10(1), 29-31.

Mitchell, J. C. (1983) Case and Situation Analysis. *The Sociological Review*, 31(2), 187-211.

Mjelde-Mossey, L. A. & Chan, C. L. W. (2007) Survey on Death and Dying in Hong Kong: Attitudes, Beliefs, and Preferred End-of-Life Care. *Social Work in Health Care*, 45(1), 49-65.

Montoya-Juarez, R., Garcia-Caro, M. P., Campos-Calderon, C., Schmidt-RioValle, J., Gomez-Chica, A., Marti-García, C. & Cruz-Quintana, F. (2013) Psychological Responses of Terminally Ill Patients Who are Experiencing Suffering: A Qualitative Study. *International Journal of Nursing Studies*, 50(1), 53-62.

Morita, T., Tsunoda, J., Inoue, S. & Chihara, S. (2000) An Exploratory Factor Analysis of Existential Suffering in Japanese Terminally Ill Cancer Patients. *Psycho-Oncology*, 9(2), 164-168.

Morse, J. M., Barrett, M., Mayan, M., Olson, K. & Spiers, J. (2002) Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods*, 1(2), 13-22.

Mulholland, R. (1895) Our Lady's Hospice for the Dying. *The Irish Monthly*, 23(269), 585-589.

Napier, A. D., Ancarno, C., Butler, B., Calabrese, J., Chater, A., Chatterjee, H., Guesnet, F., Horne, R., Jacyna, S., Jadhav, S., Macdonald, A., Neuendorf, U., Parkhurst, A., Reynolds, R., Scambler, G., Shamdasani, S., Smith, S. Z., Stougaard-Nielsen, J., Thomson, L., Tyler, N., Volkmann, A.-M., Walker, T., Watson, J., de C Williams, A. C., Willott, C., Wilson, J. & Woolf, K. (2014) Culture and Health. *The Lancet*, 384(9954), 1607-1639.

National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015–2020.* London: NHS England. Available online: http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf [Accessed 14.03.2017].

Nervi, F., Guerrero, M., Reyes, M. M., Nervi, B., Cura, A., Chvez, M. & Derio, L. (2004) Symptom Control and Palliative Care in Chile. *Journal of Pain and Palliative Care Pharmacotherapy*, 17(3-4), 13-22.

Nevada Gaming Control Board (2017) *Annual Nevada Gaming Abstract Reports.* Nevada: Nevada Gaming Control Board.

Ng, W. I. & Ku, W. H. (2010) Experiences of Diagnosis Disclosure of the Cancer Patients in Macau. *Macau Journal of Nursing*, 9(1), 10-15.

Nicolson, P. (2003) Reflexivity, ‘bias’ and the in-depth interview: Developing shared meanings, in Finlay, L. & Gough, B. (eds), *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences* Malden, MA : Blackwell Science, 133-145.

Nixon, A. (2003) Palliative Care in Saudi Arabia: A Brief History. *Journal of Pain & Palliative Care Pharmacotherapy*, 17(3-4), 45.

Palaganas, E. C., Sanchez, M. C., Molintas, M. V. P. & Caricativo, R. D. (2017) Reflexivity in Qualitative Research: A Journey of Learning. *The Qualitative Report*, 22(2), 426.

Pang, M., Wong, K., Dai, L., Chan, K. & Chan, M. (2006) A Comparative Analysis of Hong Kong General Public and Professional Nurses’ Attitudes Toward Advance

Directives and the Use of Life-Sustaining Treatment in End-of-Life Care. *Chinese Medical Ethics*, 3(107), 11-15.

Parahoo, K. (2014) *Nursing research: principles, process and issues*, 3rd edition. Basingstoke: Palgrave Macmillan.

Pastrana, T., Jünger, S., Ostgathe, C., Elsner, F. & Radbruch, L. (2008) A Matter of Definition - Key Elements Identified in a Discourse Analysis of Definitions of Palliative Care. *Palliative Medicine*, 22(3), 222-232.

Patton, M. Q. (2015) *Qualitative research & evaluation methods: integrating theory and practice*, 4th edition. Thousand Oaks: SAGE.

Payerhin, M. & Ernesto Zirakzadeh, C. (2006) On Movement Frames and Negotiated Identities: The Case of Poland's First Solidarity Congress. *Journal of Social, Cultural and Political Protest*, 5(2), 91-115.

Peng, D. & Yongmei, W. (2016) Development of Hospice Care Service for the Elderly in China. *Development and Society*, 45(2), 275-295.

Pillow, W. (2003) Confession, Catharsis, or Cure? Rethinking the Uses of Reflexivity as Methodological Power in Qualitative Research. *International Journal of Qualitative Studies in Education*, 16(2), 175-196.

Porter, R. (1996) *Cambridge illustrated history of medicine*. Cabridge: Cambridge University Press.

Pun, V. (2011) Improving Quality of End of Life Care in Macao Nursing Home, *8th World Congress on Long Term Care in Chinese Communities and Asian Ageing Development Conference.* Macao: Macau Association of Gerontology.

Punch, K. (2014) *Introduction to social research: quantitative & qualitative approaches*, 3rd edition. London: SAGE.

Ragnhild, I. (2014) Framing Integration-from Welfare to Citizenship. *Nordicum-Mediterraneum*, 9(1), A3.

Rajagopal, M. R. & Venkateswaran, C. (2003) Palliative Care in India: Successes and Limitations. *Journal of Pain & Palliative Care Pharmacotherapy*, 17(3-4), 121.

Regmi, K., Naidoo, J. & Pilkington, P. (2010) Understanding the Processes of Translation and Transliteration in Qualitative Research. *International Journal Of Qualitative Methods*, 9(1), 16-26.

Research Ethics Committee of the School of Health in Social Science at the University of Edinburgh (2008) *Research Ethics Framework*.Edinburgh.

Rhee, J. Y., Garralda, E., Torrado, C., Blanco, S., Ayala, I., Namisango, E., Luyirika, E., de Lima, L., Powell, R. A. & Centeno, C. (2017) Palliative Care in Africa: A Scoping Review from 2005–16. *The Lancet Oncology*, 18(9), e522-e531.

Rhymes, J. (1990) Hospice Care in America. *JAMA*, 264(3), 369-372.

Rifkin, D. E. (2010) Feeding the Hungry Ghosts. *The American Journal of Kidney Disease*, 55(1), A33-A34.

Ritchie, J. & Lewis, J. (eds) (2003) *Qualitative research practice: A guide for social science students and researchers*, 1st edition. London: SAGE.

Rubin, H. J. (2012) *Qualitative interviewing: the art of hearing data*, 3rd edition. London: SAGE.

Saunders, C., Baines, M. & Dunlop, R. (1995a) Other components of total pain, *Living with Dying: A Guide to Palliative Care*, 3 editionOxford University Press.

Saunders, C., Baines, M. & Dunlop, R. (1995b) Terminal pain, *Living with Dying: A Guide to Palliative Care*, 3 editionOxford University Press.

Saunders, C. D. (1981) *The founding philosophy*. Surrey: Edward Arnold.

Saunders, C. D. (1990) *Hospice and palliative care: an interdisciplinary approach*. London: Edward Arnold.

Schipper, K. (1985) Vernacular and Classical Ritual in Taoism. *Journal of Asian Studies*, 45, 21 - 57.

Schwandt, T. A. (2007) *The SAGE dictionary of qualitative inquiry*, 3rd edition. London: SAGE.

Searle, J. R. (1995) *The construction of social reality*. London: Allen Lane.

Sham, M. K. & Yang, J. C. (1997) Hospice care and pain management in Nam Long Hospital, Hong Kong. *Journal of Pain and Symptom Management* 13(4), 189-190.

Sham, M. K. M. (2004) Pain relief and palliative care in Hong Kong, in Rajagapol, M., Mazza, D. & Lipman, A. (eds), *Pain and Palliative Care in the Developing World and Marginalized Populations: A Global Challenge* CRC Press, 65-73.

Sherman, D. W. (2000) Access to Hospice Care. *Journal of Palliative Medicine*, 3(4), 407-411.

Silverman, D. (2014) *Interpreting qualitative data*, 5th edition. Los Angeles: SAGE.

Silverman, D. (2017a) *Doing qualitative research*, 5th edition. Los Angeles: SAGE.

Silverman, D. (2017b) Quality in qualitative research, in Silverman, D. (ed), *Doing Qualitative Research*, 5th edition. Los Angeles: SAGE, 376-399.

Simons, H. (2009) *Case study research in practice* London: SAGE.

Snow, D. A. & Benford, R. D. (1988) Ideology, Frame Resonance, and Participant Mobilization. *International Social Movement Research*, 1(1), 197-217.

Snow, D. A., Benford, R. D., McCammon, H. J., Hewitt, L. & Fitzgerald, S. (2014) The Emergence, Development, and Future of the Framing Perspective: 25+ Years Since "frame alignment". *Mobilization*, 19(1), 23-45.

Snow, D. A., Rochford, E. B., Worden, S. K. & Benford, R. D. (1986) Frame Alignment Processes, Micromobilization, and Movement Participation. *American Sociological Review*, 51(4), 464-481.

Society for the Promotion of Hopsice Care (2018) *SPHC: Our Mission.* Hong Kong: Available online: http://www2.hospicecare.org.hk/who-we-are/our-mission-goal/ [Accessed 23.07.2018].

Spencer, L., Ritchie, J., Ormston, R., O'Connor, W. & Barnard, M. (2014) Analysis: principles and processes, in Ritchie, J., Lewis, J., McNaughton Nicholls, C. & Ormston, R. (eds), *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, 2nd edition. Los Angeles: SAGE, 269-290.

Stake, R. (2000) Case studies in Denzin, N. & Lincoln, Y. (eds), *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications, 435-455.

Stake, R. E. (1995) *The art of case study research*. London: SAGE.

Stake, R. E. (2003) Case studies, in Denzin, N. K. & Lincoln, Y. S. (eds), *Strategies of Qualitative Inquiry*, Second edition. London: SAGE, 134-164.

Takesaka, J., Crowley, R. & Casarett, D. (2004) What is the Risk of Distrss in Palliative Care Survey Research? *Journal of Pain and Symptom Management*, 28(6), 593-598.

Tang, L. & Silbermann, M. (2017) Palliative Care Gains Roots in China. *Journal of Palliative Care & Medicine*, 7, e140.

Taylor, H. (1983) *The hospice movement in Britain: its role and its future* London: Centre for Policy on Ageing.

Teng, W. S., Lin, M. H., Hwang, S. J., Chen, T. J. & Chou, L. F. (2013) Palliative Care in Taiwan. *Journal of Pain and Symptom Management*, 46(5).

The Gaming Inspection and Coordination Bureau of Macao (2017) *Gaming Statistics.* Macao SAR: The Gaming Inspection and Coordination Bureau of Macao. Available online: http://www.dicj.gov.mo/web/en/information/DadosEstat/index.html [Accessed 21.05.2018].

The Government Information Bureau of Macao SAR (2011) *Resources Centre for Cancer Patients in the Conde Hospital San Januário* Macao: Available online: http://www.gcs.gov.mo/showNews.php?DataUcn=53158&PageLang=C [Accessed 13.04.2012].

The Patient Autonomy Act (2015) *The Patient Autonomy Act*.The Republic of China (Taiwan).

The Printing Bureau Macao (1995) *Macau Medical Mission.* Macao: The Government of Macao Special Administrative Region. Available online: http://en.io.gov.mo/Priv/record/3086.aspx [Accessed 13.04.2012].

the Printing Bureau Macao (1996) *Association of Friends of Charity of Macau.* Macao: The Government of Macao Special Administrative Region. Available online: http://cn.io.gov.mo/Priv/record/39.aspx [Accessed 13.04.2012].

The World Bank (2017) *Land Area: China.* The World Bank. Available online: https://data.worldbank.org/indicator/ag.lnd.totl.k2 [Accessed 21.05.2018].

Thomas, G. (2016) *How to do your case study*, 2nd edition. London: SAGE.

Tilley, L. & Woodthorpe, K. (2011) Is It the End for Anonymity as We Know It? A Critical Examination of the Ethical Principle of Anonymity in the Context of 21st Century Demands on the Qualitative Researcher. *Qualitative Research*, 11(2), 197-212.

Ting, F. H. & Mok, E. (2011) Advance Directives and Life-Sustaining Treatment: Attitudes of Hong Kong Chinese Elders with Chronic Disease. *Hong Kong medical journal*, 17(2), 105.

Trépo, C., Chan, H. L. Y. & Lok, A. (2014) Hepatitis B Virus Infection. *The Lancet*, 384(9959), 2053-2063.

Tsai, J. S., Wu, C. H., Chiu, T. Y., Hu, W. Y. & Chen, C. Y. (2005) Fear of Death and Good Death Among the Young and Elderly with Terminal Cancers in Taiwan. *Journal of Pain and Symptom Management*, 29(4), 344-351.

Tsai, S. & Huang, L. (2015) Hospice Palliative Care Issues in Cerebrovascular Diseases: A Nursing Experience in Taiwan. *Cerebrovascular Diseases*, 40(suppl 1), 71-72.

Tse, C. Y. (2018) *Advance Care Planning and Advance Directives in Hong Kong: Concepts and Developments.* Hong Kong: The CUHK Jockey Club Institute of Ageing. Available online: https://www.ioa.cuhk.edu.hk/en-gb/casebook/backgrounders/advance-care-planning-and-advance-directives-in-hong-kong-concepts-and-developments [Accessed 21.06.2018].

Tung, W. (2011) Hospice Care in Chinese Culture: A Challenge to Home Care Professionals. *Home Health Care Management & Practice*, 23(1), 67-68.

Tung, W. C. & Li, Z. z. (2015) Pain Beliefs and Behaviors Among Chinese. *Home Health Care Management & Practice*, 27(2), 95-97.

Turner, R. H. (1969) The Theme of Contemporary Social Movements. *The British Journal of Sociology*, 20(4), 390-405.

Twinn, S. (1997) An Exploratory Study Examining the Influence of Translation on the Validity and Reliability of Qualitative Data in Nursing Research. *Journal of Advanced Nursing*, 26(2), 418-423.

United Nations (2017) *World population prospects 2017: Total population.* United Nations Population Division,. Available online: https://esa.un.org/unpd/wpp/ [Accessed 21.06.2018].

Vainio, A. (2013) Beyond Research Ethics: Anonymity as 'Ontology', 'Analysis' and 'Independence'. *Qualitative Research*, 13(6), 685-698.

Wang, P. N. (2013) Promoting Palliative Care in Patients with Motor Neuron Disease in Taiwan. *Journal of the Chinese Medical Association*, 76(7), 361-362.

Wang, X. S., Di, L. J., Reyes-Gibby, C. C., Guo, H., Liu, S. J. & Cleeland, C. S. (2004) End-of-Life Care in Urban Areas of China: A Survey of 60 Oncology Clinicians. *Journal of Pain and Symptom Management*, 27(2), 125-132.

Wang, Z., Li, Y. S., Zhao, N., Yang, J. J., Tu, H. Y. & Wu, Y. L. (2016) Do-Not-Resuscitate Orders among Advanced-Stage Chinese Lung Cancer Patients Who Died in Hospital. *Supportive Care in Cancer*, 24(4), 1763-1769.

Wen, K.-Y., Lin, Y.-C., Cheng, J.-F., Chou, P.-C., Wei, C.-H., Chen, Y.-F. & Sun, J.-L. (2013) Insights into Chinese Perspectives on Do-Not-Resuscitate (DNR) Orders from an Examination of DNR Order Form Completeness for Cancer Patients. *Supportive Care in Cancer*, 21(9), 2593-2598.

Weng, L., Joynt, G., Lee, A., Du, B., Leung, P., Peng, J., Gomersall, C., Hu, X. & Yap, H. (2011) Attitudes Towards Ethical Problems in Critical Care Medicine: the Chinese Perspective. *Intensive Care Medicine*, 37(4), 655-664.

Wiles, R., Crow, G., Heath, S. & Charles, V. (2008) The Management of Confidentiality and Anonymity in Social Research. *International Journal of Social Research Methodology*, 11(5), 417-428.

Williams, R. S. (2016) Managing Bodies, Managing Persons: Postmortem Care and the Role of the Nurse. *New Bioethics*, 22(2), 133-147.

Wolf, Z. (1986) *Nursing rituals in an adult acute care hospital: An ethnography*. PhD University of Pennsylvania.

Wong, K. M., Choa, M., Leong, I. S., Wong, I. L. & Leong, S. M. (2002) Cognition and Attitude of the Nurses in Kiang Wu Hospital of Macau Towards Hospice Service. *Macau Journal of Nursing*, 1(1), 15-17.

Wong, S. H. (2012) Does Superstition Help? A Study of the Role of Superstitions and Death Beliefs on Death Anxiety amongst Chinese Undergraduates in Hong Kong. *OMEGA*, 65(1), 55-70.

World Health Organisation (1998) *WHO Definition of Palliative Care.* WHO. Available online: http://www.who.int/cancer/palliative/definition/en/ [Accessed 04.07.2016].

World Health Organisation (2016) *WHO Definition of Palliative Care.* WHO. Available online: http://www.who.int/cancer/palliative/definition/en/ [Accessed 04.07.2016].

Wright, D. N. M., Wood, J., Lynch, T. & Clark, D. (2006) *Mapping levels of palliative care development: a global view*. Lancaster: Lancaster University.

Wright, M., Hamzah, E., Phungrassami, T. & Bausa-Claudio, A. (2008a) *Hospice and palliative care in South-eastern Asia: A review of developments and challenges in Malaysia, Thailand and the Philipines*. Lancaster: Lancaster University.

Wright, M., Wood, J., Lynch, T. & Clark, D. (2008b) Mapping Levels of Palliative Care Development: A Global View. *Journal of Pain and Symptom Management*, 35(5), 469-485.

Xia, Y. (2016) Collective Action Frame and Cultural Context: A Study of the Anti-Express-Rail-Link Movement in Hong Kong. *Chinese Journal of Sociology*, 2(2), 300-323.

Yang, S. C. & Chen, S. F. (2009) The Study of Personal Constructs of Death and Fear of Death Among Taiwanese Adolescents. *Death Studies*, 33(10), 913-940.

Yeo, S. S., Meiser, B., Barlow-Stewart, K., Goldstein, D., Tucker, K. & Eisenbruch, M. (2005) Understanding Community Beliefs of Chinese-Australians about Cancer: Initial Insights Using an Ethnographic Approach. *Psycho-Oncology*, 14(3), 174-186.

Yick, A. G. & Gupta, R. (2002) Chinese Cultural Dimensions of Death, Dying, and Bereavement: Focus Group Findings. *Journal of Cultural Diversity*, 9(2), 32.

Yin, J. (2006) Death from the Buddhist view: Knowing the Unknown, in Chan, C. & Chow, A. (eds), *Death, dying and bereavement: A Hong Kong Chinese experience*, 93-103.

Yin, R. K. (2014) *Case study research: Design and methods*, 5th edition. London: SAGE.

Yin, Z., Li, J., Ma, K., Ning, X., Chen, H., Fu, H., Zhang, H., Wang, C., Bruera, E. & Hui, D. (2017) Development of Palliative Care in China: A Tale of Three Cities. *The Oncologist*, 22(11), 1362-1367.

Yu, X. (2007) Death and Dying in the Chinese Culture: Implications for Health Care Practice. *Home Health Care Management & Practice*, 19(5), 412-414.

Zeng, T., Chen, F., Yang, X. & Fang, P. (2008) Investigation on Attitudes of the Patients with Cancer Towards the Treatment of Advanced Cancer and Death. *Journal of Nursing Science*, 23(7), 71-73.

Zhan, H. J., Feng, Z., Chen, Z. & Feng, X. (2011) The Role of the Family in Institutional Long‐Term Care: Cultural Management of Filial Piety in China. *International Journal of Social Welfare*, 20, S121-S134.

Zhang, Z., Chen, M. L., Gu, X. L., Liu, M. H. & Cheng, W. W. (2015) Cultural and Ethical Considerations for Cardiopulmonary Resuscitation in Chinese Patients With Cancer at the End of Life. *American Journal of Hospice and Palliative Medicine*, 32(2), 210-215.

Zhou, Y. (2016) Care Issues at the End-of-Life in China. *Development and Society*, 45(2), 231-254.

Appendix 1: Interview guide

Appendix 1.1: Interview guide - English version – Community & Hospice initiators/ developers

Thank you for taking time to take part in this interview today. I am Kuai In Tam, PhD student at The University of Edinburgh, and I am the researcher of this study. The interview today will last for approximately 45 to 60 minutes and it will be an one off interview, no other interview will be required after. You have the right not to answer any particular questions during this interview.

The entire interview will be recorded digitally and the recording is confidential, no one else except me and my 2 supervisors will have access to the information. You will be kept anonymous and you will be represented by a reference number. I will not be sharing information about you or your interview with any third-party. Do you have any questions regarding this interview or the study?

Recording begins:

- Could you tell me a bit about yourself and your professional background?
- How and when did you become aware of EoLC?
- What brought you to EoLC? Is there any particular (personal/professional) experience that prompted your interest?
- When did you start being involved in the development of EoLC in Macao?
- Were there any particular reasons that lead you to develop/involve in developing EoLC?
- When you first started, what was the situation of EoLC at that time?
    - ➢ How did the healthcare system/society handle the terminally ill and their families at that time?
    - ➢ Was there any other services that you know of?
    - ➢ What kind of support did you receive when you first started EoLC in Macao? (Initiators)

  - What does EoLC (concept/ service) in Macao entail in your opinion?
  - What was your initial goal?
- In your opinion, what were the most important elements when you were starting/developing the EoLC in Macao?
- Were there any challenges in developing EoLC in Macao?
  - What were they?
  - What elements do you think, impact the most in the development of EoLC?
- What was the (professional /public) reaction at the beginning?
  - Reaction after EoLC introduction?
  - In your opinion, how do you think the society of Macao is adjusting to EoLC after it was introduced?
- Because of your background, do you think there is any differences between developing EoLC in Macao and in the west? (For community initiator)
- Over the years of your involvement in EoLC in Macao, did you notice any changes? (Service/public/professional perception/understanding)
- Do you think the EoLC in Macao now is adequate? Do you think it needs to be improved/changed?
- Anything else you want to comment/ add?
- Would you like a copy of your interview transcription?

Appendix 1.2: Interview guide - English version – Nurse Educators

Thank you for taking time to take part in this interview today. I am Kuai In Tam, PhD student at The University of Edinburgh, and I am the researcher of this study. The interview today will last for approximately 45 to 60 minutes and it will be an one off interview, no other interview will be required after. You have the right not to answer any particular questions during this interview.

The entire interview will be recorded digitally and the recording is confidential, no one else except me and my 2 supervisors will have access to the information. You will be kept anonymous and you will be represented by a reference number. I will not be sharing information about you or your interview with any third-party. Do you have any questions regarding this interview or the study?

Recording begins:

- Could you tell me a bit about yourself and your professional background?
- How and when did you become aware of EoLC?
- What brought you to EoLC? Is there any particular (personal/professional) experience that prompted your interest?
- Were there any particular reasons that lead you to be involved in teaching/promoting EoLC?
- When did EoLC become apparent in public promotion/ nursing education in Macao?
- When did you start/ begin to become involved in teaching/ promoting about EoLC?
    - ➢ Were there other education services available that you know of?
    - ➢ Was there a particular area/subject you focus on?
    - ➢ Did you receive any kind of support in starting teaching/promoting EoLC?
    - ➢ Could you tell me about the concept/ elements of EoLC that is involved in your teaching? Any particular emphasis you try to convey?
    - ➢ What was your initial goal?

    - What elements do you think is important in teaching/promoting EoLC in the context of Macao?
- What was the reaction at the beginning?
- Over the years of your involvement in EoLC in Macao, did you notice any changes regarding students' attitude towards EoLC? Or changes beyond nursing education?
- Were there any challenges in developing and delivering EoLC education?
    - What were they?
    - What elements do you think, impact you the most?
- What is your thought on EoLC education in the future?
- Anything else you want to comment/ add?
- Would you like a copy of your interview transcription?

Appendix 1.3: Interview guide - Chinese version – Nurse Educators

訪談指引: 有關澳門臨終關懷的質性研究

本研究採用一次性的深度訪談法，訪談時間預計 45 至 60 分鐘。

為便於資料的整理與分析，將於訪談過程中全程數碼錄音。對所有有關本研究的資料，只有本人及課程督導才會得到，而所有資料亦會嚴謹按保密的原則來進行處理。在研究結果中，所有參與者的信息以匿名儲存，並以研究代號標記。本人很高興亦很感謝閣下願意參與成為此研究的訪談對象。在開始前想先邀請你簽署自願參與的同意書，亦不想署名，可在錄音記錄說明自願參與同意。

<< 錄音開始 >>

若有需要:在此時錄音記錄說明自願參與同意

訪談內容

個人對臨終關懷的接觸及理解

1. 你從什麼時候開進入護理教育行業?
2. 你是什麼時候開始涉及到有關生死及臨終關懷的護理教育呢? 而你所涉及的有那些範疇?
3. 為何要選擇這些內容?是否對你個人來說有著某種意義?
4. 從你個人的觀察, 澳門護理教育在那個時候有開始涉及一些有關生死及臨終關懷的教育? 範疇有那些?
5. 現時澳門護理教育,有無一個系統性的臨終關懷的教育, 其實在那個時候開始有一些比較系統性的 臨終關懷教育出現?
6. 現時澳門護理基礎教育上,有關臨終關懷的課題大概包含了那些內容? 實習?課本?
7. 而你個人認為, 在澳門有關臨終關懷教育課題上, 那方面的內容是對澳門這社會比較重要的?需要強調的呢?
8. 在學育有關生與死, 臨終關懷的課題上,你應為外界對於你的支持有多少? 病房以及社區?

9. 在現時澳門護理教育上,所涉及到臨終關懷及生與死教育的範疇多嗎?除你以外,還有其他老師對有關課題都在教學呢?

學生們表現

10. 在你教學生涯這段時間內,從你個人的觀察,當學生剛剛開始接有關生與死的課題時,他們的態度是怎樣?
11. 在你教導有關生與死、臨終關懷的課題的過程中,你認為學生們對此課題的接受程度是如何?他們對此服務有什麼表達?
    - 有什麼原因令他們接受? 或對此有興趣?
    - 有什麼原因令他們不接受? 或對此沒有有興趣?
12. 出房完/學習完, 學生的反朒/應又是如何? 能幫助到他們將來在病房的工作嗎? 有令他們改變看法嗎? 會令他們有向社區發展此服務的感受嗎?
13. 你在教授有關臨終關懷的課題過程中, 有遇上什麼樣的問題嗎?
    - 在遇上的問題上, 有否改變?
14. 當你在護理教育這些年中, 有關臨終關懷的教育的範圍有沒有擴大,或減少?
15. 你認為現時澳門臨終關懷在護理教育上足夠嗎?
16. 你認為現有的澳門臨終關懷教育,在將來需要有些改變嗎?
17. 你臨終關懷在整個護理教育中,重要嗎?為什麼?
    - 在你個人的觀察上, 社會對於有關臨終關懷的看法有沒有改變?
    - 你在接受臨終關懷教育前對此服務的理解是什麼?有多少?
    - 你在接受臨終關懷教育后對此服務的理解有改變嗎?

十分感謝您對本研究的參與及支持!

<< 錄音完畢 >>

Appendix 2. Invitation Pack

Appendix 2.1: Invitation Pack – English version – Information Sheet

Research Title: A qualitative case study analysis of the development of end of life care in Macao

My name is Kuai In Tam and I am a PhD student at the University of Edinburgh. As part of the requirements of my PhD degree in Nursing Studies, I am conducting a qualitative research, focusing specifically on the end of life care in Macao. The core of my study is to understand and discuss the initiation and the development of end of life care in Macao. In order to achieve this objective, my study aims to engage people who have played a significant part in developing this care in Macao.

Therefore, I would like to invite you to participate in this study. The following information provides you a more detailed description of this research and what is required for participation.

Background of the research

Cancer, circulatory diseases and chronic illnesses have overtaken many acute diseases to become the major causes of death in contemporary Macao society. Mortality related to cancer, in particular, has been on the rise since 1991. By 2010, the mortality rate of cancer had doubled and accounted for one third of the total death population in Macao, while the number of the total death population has remained stable. The growing prevalence on cancer and chronic illnesses has marked an increasing demand on end of life care in Macao. Based on this shifting dynamics of care, this research aims to understand the initiation and development of end of life care in Macao, in order to provide an outlook for future advancement.

Purpose of the research

Centred on the realm of end of life care, this research is proposed to investigate the development of end of life care in the context of Macao. This study is particularly interested in the founding ideas and concepts of the current end of life care that key initiators and developers have adopted and developed. Furthermore, in considering the close bond shared between nursing and end of life care, this research is also interested in exploring nurse educators' understandings on end of life care and how they communicate the knowledge of end of life care to student nurses. The result of this research seeks to serve as a foundation for the future development of end of life care in Macao, on both practical as well as theoretical levels.

Because of your background and contribution into the initiation and development of end of life care and your experience in relation to end of life care in Macao, your knowledge will be immensely beneficial for this project. Therefore, I would like to invite you to participate in this study, in order to assist with the understanding of the end of life care in Macao.

Requirements upon participation

This research will involve your participation in an interview. The interview will last for approximately 45 to 60 minutes and it will be an one off interview, no other interview will be required after. The process of this interview will allow me to explore solely from your perspective and understanding on end of life care in particular reference to the context of Macao. The interview will take place in a protected and secure environment arranged by me or a secure place you prefer.

You do **not** have to answer any question or take part in the interview if you feel the question(s) are too personal or sensitive. Although there will be no known direct benefit to you, your participation is likely to help enhancing the current understanding in relation to end of life care in Macao.

Confidentiality

The entire interview will be recorded digitally and the recording is confidential, no one else except me and 2 of my academic supervisors will have access to the information. You will be kept anonymous and you will be represented by a reference number and a corresponding reference code will be assigned to your interview. I will not be sharing information about you or your interview with any third-party. The recording and transcription of your interview will be kept in a locked and secure place for a maximum of five years after the end of the research and will then be destroyed safely and securely.

Voluntary Participation

Your participation in this research is entirely voluntary. You may change your mind later and stop participating even if you agreed earlier. You may ask to have a copy of your recording and transcript and you may ask to have your data withdrawn or destroyed at any time.

If you are interested in participating in the study, you can do so by contacting me through my contact details below. If you have any questions, please do not hesitate to contact me.

Thank you very much for taking the time to read this information and hope to hear from you soon.

Contact details

Kuai In Tam

Macao Address: Kiang Wu Nursing College of Macau
Est. Repouso No.35, R/C
Macau

U.K. Address: The University of Edinburgh
Nursing Studies
Medical School
Teviot Place
Edinburgh
EH8 9AG

Mobile Tel: (853) 66640956

Email: kuaiin919@gmail.com or k.i.tam@sms.ed.ac.uk

Appendix 2.2: Invitation Pack – Chinese version – Information Sheet

事由：邀請參與[有關澳門臨終關懷的質性研究]

尊敬的 xx 台鑒:

敬啓者：本人譚瑰賢，在澳門中學畢業後赴英學習護理專業。現就讀英國愛丁堡大學人文與社會科學學院 護理博士研究課程。 承蒙　閣下的支持下，現有幸能於澳門鏡湖護理學院參與交流生計劃，以助本人的博士研究進行有關於澳門臨終關懷的質性研究工作。

現誠邀　閣下為本研究的訪談對象，以更多理解澳門這方面課題的實際情況，並懇請　閣下閱讀以下有關本研究的資料，以助清楚這項研究的目的。

研究背景

正如很多生命中注定的事---生、老、病、死，是一個無可避免的切身問題。就目前醫學的發展，並沒有任何措施可以避免死亡。對於末期病患的病人及其家屬，即將來臨的死亡問題可以伴隨著很多精神上，肉體上及生理上的痛苦與折磨。雖然醫學技術沒有治癒他們的能力，但臨終關懷就是致力於紓緩他們的痛苦以及維護他們的尊嚴。

在澳門，癌症、循環系統疾病以及慢性疾病的患病及死亡率已超越許多急性疾病，成為澳門社會主要死亡的原因。與癌症相關的死亡人口，自 1991 年以來也一直上升。至 2010 年為止，與癌症有關的死亡人口已增加了一倍，佔澳門總死亡人口的三分之一。

在癌症和慢性疾病的死亡率不斷增長的情況下，對澳門臨終關懷及其服務的需求也不斷增加。澳門第一所與臨終關懷有關的服務成立於 1996 年。在獲得澳門政府的支持下，第一所具有醫護性質的臨終關懷住院服務於四年後(2000 年)成立。基於此所臨終關懷住院服務上，本研究的目的就是要為了更進一步探討及理解澳門的臨終關懷及其服務的發展。

研究目標

本研究會就澳門的獨有背景條件下，為臨終關懷的思維及觀念進行以理論為中心的調查。理論與實踐是相互相成的，要輔助臨終關懷的整體發展，必要先熟悉理解理論基礎，再進而計劃實踐。因此，本研究對澳門臨終關懷的建基思維及觀念特別感興趣。此外，臨終關懷的核心價值包括為病者及其家屬提供全人的照護。在提供全人照護的過程中，護理服務扮演著一不可或缺的重要角色。就此，亦希望從護理基礎教育的角度，了解分析澳門護理教育在臨終關懷領域上的傳譯。考慮到護理和臨終關懷之間的緊密關係，本研究望探索護理教育者對澳門現有臨終關懷的理解，以及他們如何與護士學生溝通關於臨終關懷的知識。本研究旨望能為成為澳門臨終關懷未來發展的一個基礎，不論在臨床或理論水平上，促成更全面的發展。本人亦希望通過本次學習，使對澳門臨終關懷的認知情況及研究能力有不同程度的提升，以至本人能夠從中得到全面的成長。

素仰　閣下對澳門臨終關懷的工作貢獻良多。現誠邀　閣下為本研究的訪談對象，以更多理解澳門這方面課題的實際情況。

研究方法

本研究採用一次性的深度訪談法，訪談時間預計 45 至 60 分鐘。訪談地點可由閣下決定採用您認為合適的地點。在訪談過程中，如有某些問題或有所顧忌，可以拒絕回答，亦可隨時要求中止訪談。雖然　閣下不會因參與這研究而直接有所受益，但因有您的真誠參與，對臨終關懷在澳門的發展、以及促進和改善相關的社會服務及需求，可提出更多寶貴的參考依據。

保密

訪談過程中全程數碼錄音。訪談錄音的內容及訪談過程的筆錄僅供研究資料分析用。除了本人及課程督導外，沒有其他人能獲得全部訪談的資料。所有與參與者有關的信息會以匿名儲存，更會嚴謹按保密的原則來進行資料處理。匿名的

訪談記錄和轉錄將儲存在加鎖保密的地方，存放期限由研究結束後算，最多五年，期限後所有資料將被安全地銷毀。

自願參與

本研究希望 閣下是自願參與的。您有絶對的權力去決定參加這項研究與否。參與中途您若改變主意，您有絶對的決定權去停止參與。您亦不用為您的決定作任何解釋或承擔。

本人現誠邀 閣下參與為本研究的訪談對象。若能得到 閣下的答應，懇請致電或通過電郵回覆參與決定及適合為 閣下的訪談日期，同意書可在訪談當天交回。有關研究的任何問題，歡迎隨時指正，本人會誠懇及虛心接受 閣下提出的寶貴意見，敬請通過以下細節與我聯繫。

耑此

順祝

台安

英國愛丁堡大學 人文與社會科學學院 護理研究系

博士研究生 譚瑰賢 謹啟

聯絡人： 譚瑰賢 Kuai In Tam

研究工作地址： 澳門鏡湖護理學院(本澳)

電話： (+853) 66640956 (+44) 7500338209

電子郵件地址： kuaiin919@gmail.com k.i.tam@sms.ed.ac.uk

Appendix 2.3: Invitation Pack – English version – Certification of Consent

Certification of Consent

Name of Study: A Qualitative Examination on End of Life Care in Macao

1. I have read and understand the information on the information letter in relation to the abovementioned study.

   Yes / No

2. I have had the opportunity to raise questions about my participation in this interview and I am aware the potential risks in participating in this interview.

   Yes / No

3. I understand and agree to be digitally recorded through the interviewing process.

   Yes / No

4. I understand and agree that all information related to me and my interview will be kept anonymous and confidential throughout the research process and for a further maximum of five years, then all information will then be destroyed safely and securely.

   Yes / No

5. I consent voluntarily to be a participant in the abovementioned study.

   Yes / No

Print Name of Participant ________________________

Signature of Participant ________________________

Date ________________________

Day/Month/Year

Appendix 2.4: Invitation Pack – Chinese version – Certification of Consent

事由：邀請參與[有關澳門臨終關懷的質性研究]

同意書

1. 我已閱讀並了解上述邀請函內有關研究的信息。

   是　/　不是

2. 我有機會就參與此研究訪談上提出問題。我亦了解參與此研究訪談的潛在風險。

   是　/　不是

3. 我了解並同意訪談全程被數碼錄音及筆錄。

   是　/　不是

4. 我了解並同意，在整個研究過程中，有關我及與我訪談相關的所有信息將保持匿名及保密。我亦了解並同意所有資料會在研究結束後算，存放最多 5 年，期限後所有資料將被安全地銷毀。

   是　/　不是

5. 我自願同意參與上述的研究。

   是　/　不是

參與者名稱：________________

參與者簽署：________________

日期：________________

年/月/日

見證者名稱：________________

見證者簽署：________________

日期：________________

年/月/日

Appendix 3. Analysis Memo

Appendix 3.1: Analysis memo_P007

P007_ Analysis Memo

Negativity on the discussion of death

Word frequency test run on the transcript of P007

Word	Count	Similar Words
Life	103	Life
Care	90	Care, caring
Death	64	Death
Home	59	Home, homes
Need	51	Needs, needed
Family	49	Family ,families
Nurses	41	Nurse, nursing
Education	40	Education, educational, educators
Community	39	Communities
Hope	38	Hope, hoped, hopefully, hoping
Fear	31	Fear, scared, afraid

Reference Frequency

Name of Code	Number of Reference
Cultural_Fear_Of_Death	13
Cultural_Tendency_to_go_Acute_Care_Settings	10
Professional_The_Importance_Of_Clinical_Expertise	8
Conceptual_Public_Health_Knowlege_Deficient	7
Cultural_Reliance_Personal_Relationship	7
Conceptual_Public_Awareness_Still_Weak	6
Cultural_Taboo_Death	6
Cultural_Qualities_In_Civil_Kowledge_Standard_Is_Low	6
Cultural_Rejction_Death	6
Education_Emphasis_On_Community_Education	6

These two participants have really mastered the core values of palliative care. The emphasis on spiritual and psychological care on patients and families as well as the recognition of the importance of clinical expertise in order to perform palliation of symptoms. These are the key elements of palliative and end of life care. Perhaps they are Christian based(?), they have managed to adhere to the origin of palliative care.

However, I do not see any integration of the Chinese culture into their practice. It can still be seen as relatively isolated within their own boundary. (The division)

The two participants of this interview, both of them have nursing background, one remains as a nurse and one became a Chaplain. But both have strong beliefs in Christianity. As they work for the same Christian healthcare organisation serving the community of Macao.

As described by P007b, it shows that the X Clinic of Macao was the first to offer home based healthcare service in Macao, dominantly delivered by community nurses. (P007_P007b_10)

Despite attempts were made to establish collaboration between gov. hospital and the clinic in providing a more comprehensive end of life care service in the community in Macao, due to political restriction on the use of controlled drugs, or rather, due to the non-existence policy in relation to this area, collaboration has never been made, and the service offered by the clinic is restricted with merely home visit, with no pharmaceutical input for patients.

Being a Western missionary based service runs mainly by foreign missionaries, the clinic decided that the local people of Macao should take over the management and operation of this service and continue to deliver the service through them. This transition of management of this end of life home care service marked that the service was no longer something foreign and introduced by an external source. It is a local service, provided by and provided for local people of Macao. In addition, other local forces were asked to assist with the independence of the service during the process.

P007a	＝ｅｒm:: 其實呢就ｅｒ: 開始既時候唔係話好熱切，‘哎呀！’｛熱情的表達｝即〔係〕咁容易就，呀！接受我地既關心，就算話我地都係完全免費既其實哩個服務。咁唔係咁－多－病人係即〔係〕好主動架。ｅｒ．多數都係，即〔係〕因為我地有基督教既背景，好多時即〔係〕ｅｒ．教會既弟兄姊妹呀，佢地呢，就知道我地有哩個服務。咁ｅｒ介紹佢地既家人既病人，咁ｅｒ黎我地哥度。多數都係ｅｒ，即〔係〕有人介紹囉。好少即〔係〕病人係主動既，開始哥幾－兩三年都真係比較少既其實。咁呢就，好記得ｅｒ．好深刻印象就係第一個病人，姓陳既。咁呢即［係］當我真係好願意啦，係男性黎架，好願意去－去，比我地去探訪，因為係一個義工轉介既。咁就ＥＲ:: 但係呢，就感受好深，就係ＥＲ:: **隔離鄰舍呢，都好排斥佢**，因為佢有哩個癌症。驚話傳染呀，驚即［係］係囉，佢地都遠離遠——疏離佢既。即［係］ＥＲ——ＥＲ保持距離既。但係佢話‘呀:: 我地都同你都唔－－唔熟識既，又唔認識既，點解你地咁樣關心我呢？’哈哈｛微笑｝咁樣。我地又，即［係］同佢分享話，因為我地有主耶穌既愛都希望同－用哩份愛黎去ＥＲ·即［係］同你分享，去關心你，咁樣。咁·即［係］建立得好好個關係，直到到現在，佢個太太:: 哈哈｛會心笑｝都有同我地接觸，有時都買Ｄ野黎診所呀，咁樣。間中都會·哩段時間間中即［係］都·有·下。疏左Ｄ啦，之前好密切，係呀。

Client not passion not accepting the service

- It could be that they don’t know about this service and they are not familiar with this service. Only can be recommended by relatives to be able to know about this service.
- Client questioning the love and care that has been given to them
- Not used to / cannot belief why this love and care is given to them

This Christian based social organisation “the foreign organisation” are focusing more on the establishment of relationship with the clients and its relationship with the other organisations in Macao.

This Christian organisation as the outsider needs to get into the circle of relationship and therefore they want to pass this service back to the local people, in order for them to be accepted as the local, the insider.

Whereas the local organisation is worried more about the resources that is being given. They are the insiders - these organisations already had the necessary “relationships” and what they are looking more is to be able to get more resources.

P007a	仲係好（（避））諱哩個話題。係呀。ｅ ｒ:: 對哩個死亡既話題，好害怕，好怕涉及去，因為可能中國人既思想呢，即〔係〕覺得係好——好不吉利呀，講哩ｄ說話好不吉利呀，下。咁呢所以．如果咁既時候，我地探訪都會（（有））一定既難度。就當我地想涉及哩個話題既時候好需要有種技術咁樣，技巧咁樣樣。唔係想上——上度黎講．ｏ夏ｏ夏｛夾雜笑聲｝家人或者病人都係唔願意接受。就算有ｄ病人去到臨終．佢都係唔願意接受哩個觀念，下。唔覺得 - 即〔係〕佢覺得，佢知道認識死亡係會係佢身邊，即將發生架啦。但係佢仍然推開佢，佢唔願意接受，拒絶一切既．身 - 係佢身上面發生既事。所以帶好多忿怒呀，帶好多佢情緒裏邊既掙扎呀。

The cultural taboo towards death are being manifested in many ways.

Avoidance

- Avoiding talking about it, avoiding anything to do with it- cause major communication failure between patient and family, patient and professional, family and professionals

Rejection

- Client and family will reject the fact of impending death. The cultural taboo has given them a pathway for rejection.

Therefore, avoidance and rejection will the manifest themselves to become anger. A lot of anger and resentment that cannot be express – then it will go back to the cycle of avoidance

The role of professional here is to break through this cycle. And dig a way that can let these anger and resentment to expel out of this cycle. This process is not linear and it is a cycle.

According to P007, they mentioned 3 things that can help to reduce the fear towards death

- Christian Beliefs
- The other is detail explanation of the available service and encourage them to use the hospice service.

- Relationship and information achieved from other patient friends. If other people have experienced it and they have personally known these people, they will listen to them and accept their explanation about the service.

P007b	＝因為ｅｒ，我都補充番就係，就係因為我有聽·到…如果講生死教育，既話啦，就好似一剎ｅｒ麻藥咁。即［係］麻醉藥，我既麻醉藥。即［係］話好似ｅｒｍ，一種放棄。好似彷彿講生死呢個話題，我講病人啦，唔講普通既平民呀或者普通人。就好似呢，叫佢放棄，唔再奮鬥。下。因為話生死你就接受啦，但係生命就係咁樣架啦，下，規律架啦。即［係］有…一點咁既體法既時候呢，從而都係一種抗·一種咩呀，阻礙力呀。阻礙力呀，即［係］因為ＥＲ，係我ＥＲ，聽到或者係我自己實——際既觀察裏邊呢，ＥＲ哩個都係一部分既病人家人呢，所拒絕既。＂唔好同我講＂＂你唔好同我講哩部分既話題＂＂我而家係治病，而家係治療。＂＂我要呢一往·咩·勇往直前，下。哩Ｄ呢，只係一種，亦都係一種障礙、阻礙。亦都係一種阻礙。無涉及哩個話題。

Very interesting point made by P007b.

Life and death education is being symbolised as a dose of anaesthetics, it is somehow felt by the patients that once they have been anaesthetised, although they won’t feel the pain of impending death, it is all but a dream. But one day, they will wake up and will again, suffer from this pain. Therefore, instead of facing it, they see this life and death education as a way to give up (admitting one’s defeat) stop fighting against it no more.

Cultural rejection towards death is also because people feel that the acceptance of death is a failure. To accept death is to admit defeat.

One cannot be a failure. In a culture where victory and personal achievement is essentially representing one’s worthiness and standing in the society, the admission of failure means one will lose all respect and power in the society. One is seen as a failure.

Appendix 3.2: Idea memo

Filial Piety VS Medical Futility

It is suggested that primary carers, predominantly adult children of older people, are less willing to provide emotional or psychological support comparing to offer practical care or material support.

The concept of filial piety has been in existence in the Chinese culture for centuries and is philosophically conceptualised by Confucius. The meaning of filial piety is to respect parents and one's ancestors through taking care of one's parents in all aspects of life and worshipping one's ancestors. Filial piety remains a crucial philosophical concept to which the majority of modern Chinese population still adhere. Following filial piety, the relationship between parents and children is reciprocal (Lee & Hong-kin, 2005). In other words, children after they have grown up, are expected to return what their parents have given to them. This repayment is all encompassing, grown-up children are expected to physically take care of their parents, ensure their financial stability and at the same time, care for their emotional and psychological wellbeing through maintenance of a healthy relationship.

Lee, W. K., & Hong, K. K. (2005). Differences in Expectations and Patterns of Informal Support for Older Persons in Hong Kong: Modification to Filial Piety. Ageing International, 30(2), 188-206.