NANYANG TECHNOLOGICAL UNIVERSITY

ELICITING AND HONOURING END-OF-LIFE CARE PREFERENCES: A MULTIPLE METHODS STUDY ON PLACE OF DEATH

TAN WOAN SHIN

INTERDISCIPLINARY GRADUATE SCHOOL

NTU INSTITUTE FOR HEALTH TECHNOLOGIES

2018

ELICITING AND HONOURING END-OF-LIFE CARE PREFERENCES: A MULTIPLE METHODS STUDY ON PLACE OF DEATH

TAN WOAN SHIN

Interdisciplinary Graduate School
NTU Institute for Health Technologies

A thesis submitted to the Nanyang Technological University in
partial fulfilment of the requirement for the degree of
Doctor of Philosophy

2018

Acknowledgements

I would like to acknowledge my dissertation advisor, A/Prof. Josip Car, who not only stretched me to my fullest but also believed that I could excel. I am also grateful to my co-advisor, Prof. Euston Quah, and clinical mentor, Dr. Wu Huei Yaw, for their support and mentorship. The guidance from the dissertation advisory committee has been instrumental in the development of an interdisciplinary approach in this research.

My gratitude goes to Dr. Heng Bee Hoon and A/Prof. Ding Yew Yoong, who have been a source of inspiration and guidance throughout my career. Without their encouragement, I may never have embarked on this learning journey.

I thank Asst. Prof Andy Ho and Dr. Priya Lall for their guidance and collaboration on the qualitative segment of this dissertation. I thank A/Prof. Low Chan Kee for his comments on the statistical approaches; Dr Ram Bajpai for co-analysing the quantitative data; and Geronimo Jimenez, Dr. Edward Tan, Dr. Sng Ming Keat, Wong Lok Hang, Paul Victor, and Oindrila Dutta for their friendship and support on the project. I would also like to acknowledge all co-authors of manuscripts that were submitted or published during my studies.

I thank my colleagues from the Centre for Population Health Sciences, Nanyang Technological University (NTU); Health Services and Outcomes Research, National Healthcare Group; and classmates from the various schools in NTU for their support throughout the last four years. To all healthcare professionals who participated in this research, I sincerely thank you for sharing your experiences. It has truly been an enlightening, as well as humbling experience for me.

This work was supported by scholarships from the National Medical Research Council and the National Healthcare Group. I also acknowledge the Agency for Integrated Care for funding the evaluation of the national ACP programme from which I drew data from.

Finally, I would like to thank my family and friends for going on this exploratory journey with me, and for always believing in me. Without your emotional support, this work would not have been possible.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

ACHI	Australian Classification of Health Interventions
ACP	Advance Care Planning
AIC	Agency for Integrated Care
AMD	Advance Medical Directive
AD	Advance Directive
AUC	Area Under the Curve
CAD	Canadian dollar
CCI	Charlson Comorbidity Index
CGH	Changi General Hospital
CI	Confidence Interval
CPR	Cardiopulmonary Resuscitation
DNR	Do Not Resuscitate
DRG	Diagnosis-Related Group
ED	Emergency Department
EIU	Economist Intelligence Unit
EOC	Extent of Care
FDW	Foreign Domestic Worker
FGD	Focus Group Discussion
GBP	British pounds
HL	Hosmer-Lemeshow
GLM	Generalised Linear Model
ICD	International Classification of Diseases
ICU	Intensive Care Unit
IRR	Incident Rate Ratio
ISF	Interpretive Systemic Framework
IT	Information Technology

KKH	KK Women’s and Children’s Hospital
KTPH	Khoo Teck Puat Hospital
LOS	Length of Stay
LPA	Lasting Powers of Attorney
MCA	Mental Capacity Act
MOH	Ministry of Health
MV	Mechanical Ventilation
NTU	Nanyang Technological University
NCCS	National Cancer Centre Singapore
NHCS	National Heart Centre Singapore
NMEC	National Medical Ethics Committee
NPT	Normalisation Process Theory
NUH	National University Hospital System
NRIC	National Registration Identity Card
OR	Odds Ratio
PPC	Preferred Plan of Care
PSDA	Patient Self-Determination Act
PUIN	Project Unique Identifying Number
RCT	Randomised Controlled Trial
SGD	Singapore dollar
SGH	Singapore General Hospital
SOC	Specialist Outpatient Clinic
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments
TTSH	Tan Tock Seng Hospital
UK	United Kingdom
US	United States
VWO	Voluntary Welfare Organisation

List of Definitions

Advance Care Planning The definition adopted by the National Medical Ethics Committee is used. It is a voluntary process of discussion about future care between an individual, their care providers and often those close to the individual, should the individual become seriously ill in the future and be unable to make decisions, and/or communicate their wishes to others (National Medical Ethics Committee, 2010).

Advance Directive It is a legal document signed in advance to inform one's doctor regarding the use of any life-sustaining treatment to prolong one's life in the event that the individual become terminally ill and unconscious and where death is imminent (Ministry of Health, 2008).

End-of-life care It is care that supports people who are in the last months or years of their life. End-of-life care may include palliative care, supportive care, and hospice care (National Health Services Choices, 2015).

Lasting Powers of Attorney In Singapore, it is a legal document which allows a person who is at least 21 years of age, to voluntarily appoint one or more persons to make decisions and act on an individual's behalf should he/she lose mental capacity one day. A donee can be appointed to act in the two broad areas of personal welfare, and property and affairs matters (Menon, 2013).

Palliative care It is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and the treatment of pain and other physical, psychosocial and spiritual issues (World Health Organization, 2018).

Abstract

“Home” is not just a physical compound. It is our natural habitat where meaningful and intimate time with our loved ones can be shared. This narrative has underpinned the motivation for individuals wanting to live out their last days at home. With swift medical advancement and growing perceptions that hospitals provide higher quality end-of-life care, deaths have however shifted from the home to hospitals.

This dissertation aimed to explore the complex contextual factors involved in eliciting end-of-life care preferences and to identify facilitators and barriers of home deaths in Singapore with a specific focus on the impact of Advance Care Planning (ACP). A multiple methods approach using qualitative and quantitative research methodologies were used: (i) retrospective cohort study to identify factors associated with home deaths, and to profile end-of-life care preferences and determine concordance of care with these preferences; (ii) semi-structured focus group discussions with 63 healthcare professionals to understand the implementation of ACP and the elicitation of end-of-life care preferences; (iii) quasi-experimental study to ascertain the impact of ACP on the place of death.

The dissertation results challenged the popular viewpoint that home is the most preferred place of death. Among individuals diagnosed with advanced illnesses, only 40% had a documentation of “home” as the preferred place of death in their ACP documents. Instead of being an independent decision, preferences for place of death were formed through negotiation between and co-constructed by the patient, family, and healthcare professionals. Families also often believed that better care can be provided for, in the hospital.

Besides non-modifiable person- and family-level factors, our results suggested that receiving home palliative care and having an ACP documentation, were associated with a higher chance of dying at home. For non-cancer patients - who had limited access to home palliative care – ACP was associated with increased home deaths, and a significant reduction in unnecessary life-sustaining treatments and health resource use in their last month of life.

With the expansion of the national ACP programme already underway, our results underscored the importance for policy makers to focus on changing societal mindsets regarding conversations about death and dying and shifting healthcare practices towards one that supports pro-active patient participation and shared decision-making. Further, given that most deaths still occurred in hospitals, hospitals must continue to be viable sites where high-quality end-of-life care is available.

Chapter 1 Introduction

Abstract

This chapter describes the value of “home” as the place of death and discusses the differences that exist across high-income countries in having this preference. The experiences of selected Asian, European, and North American countries are contrasted. Other than individual and clinical factors, sociodemographic changes also act in concert with shifts in caregiving and death culture to influence the organisation and operationalisation of health and social care services over time. Legal means are used in some countries to sanction the idea of self-determination in end-of-life care decision-making; and since the late 1990s, ACP has become a significant non-legalistic mechanism, through which end-of-life care preferences are made known. In some countries, changes to end-of-life care service delivery and financing have supported the shifts in deaths from inpatient to out-of-hospital care facilities. These forces shape, and act jointly with the availability of formal and informal care, to support the individual living at home. The research objective, and specific research questions to be addressed in this dissertation, are outlined in this chapter.

1.1 Introduction

“Home” is traditionally viewed as our natural habitat where life is comfortable, familiar, and allows for intimate moments to be shared with loved ones (Milligan et al., 2016; Williams, 2004). For the dying, this physical space serves not only as the place of care, but also where shared experiences occur (Payne et al., 2012). In contrast, when one thinks about care in the hospital, it is associated with images of unnecessary aggressive treatments, poor quality of care and suffering at the end-of-life. This narrative has underpinned the motivation for individuals wanting to live out their last days at home. Much of published health literature, which is largely centred on the North American and European experience, also seems to assume that this preference is universal.

This chapter first describes the value that individuals and families place on dying at home, and how this may evolve, as societies go through different stages of economic, social and health services development. Second, a comparison across high-income North American, European and Asian countries is presented, to offer insights on the influence of history, culture and organisation of health services, on preferences of the place of death. Third, a review of factors that have been described in the literature to influence the place of death, including a brief introduction to Advance Care Planning, is presented. This helps to set the stage for the statement of research questions to be addressed in this dissertation.

1.2 Home as the preferred place of death

In high-income countries, sociodemographic changes such as smaller family sizes and longer life expectancies, together with growing perceptions that hospitals provide higher quality end-of-life care, has shifted the occurrence of deaths from the home to hospitals in the last century (Grande, Addington-Hall, & Todd, 1998). Gu et al. posited that societies undergo three evolutionary stages, where sociodemographic changes, economic growth, medical technology advances, and public perceptions interact to produce preferences for the place of death (Gu, Liu, Vlosky, & Yi, 2007). With each new generation, perceptions of death and dying, and the framing of the role of the family in caregiving may also change. This may in turn influence legislation about individual autonomy over end-of-life care, and also, the role and form of formal health and social care.

1.2.1 Three stages of evolving preferences

In the first stage, countries with lowly-resourced healthcare systems and underdeveloped medical technologies are characterised by a high rate of home death. With growing affluence, improvements in medical technologies, and greater access to healthcare facilities, countries then enter the second stage, where hospitals begin to play a critical role, both medically and socially, as places where end-of-life care can be provided. In tracing the history of attitudes towards death in Western countries, Ariès noted that this "displacement" of the site of death, from the home to the hospital, occurred in the 1930s-1950s, where the dying person no longer took his or her last breath at home surrounded by loved ones, but has become a "technical cessation" determined by physicians (Ariès, 1975) in formal care settings. In societies like the US, economic forces driving greater monopolisation of acute care, together with improved cure rates, have also led to increases in hospitalisation, and therefore hospital deaths, from the 1940s onwards (Rothman 2014).

As societies mature, they will reach a turning point where greater consideration and resources are allocated to meet the stated preferences of dying persons and their families. This is termed as the third and final stage by Gu et al.. As the quality of end-of-life care comes into focus, high-income countries naturally start to pay more attention to the place of death, as well as health and social care services provided to the dying, to honour their preferences (McMillan, Mentnech, Lubitz, McBean, &

Russell, 1990; Pollock, 2015) and to enable a “good death”. Concerns about improving care at the end of life surfaced in the United Kingdom (UK) and the US in the 1950s. In the UK, the public was concerned about the medical “neglect” of dying people (Clark, 2002) (Clark, 2002). Starting with St. Christopher’s Hospice in the UK in 1967, the modern hospice movement was born, which led to a natural extension to facilitate dying at home through the introduction of home care teams (Boyd, 1994). On the other hand, in the US, the concern was about the use of futile treatments when faced with impending death (Institute of Medicine, 2015); which led to a movement by the public to assert their right to control their end-of-life care, giving rise to Advance Directives (ADs), and this also catalysed the introduction of palliative care and home-based care (Rothman 2014).

1.2.2 Intimacy, familiarity and autonomy

Dying at home is one of the key elements recognised to contribute towards a good death. Other attributes may include being pain-free; being able to acknowledge that death is imminent; resolving unfinished business; experiencing life completion; maintaining dignity; having access to spiritual support; and being able to exercise autonomy in relation to personal preferences about treatments and the dying process (Clark, 2002; Meier et al., 2016). Hospital deaths are considered “less ideal” (Cohen et al., 2008) as patients often prefer home as the place of death. Underlying this wish, is the desire to be with family and friends; and be amidst a comfortable environment when death comes (Gilley, 1988; Williams, 2004). Being able to maintain a sense of independence and control over one’s way of life also contributes to a person’s well-being (Peter A Singer, Martin, & Kelner, 1999). In an institutional setting where staff might be managing heavy workloads, care can be poorly planned with little flexibility for patients to have their preferences or needs met (Thorley, 2015).

1.2.3 Less pain and better psychological outcomes

Studies have also found hospital care to be sub-optimal. Close to half of all hospital inpatients may experience moderate to severe pain or mental distress about their impending deaths. However, hospitals were found to have offered little to alleviate pain, anxiety or depression (Connors, Jr, Dawson, Desbiens, & et al., 1995; Finlay, 2006; National Audit Office, 2005). The receipt of home palliative care was however found to raise the likelihood of dying at home, and lower the burden of symptom management specifically for patients with cancer (Gomes, Calanzani, Curiale, McCrone, & Higginson, 2013). Home deaths were also associated with greater peace for patients with terminal cancer in their final weeks (Gomes, Calanzani, Koffman, & Higginson, 2015).

1.2.4 Positive feelings and reduced burden for caregivers

Besides patient-associated benefits, relatives were also found to experience less intense grieving at the time of death and in the post-bereavement period if the person had died at home compared to those who experienced a hospital death (Gomes et al., 2015). In a longitudinal study of 342 patient-family dyads, bereaved caregivers of patients who passed away in a hospital or in an intensive care unit (ICU) were more likely to be suffer from psychiatric diseases relative to caregivers of individuals who experienced home deaths (A. A. Wright et al., 2010). Family caregivers are vital for support in the event of home deaths. Although caring for the dying at home can exert an emotional and financial toll on the family, studies have found that with adequate support from the formal care sector, caregivers do enjoy the overall experience of caring for and supporting their loved ones to satisfy their wishes to die at home (Carlsson & Rollison, 2003; Y. Singer, Bachner, Shvartzman, & Carmel, 2005).

Caregivers of patients who died at home also perceived the quality of life to be better for them than those who had passed on in inpatient hospices (Carlsson & Rollison, 2003). These positive feelings are associated with acquiring the ability to confidently care for the patient (Henriksson, Carlander, & Arestedt, 2015), and the strengthening of relationships within the family or caregiving network during the care process (Brown & Stetz, 1999). In East Asian countries, the act of caregiving is thought to provide children with the opportunity to express and fulfil their filial duty - fundamental to the relationship between a parent and a child (Mok, Chan, Chan, & Yeung, 2003) in societies that have embraced Confucian philosophical traditions. Even so, we must not deny that the actual experience of caregiving could differ from what is culturally expected.

1.2.5 Challenges faced when dying at home

Others may argue that the above presents an idealised view of home as the location of death. By only focusing on the location and not reflecting on the actual circumstances of death, we discount the likelihood that the home may not provide the best management of pain and disease symptoms (Pollock, 2015), which are aspects of end-of-life care strongly prioritised by individuals at the end-of-life (Waghorn, Young, & Davies, 2011). Lack of access to hospital services can also subject individuals to dying at home, which if inadequately supported, can result in great pain and distress (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004; C. Thomas, Morris, & Clark, 2004). Emotionally and economically, it can be difficult for family caregivers and loved ones to support death at home, when they are grieving for the potential loss of a family member at the same time. Caring for the dying can be all-consuming with caregivers putting in care 24-hours round the clock (Currow, Agar, & Abernethy, 2013), which leave little time to be shared meaningfully with the dying (Steinhauser et al., 2000).

While some studies have reported the positive effects of caregiving as mentioned earlier, others reported that family caregivers caring for terminally ill patients can also suffer high levels of distress due to the helplessness experienced when death approaches (Oechsle, Goerth, Bokemeyer, & Mehnert, 2013); as well as the lack of social interaction and experience of social isolation during the home care process (Gotze et al., 2016). Spousal caregivers are also more predisposed to psychological distress than other familial caregivers (Gotze, Brahler, Gansera, Polze, & Kohler, 2014). Witnessing the physical deterioration at the deathbed of a loved one can be traumatising, despite the best efforts of palliative care professionals to support the management of the patient's physical symptoms, and to prepare caregivers for the impending death of the individual (Sanderson et al., 2013). Patients and families not receiving any palliative care support may be even worse off (Institute of Medicine, 2015).

1.2.6 Health economic impact

The prospect of dying at home cannot be totally removed from the allocation of healthcare resources, and its substitutive use. Presently, many societies incur substantial amounts of funds in the medical treatment of individuals in the last year of life. Such expenditures are often a result of the administration of intensive curative treatments in hospital settings. In the US, a decedent cost 6.8 times that of the cost incurred by a survivor due to life-sustaining measures, such as artificial ventilation and feeding (Calfo, Smith, & Zezza, 2004). A separate Swiss study estimated that the average healthcare expenditure in the last 6-months of life for individuals dying in hospitals was double that of individuals who died at home (Reich, Signorell, & Busato, 2013). By meeting wishes to die at home, it was thought to yield potential savings to the healthcare system by shifting from the more expensive inpatient setting to community- or home-based care.

Home-based palliative care was observed to be linked to a higher likelihood of dying at home (B. Gomes et al., 2013), and to reduce acute care utilisation and overall healthcare cost for terminally-ill patients (Brumley et al., 2007; W. S. Tan et al., 2016; Zimmer, Groth-Juncker, & McCusker, 1985). Several projection models have been built to extrapolate the economic impact of strategies targeted at shifting care to the community or home, with the intention of better meeting preferences to be cared for and to die at home. A Canadian study found home palliative care to increase the likelihood of dying at home by 10%, and reduce the use of hospital-based services. This resulted in an estimated savings of Canadian dollar (CAD) 191 – 385 million (Singapore dollar (SGD) 199 – 402 million; 2018 exchange rate of CAD 1: SGD 1.05) for the Ontario health system (Pham & Krahn, 2014). A similar analysis was also carried out in the UK by RAND Europe. It was found that the expansion of community-based care could reduce the costs incurred by the health and social care sectors by up to British pounds (GBP) 104 million (SGD 191 million; 2018 exchange rate of GBP 1 : SGD 1.84) and GBP 67 million (SGD 123 million) during the last year of life for patients with cancer and end-organ failure respectively (Hatziandreu, Archontakis, & Daly, 2008). This was premised upon community-based care being able to reduce emergency hospitalisations by up to 10% and to lower the average length of stay (LOS) by 3-days.

1.3 International comparison of preferences for place of death

Given swift medical advancements and the fast pace of population ageing, heath policies and research in high-income countries have underscored the importance of meeting end-of-life care preferences, and actualising the value of home deaths. In a comprehensive systematic review that examined the preference for home deaths, 69% of the 210 included studies were conducted in North American and Western European countries (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). The literature from other regions except for Japan (Fujimori & Uchitomi, 2009; Fukui, Yoshiuchi, Fujita, Sawai, & Watanabe, 2011; Ishikawa et al., 2013), was instead sparse. Therefore, the current discourse about home deaths is, to a great extent premised upon an Anglo-Saxon perspective (S. K. Lee, 2009) that advocates the democratic ideal of exercising one's autonomy till the end of life (Peter A. Singer & Bowman, 2002). The following sections highlight important differences in home death preferences and actual place of death trends in Western countries, and in Asia.

In the following sections, the experiences of Canada, the UK, and the United States (US), were contrasted against Japan and four East Asian countries –- Hong Kong, Taiwan, South Korea, and Singapore – commonly known as the Asian Tigers. The three East Asian countries were chosen because of their similarities with to Singapore in their rapid economic growth, as well as the ability to contain healthcare spending despite having different financing structures (Wagstaff, 2007). Although one might suggest including Malaysia for her proximity to Singapore in terms of geographical distance and culture, significant dissimilarities in at the stage of healthcare and palliative care sector development between these two countries rendered the comparison inappropriate.

1.3.1 Preferences in Europe and North America

Despite variations in survey coverage, and methodology across studies, the evidence pointed towards home being the preferred place of death by most of the general public. In a cross-sectional population-based telephonic survey covering 9,344 individuals across seven European countries (England, Flanders, Germany, Italy, the Netherlands, Portugal, and Spain), at least two-thirds of the respondents (general public aged 16 years old and above) preferred to die at home with the exception of Portugal where it was one in two (Barbara Gomes et al., 2012). In the US, the figures were even higher with 9 out of 10 respondents preferring to be cared for at home if they had six months or less to live (Cassel & Field, 1997). Two other studies confirmed this strong preference for home as the preferred place of death (Leff, Kaffenbarger, & Remsburg, 2000; Tang, McCorkle, & Bradley, 2004).

After accounting for missing preferences, however, the results of a national Canadian survey, using an online panel, were inconsistent with those reported above. Only forty-four percent of the public preferred to die at home. The results demonstrated that 42% did not have a preferred place of death, and among those who did, 75% preferred to die at home (Canadian Hospice Palliative Care Association, 2013). By excluding "missing preferences" from the computation of the proportion of the preferred place of death, we may risk overstating the popular vote for home deaths (Hoare, Morris, Kelly, Kuhn, & Barclay, 2015)

1.3.2 Preferences in Asian countries

The preference for home deaths however seemed to be less consistent and more varied across surveyed populations in similarly high-income countries in Asia. Even amongst Asian countries, due to different cultural beliefs and priorities, traditions about death and dying are unique to individual countries (Glass, Chen, Hwang, Ono, & Nahapetyan, 2010).

In Hong Kong, given the crowded living arrangements, and the perception that deaths in the home will lower the value of the real estate in a country where housing is extremely expensive (H. W. Cheng, Li, Chan, Ho, & Sham, 2014), only 31% of the surveyed Hong Kong public opted to die at home (R. Y. Chung et al., 2017).

The figures were higher in Japan and the Republic of Korea but remained far below those observed in the West. Two population-based studies reported that 44% - 50% of the Japanese public preferred home as the place of death while the rest opted for hospital, nursing home, palliative care unit or were unsure (Fukui, Yoshiuchi, et al., 2011; Yamagishi et al., 2012). A cultural concept central to Japanese society has been put forth as a plausible explanation for a stronger preference for institutional care. In Japanese culture, "Sekentei" compels an individual to behave in a socially acceptable manner, and to view or reflect upon his or her actions through the eyes of others (Asai & Kameoka, 2005). Given that one should consider the burden that dying at home has on the family (K. Hattori & Ishida, 2012; Yamagishi et al., 2012), a relatively higher preference for hospital care may reflect this sentiment (I. J. Higginson & Sen-Gupta, 2000; C. Thomas et al., 2004). In the Republic of Korea, although we could not locate population-based studies, the preferences elicited from patient samples indicated that between 31% - 47% of cancer patients preferred to die at home (Choi et al., 2005; Yun, You, et al., 2006).

On the other hand, in Taiwan, the rates of home death preferences were almost as high as those observed in European countries, although the underlying rationale could not be more different. A survey carried out with patients registered with family physician clinics found that home was the preferred location of death by 67% of the respondents (Shih et al., 2015). Despite strong reservations about burdening the family to fulfill their wish to die at home (Shih et al., 2015), the majority of cancer patients surveyed in a separate study also preferred home as the place of death (C. H. Chen, Lin, Liu, & Tang, 2014). Besides the intrinsic value of dying at home, many Taiwanese subscribe to a set of beliefs – a collection of shamanism, veneration of ancestors and belief in the supernatural – that is embedded in the Taiwanese consciousness (Glass et al., 2010). Therefore, in Taiwan, dying at home is perceived to be a key element of a good death because “the fallen leaf can return to its root”, or that one’s soul can return home and be reunited with its ancestors (S.-Y. Cheng et al., 2015; Lin, Lin, Liu, Chen, & Lin, 2007; Tang, 2000). If death were to occur outside of the home, for instance, in the hospital, it is believed that the spirit might become a wandering and forsaken ghost (S.-Y. Cheng et al., 2015; Shih et al., 2015).

1.4 Methodological considerations

Beyond social and cultural factors, methodological differences could also influence our interpretation and comparisons of place of death preferences. With trends in place of death increasingly being used to inform health infrastructure and manpower planning (Gomes & Higginson, 2008), policy makers should be aware that at a given time-point, preferences for home deaths could differ significantly between healthy, sick and terminally-ill populations.

In the above sections, elicited preferences were largely based on population-based surveys. Public opinions, however, often do not coincide with the preferences of individuals close to the end-of-life (Hoare et al., 2015). The lack of alignment between these two perspectives is hardly surprising, as other research, such as those examining health state valuation, have pointed out the differences between these two groups (Stamuli, 2011); reflecting different priorities and changing experiences. The complexity of choices also grows as death draws near (Wood & Salter, 2013). When healthy participants are asked to make decisions regarding hypothetical scenarios about death and dying, the 'shock' or fear that he or she experiences (Kahneman, 2005) about potentially dying in an unfamiliar environment, could sway decisions towards the familiar – meaning the home. Juxtaposed against other priorities, such as pain and symptom management, and alleviating caregiver burden, the “cost” of maintaining one’s decision to die at home may also increase (Townsend et al., 1990). At the same time, the fear of the unfamiliar could decrease over time, as patients increasingly adapt to new living and care arrangements in other settings, such as nursing homes or hospices (Barclay & Arthur, 2008). One in five individuals have been found to change their preferences over time (Barbara Gomes et al., 2013).

It is frequently unclear which set of preferences should be used when making resource allocation decisions for end-of-life care. We would argue that it is important to consider a range of perspectives, since there is no right or wrong. Rather, the decision-making context should guide our choice. For instance, it would be appropriate to rely on patients' preferences when making individual care plans to support home deaths. However, when the decision involves a reallocation of resources within healthcare to meet home deaths, it is arguable that, since funds are contributed by taxpayers for a greater good, their perspective should be counted (Stamuli, 2011); notwithstanding the fact that the general public usually does not have sufficient information to make a considered choice. Surveys need to be better designed to mirror real-life trade-offs, to give a more accurate estimate of place of death preferences.

1.5 Factors influencing place of death

To identify factors influencing the place of death, a literature search was performed on PubMed (title search for "place of death" or "death at home" and "systematic review" or "meta-analysis" or "meta-ethnography") to search for relevant review articles published between January 2000 and February 2018. The initial search yielded 12 articles. After screening the abstracts and full-texts, three articles were included because they specifically sought to identify factors associated with the place of death. In addition, an unpublished systematic literature review was identified during an internet search and also included in the following section.

Articles were purposefully selected to offer a short discussion on the effects of culture and health policy on place of death across different countries. Each country or context may embrace different perceptions on death and dying, and have different philosophies and cultural norms related to caregiving. This not only influences preferences about the place of death, but also contributes to the development of home palliative care services.

Relevant articles identified during a review of systematic reviews (G. Jimenez et al., 2018a, 2018b) that the doctoral candidate contributed to during her candidature were also included to provide a background on ACP, and to highlight the gaps in literature.

1.5.1 Reversing home death trends in North America and UK

Countries such as the US (Flory et al., 2004), Canada (Wilson et al., 2009), and the UK (Gomes, Calanzani, & Higginson, 2012) have entered the third stage suggested by Gu et. al in their hypothesis on the evolution of the place of death (Gu et al., 2007). A host of government policies related to legislation, healthcare financing, hospital bed supply, and clinical guidelines intersecting with sociodemographic changes, have led to a noticeable reversal in the downward trend of home deaths in these countries.

The American experience

From 1980 to 1998, the share of inpatient deaths in the U.S. fell from 54% to 41% while home deaths increased from 17% to 22% (Flory et al., 2004). Government policies and legislation caught up to meet end-of-life care preferences, and better manage escalating healthcare costs in a climate of population ageing. In the early 1980s, two milestone changes to Medicare's payment system worked jointly to shift care for the terminally-ill out of acute hospitals (McMillan et al., 1990). In 1982, the Medicare hospice benefit was introduced to substitute curative hospital care for home hospice care in patients certified by their physicians to have less than 6 months to live (Davis, 1988). In the subsequent year, faced with tight budgetary constraints, there was a shift from a retrospective reimbursement system to a case-mix-based prospective payment system. This introduced strong incentives for hospitals to contain costs (Qian, Russell, Valiyeva, & Miller, 2011) leading to a rapid decline in hospitalisation rates (Feinglass & Holloway, 1991; Qian et al., 2011) and shifted deaths out of the hospital (Sager, Easterling, Kindig, & Anderson, 1989).

Next, the 1990 legislation – Patient Self-Determination Act (PSDA) – solidified the inviolability of patient autonomy in end-of-life care decision-making in the US (McMillan et al., 1990). By mandating healthcare organisations to inform patients of their right to accept or refuse treatment, PSDA sought to promote the benefits and use of ADs to the public, and to create opportunities for meaningful discussions about end-of-life care preferences (Hunsaker & Mann, 2013). The nomination of a healthcare proxy as part of an AD, was found to be the main contributor to adherence with patients' preferences (Kelley et al., 2011). Having an AD also increased the possibility of meeting preferences to die at home (Jeurkar et al., 2012).

In the mid-1990s, results from the landmark SUPPORT trial, which sought to improve end-of-life care using a comprehensive intervention aimed at improving communication about care preferences, provided a sobering view of the state of end-of-life care in the US. Despite the lack of positive impacts, research insights from the trial prompted a re-assessment of the delivery of end-of-life care and contended that a systemic shift in physician-patient communication, as well as a change in social mindset, were essential for improving end-of-life care (Covinsky et al., 2000).

This series of policy and legislative changes, and research insights from the SUPPORT trial, have also been cited to have altered end-of-life care in the US and contributed to the reversal in home death trends (Flory et al., 2004).

The Canadian experience

On the other hand, the case of Canada was not supported by deliberate policy changes specific to palliative care delivery. Between 1994 and 2004, there were rapid declines in hospital deaths from 78% to 61% and a corresponding increase in home deaths from 19% to 30% (Wilson et al., 2009). Although community-based palliative care services did increase in the mid-1990s within specific Canadian provinces (Burge, Lawson, & Johnston, 2003), the reversal in home deaths was largely attributed to the widespread downsizing of acute care hospitals in the mid-1990s in response to budgetary constraints. During this time, 25% of hospital beds were shut down (Wilson et al., 2009).

The British experience

In the UK, although home deaths fell from 31% in 1974 to 18% in 2004 (Murtagh et al., 2012), it gradually increased to 21% in 2012 (B. Gomes et al., 2012). Today, the English data indicates that deaths occurred at home for 23% of all decedents, while hospitals accounted for 46% (National End of Life Care Intelligence Network, 2015). The implementation of specific end-of-life care strategies at the national level (Gao, Ho, Verne, Glickman, & Higginson, 2013; B. Gomes et al., 2012) to support deaths at home, could have contributed to the observed gradual increase in the proportions who died at home. The National End of Life Care Programme, implemented in 2004, aimed to better meet patients' choice of location of death by increasing the provision of, and accessibility to high quality end-of-life care (C. Henry & Hayes, 2009). This was followed by the Department of Health's End of Life Care Strategy published in 2008, which sought to facilitate people's discussion of their own preferences and to document, respect and act upon their needs and choices (Department of Health, 2008).

1.5.2 Cultural and health system influences in East Asia

Besides the policy and legislative changes mentioned earlier, social roles and cultural factors are also at work. The above experiences provide useful historical and policy insights for countries aspiring to reverse the at-home death trends, but each country should consider and interpret them against the background of their local culture, legislative traditions, and organisation of health services. The percentage of home deaths in East Asian countries varied significantly between countries, and reflected a confluence of cultural features and health system policies.

The Hong Kong experience

In a study carried out on older adults, it was found that only 2.7% died at home (H. W. Cheng et al., 2014), Shifting care from the hospital to the home requires the home space to be large enough to accommodate medical technologies and services to support home-based care. In certain urban environments such as Hong Kong (Tse, Chan, Lam, Leu, & Lam, 2007),, home deaths may not be practical due to space limitations. Besides, there is also a legal requirement in Hong Kong for home deaths to be certified by a physician who has cared for the patient at least in the fortnight before death. This places heavy legal liability on doctors (Cheung, 2016). With few doctors willing to certify a home death, dying at home becomes impractical.

The Japanese experience

Despite efforts to increase the provision of home hospice services (Mori & Morita, 2016), much of the general population who wished for a home death (Fukui, Yoshiuchi, et al., 2011) were unable to meet their goal. The proportion of home deaths fell from 82% in 1951 to 13% in 2015, as a result of rapid expansion of hospital services and financing of hospital-based services by the government (Ministry of Health Labour and Welfare, 2015; Yang, Sakamoto, & Marui, 2006). Growing numbers of single-person elderly households and a lack of support at home also led to hospitals becoming the principal site for end-of-life care.

Cultural norms further shaped two sets of behavior, that often acted together to render the fulfillment of home death preferences challenging. First, given that one is expected to care for one’s parents, Japanese families often do not engage formal caregivers, out of fear of criticism from friends and relatives (Glass et al., 2010).

This placed the full responsibility of care on the shoulders of the family. Second, without sufficient medical and nursing support at home, families naturally default to admitting the patient to the hospital during medical crises – which is considered to be “good for Sekentei” (Asai & Kameoka, 2007). Reflecting these social norms, the level of provision of home palliative care in Japan is very low, with most of end-of-life care provided by hospital-based palliative care units (Mori & Morita, 2016).

The South Korean experience

In the Republic of Korea, hospitals were the most common places of death (58%), followed by homes (32%) for older persons (Mai, Lee, Cho, & Chang, 2018). The South Korean culture is very much rooted in Confucianism, with strong traditions in maintaining harmony within the family and performing one’s designated role. Similar to Japan, filial piety, where the child is subordinate to their parents, is the cultural norm, with strong societal expectations for the child to respect and support their parents. In the context of aged care and end-of-life care, the child is expected to take care of a dying parent (Glass et al., 2010). This belief has led to the underdevelopment of hospice home care. With limited hospice home care support and increasing nuclearisation of the family unit, the majority of older people still get admitted at their last stage of life, and eventually die there (Mai et al., 2018).

The Taiwanese experience

In Taiwan, a smaller gap, between what is preferred and what is actualised, was observed. One often-cited reason for the high incidence of home deaths is the practice of terminal discharge – discharging the patient from the hospital so that he or she can go home to die in the last hours of life (Y. C. Huang, Huang, & Ko, 2009). This is legal even if the patient were unconscious at the time of discharge (S.-Y. Cheng et al., 2015). Strong cultural inclination, supported by legislation and expansion of the national health insurance to cover hospice and palliative care in

Taiwan (Glass et al., 2010), could have stemmed the speed of decline in home death rates. Home death rates fell from 36% to 32% between 2001 and 2006 among decedents with cancer (Tang et al., 2010), but remained higher relative to other East Asian countries.

In 2000, Taiwan also became the first country in Asia to introduce the Natural Death Act, which enforced the right for an individual to the patients' right to choose hospice and palliative care, as well as to refuse cardiopulmonary resuscitation (Glass et al., 2010). At the same time, the Department of Health also launched the "National Cancer Control Project" from 2005 to 2009, to increase the coverage of hospice palliative care for cancer patients (R. Chen, 2016). Also, in 2015, another pioneering law, entitled the "Patient Autonomy Act", was passed to uphold the importance of patients' self-awareness and autonomy. This Act came into effect in 2018.

1.5.3 Evidence from systematic reviews

Several systematic reviews have pooled and synthesised results across multiple primary studies examining the topic of home deaths. A summary of factors from the four systematic reviews discussed below, can be found in appendix 1.

The theoretical framework presented by Gomes and Higginson (Gomes & Higginson, 2006) conceptualised factors influencing variations in the place of death for patients with advanced cancer. Gomes and Higginson reviewed and extracted information from 58 studies conducted in 13 different countries, with a total of 1.5 million subjects. The conceptual model was developed through a systematic review of the literature, in reference to theories on the ecology of human development (Bronfenbrenner, 1979), crisis theory concerned with coping with physical illness (Moos, 1977), behavioural theory in relation to health services use (Andersen, 1995), model of dignity in the terminally ill (Chochinov et al., 2002), and complexity systems theories (DF Munday, Johnson, & Griffiths, 2003).

Specifically, the model comprised three constructs encapsulating (i) factors related to illness, which refer to health status changes experienced by the individual as a result of their illness; (ii) individual factors, which pertain to characteristics, values, beliefs and preferences that defines the person, and (iii) environmental factors, which comprise contextual elements including contributions from the healthcare system, family support networks, and macrosocial factors. Seventeen factors with strong evidence of their influence on the place of death were included in the theoretical framework and categorised under one of the three constructs. (Figure 1.1).

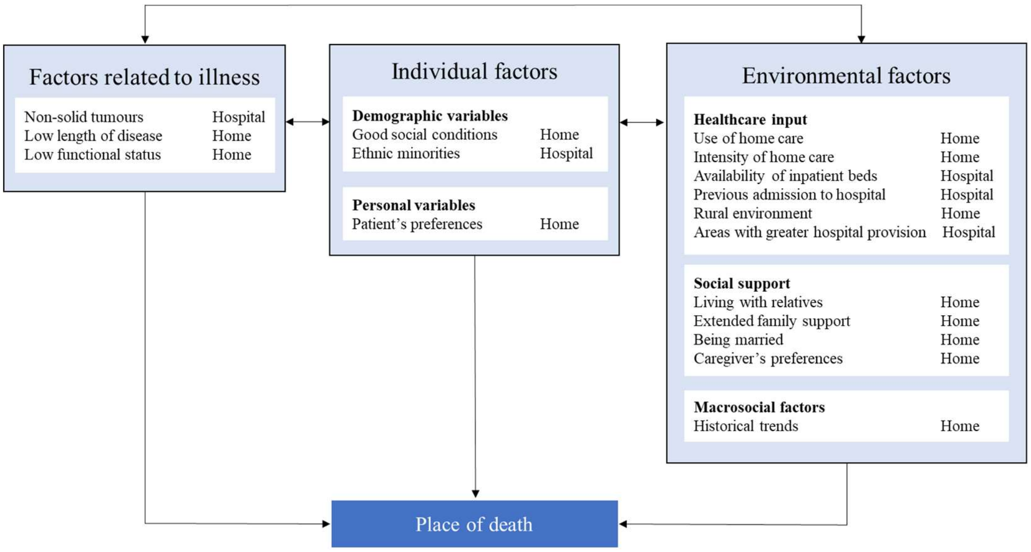


Figure 1.1 Model of variations in place of death (Gomes & Higginson, 2006)

The seventeen factors interlink and may interact to influence the place of death. Deteriorating physical and cognitive function can influence whether an end-of-life care discussion was triggered to allow the individual to state his or her preferences and therefore receive care at the preferred location. The achievement of these preferences in turn depends on the availability and extent of social support from one's family as well as access to hospital and home care services. Although Gomes and Higginson included macrosocial factors in the model, it was also suggested that more research is needed to examine the effects of changes in health policies, and cultural differences on place of death.

Subsequently, other authors have made reference to, and built their results upon Gomes and Higginson's framework. Complementing a systematic review of 35 articles with an expert panel consultation, Murtagh et al. applied and extended the above framework for non-malignant illnesses (Murtagh et al., 2012). The authors pointed out that the preference for home deaths was lower in this group of patients (<50%) compared to those with malignant conditions. Although the three constructs remained, the authors included a separate category related to "symptom, illness burden and trajectory" under the construct of "factors related to illness" to reflect the longer and also more varied trajectories of non-malignant conditions. Cancer, end-organ failure and cognitive disorders (S. A. Murray, Kendall, Boyd, & Sheikh, 2005) have different trajectories, which could affect the accuracy of prognostication and initiation of palliation, and may give rise to diverse symptom and pain management requirements. The authors also highlighted that, due to the protracted nature of end-organ illnesses and dementia, family or informal care support must be available in a sustained manner over time, to support care and dying at home.

A later systematic review, published in 2016, covered both cancer and non-cancer adult populations (Costa et al., 2016). Rather than seeking to validate or develop a framework, this study aimed to identify factors that have influenced home and nursing home deaths across 26 studies that included adult patients with advanced and life-limiting conditions. As most of the included studies adopted observational designs, the quality of the accumulated evidence was therefore judged to be low. Nonetheless, factors found to influence the likelihood of home deaths included having stated a preference for home death, a diagnosis of cancer, living with others, availability and coping ability of informal caregivers, and receiving care as a hospital inpatient during the last year of life. Individuals who received an early referral to the palliative care services, and those who had received care delivered by multidisciplinary home palliative care teams (Costa et al., 2016), were more likely to be able to pass away in their homes (Costantini, 2008).

In a meta-ethnography study that synthesised qualitative research data across 38 U.K. studies, Wahid et al. developed a summary list of barriers and facilitators of home death (Wahid et al., 2017). As described by the authors, their findings built upon the model developed Gomes and Higginson. Reinforcing the importance of the social support system outlined in Figure 1.1, the study described four factors that acted as barriers against home death: informal caregivers and healthcare professionals lacking in knowledge and skill to care for a dying patient at home; informal caregivers struggling to meet the physical and emotional demands of care; receiving inaccurate prognoses that create uncertainties about the duration of care; and unfavourable social circumstances. Three other barriers relevant to the healthcare system included: inadequate discharge planning; lack of community-based end-of-life care services for non-cancer conditions; and poor planning that resulted in low rates of discussions and documentation about end-of-life care preferences. On the other hand, facilitators of home death were: ready access to healthcare professionals at home by patients and their families when assistance is needed; skilled staff acting in response to the changing requirements of the patients and their families; strong coordination between services and continuity of care between settings; and effective communication and monitoring of patient preferences through ACP.

1.5.4 Preference elicitation process

ACP signalled a shift away from a paternalistic model of clinician-patient communication towards one that empowers the patient and respects his/her needs. Knowing a patient's end-of-life care preferences seemed to have a strong effect on dying at home (Brazil, Bedard, & Willison, 2002; Cantwell et al., 2000; Fukui, Fujita, et al., 2011; Fukui et al., 2003; Houttekier, Cohen, Van den Block, Bossuyt, & Deliens, 2010; Ikezaki & Ikegami, 2011; Karlsen & Addington-Hall, 1998); whereas individuals with undeclared preferences tended to die in hospitals (Ali, Capel, Jones, & Gazi, 2015; Arnold, Finucane, & Oxenham, 2015). It appeared that making one's wishes known spurs family members and healthcare professionals to contribute resources and efforts towards supporting the patient to achieve his or her goals (Gomes & Higginson, 2006).

Indeed, the World Health Organisation has recommended that "policy-makers should encourage the health services to inquire of people their preference for place of care and death." (Davies, Higginson, & Organization, 2004). The Institute of Medicine further recommended the conduct of ACP to support better alignment, of services received by the individuals in relation to their care objectives and preferences (Institute of Medicine, 2015). Such recommendations implicitly posit that all patients are reflective and would prefer to exercise autonomy over their end-of-life care.

Definition and value of ACP

A recent Delphi expert panel defined ACP as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness" (R. L. Sudore, Lum, et al., 2017). With a growing body of evidence about its positive impacts, ACP is becoming an increasingly important aspect of end-of-life care (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Houben, Spruit, Groenen, Wouters, & Janssen, 2014; R. L. Sudore, Heyland, et al., 2017; Weathers, Cornally, Daly, Coffey, & Molloy, 2014).

By having a conversation about what is acceptable and important to them at the end-of-life, patients could feel more strongly of that they are being “cared for” and are “in control”, which in turn provided them with a greater sense of peace and relief (L. Murray & Butow, 2016). ACP was also found to be strongly related to a reduced rate of hospital death (Josie Dixon, King, & Knapp, 2016), and higher likelihood of patients dying at home (Ratner, Norlander, & McSteen, 2001; Schamp & Tenkku, 2006; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). Other than place of death, ACP is also associated with higher levels of concordance with patients’ preferences for care (Houben, Spruit, Wouters, & Janssen, 2014), improved agreement between patients’ and families’ wishes (Martin, Hayes, Gregorevic, & Lim, 2016), and increased satisfaction with care (Weathers et al., 2016). The use of unwanted life-sustaining treatments were lowered as a result of ACP (Martin et al., 2016) , and there was evidence of healthcare savings for specific populations, such as nursing home residents or community-dwellers diagnosed with dementia (J. Dixon, Matosevic, & Knapp, 2015).

ACP Implementation challenges

Implementing ACP in routine clinical practice can be fraught with practical challenges (Institute of Medicine, 2015). Discussions about end-of-life care are not well-integrated into other aspects of medical care (Daniel Munday, Petrova, & Dale, 2009), outside of specialist palliative care (Arnold et al., 2015). Often, implementation sites do not have sufficient manpower and time committed to ACP (Fosse, Schaufel, Ruths, & Malterud, 2014; Wicher & Meeker, 2012) and they face challenges integrating complex interventions, such as ACP, in high-pressure clinical environments (Gilissen et al., 2017; Lund, Richardson, & May, 2015). Prognostic uncertainty, lack of consensus about introducing ACP, lack of a clear picture of disease trajectory, physicians' communication skills, knowledge about ACP, and the length of relationship with patients (De Vleminck et al., 2013; Sessanna & Jezewski, 2008), are factors that have been found to influence ACP implementation.

Furthermore, talking about death and dying is still off-limits in many cultures. Healthcare professionals have described the process as daunting, as it requires them to overcome their own reluctance to contemplate and talk about death (Woo, Maytal, & Stern, 2006). The degree of openness of individual patients to discuss their preferred care and place of death also varies significantly. Some may speak about it without prompting from healthcare providers; others may not have accepted their terminal status; some may be indifferent to the place of death; and others may only speak about it if the topic were broached in a sensitive manner (Daniel Munday, Dale, & Murray, 2007). Primary care nurses in the UK have also described discussions about the preferred place of death to be emotionally charged, and that patients rarely have an outright preference. In some instances, healthcare providers may not even ask an explicit question about the preferred place of death, and would infer the patients' preferences from what was implied during the conversation (Daniel Munday et al., 2009).

It is difficult for a society, healthcare system or individuals to decide when to stop intervening at the end-of-life, or when medical care is no longer helpful to the patient (Manalo, 2013). Factors other than medical considerations may influence decisions about life-sustaining treatments. While the withdrawal or withholding of life-sustaining treatments is well-accepted in Western countries, physicians in Asia are less likely to implement do-not-resuscitate orders or to withhold or withdraw artificial nutrition (Phua et al., 2015; Raijmakers et al., 2011). This may reflect societal or cultural norms prevalent in these countries. For instance, studies conducted on Asian populations have found that caregivers of Chinese ethnicity may opt for artificial feeding as a way of showing filial piety and sense of duty by sustaining and prolonging the life of the elderly parent (Chai, Krishna, & Wong, 2014). Further, according to Islamic laws, family members are obliged to continue providing nutrition and hydration, which are considered basic care for the individual (Alsolamy, 2014). In Singapore, the responsibility to decide when curation should cease falls onto physicians (J. Tan & Chin, 2011), and in Singapore, due to the healthcare financing structure (further discussed in Chapter 2), families bear the burden of the decision in trading off care against their ability to pay.

1.6 Aim and objectives

To enable more home deaths, the Singapore government has invested heavily to strengthen several elements pertinent to the deployment of ACP and palliative care provision (Gan, 2014, 2017). The multi-faceted approach included the enhancement of the quality of palliative care services across different levels of care, capacity expansion of residential and non-residential palliative care services, reductions in out-of-pocket payment, and increases in public outreach to promote awareness about end-of-life issues.

With the widespread interest in high-income countries to better meet end-of-life care preferences, the aim of my research was to answer the primary question of eliciting and respecting individuals' preferred place of death. Despite wide-ranging evidence available on this topic, little research has been carried out in Asia and in Singapore.

1.6.1 Aim

Given the complex contextual factors involved in the development of preferences and in influencing the eventual place of death, this study aims to first explore and identify facilitators and barriers of home deaths in Singapore with a special focus on the influence of ACP.

1.6.2 Specific objectives

The specific objectives were to:

1. quantify and ascertain preferences for place of death in the local patient population;
2. explore the process of end-of-life preference care elicitation and formation;
3. identify and explore factors associated with home deaths;
4. describe the implementation of preference elicitation in the form of an ACP programme; and
5. assess the impact of ACP on home deaths and health resource use.

1.7 Content of the dissertation

Chapter 2 describes the Singaporean cultural and policy context and how it has influenced changes in place of death over the years. Chapter 3 explains the adoption of quantitative and qualitative research methods to answer the research questions, broadly describes the methodological approach, sources of data and analytical approaches. Before examining the factors and interventions that could influence home deaths, we first ascertained the end-of-life care preferences, including the preferred place of death in Singapore. The results are reported in Chapter 4. Chapter 5 explores the process undertaken by healthcare professionals to elicit preferences for end-of-life care, including the place of death in practice, and to explore the contextual factors that have influenced the fulfilment of preferences for the place of death. To complement these findings, Chapter 6 examined the association between individual, clinical, and healthcare system factors with the likelihood of home death, focusing on policies to elicit end-of-life care preferences, and healthcare provision in the home setting. For this purpose, we linked data across five different national databases in Singapore to obtain a system-level perspective. The final analytical sample included 75,650 decedents.

Chapters 7 through 9 focus on advancing knowledge about the implementation of ACP in acute care settings. The impact of ACP on meeting individual place of death preferences, and its influence on the incidences and quantities of healthcare use that might not confer significant benefits to the individual at the end-of-life, were also assessed. Chapter 7 explores how ACP is initiated and integrated into routine clinical care across seven acute care hospitals in Singapore. Chapter 8 examines the use of routinely-collected clinical procedure and diagnosis-related group codes, to evaluate whether end-of-life care preferences were honoured. In Chapter 9, using a statistical matching technique, a comparable control group was created to allow for the evaluation of the impact of ACP on home deaths, life-sustaining treatments, as well as health service utilisation. To account for potential heterogeneity in intervention effects due to differences in disease trajectories and clinical practice or treatment patterns, the analysis also differentiated between cancer and non-cancer patient groups. Finally, the key findings of this dissertation are summarised and discussed in relation to eliciting and honouring end-of-life care preferences in Chapter 10. The strengths and limitations of the methodological approaches adopted in this dissertation, policy and practice implications of the findings, and suggestions for future research are also discussed.

Chapter 2 Study Context

Abstract

This chapter introduces the Singapore societal context, and briefly describes the challenges faced by the country in the face of a rapidly-ageing population. It provides the cultural and health care context that this study is situated within, to give meaning to the presentation and discussion of results in the following chapters. A detailed description of changes in policies, related to elderly, palliative, and end-of-life care, was provided. Key among them is the introduction of a national ACP programme in 2011, to encourage conversations about end-of-life care preferences, including the location that one prefers to die at. In this chapter, the evolution of place of death preferences, at the societal and policy level in Singapore, is presented chronologically. Today, while the home is still widely recognised as the preferred location to die in, overall national trends indicate that most deaths still occur in hospitals. This discrepancy, between what is preferred, and the actual percentage of home deaths, forms the motivation for the conduct of this study.

2.1 Introduction

Following the earlier statement of research questions in Chapter 1, this chapter aims to describe the historical context and evolution of public sentiments as well as government policies related to end-of-life care preferences and to the place of death in Singapore. Before this, an overview to the Singapore will be provided, including the prevailing culture towards caregiving and death, and the organisation of its health and social care system.

2.1.1 Overview of Singapore

The Republic of Singapore is an island-state in South-east Asia. She gained independence from British colonial rule in 1963 and went on to form the Federation of Malaya. However, in 1965, over ideological differences, Singapore separated from the Federation to become a sovereign state (K. B. Tan, Tan, Bilger, & Ho, 2014). In the decades since, the country went on to exponential economic growth with the standard of living increasing by five- to six-folds (Quah, 2015). Today, Singapore is among one of the most affluent countries in the world with a gross domestic product per capita of SGD 73,167 (Department of Statistics Singapore, 2018).

In 2017, citizens and permanent residents accounted for 65% of a 5.6 million population (Department of Statistics Singapore, 2018). The population is multi-ethnic comprising Chinese (74%), Malay (13%), Indian (9%), and individuals belonging to other ethnic origins (3%) (Department of Statistics, 2016). Like other high-income countries, Singapore is experiencing rapid population ageing. Based on government estimates, 900,000 or 19% of the resident population will be 65 years or older in 2030 (Inter-Ministerial Committee, 1999). Due to a higher prevalence of cancer and chronic illnesses among the elderly, the demand for palliative care services is likely to grow. In a projection exercise carried out by the National

Strategy for Palliative Care workgroup, it was estimated that the number of decedents diagnosed with cancer or chronic illnesses, will increase by 25% from 2007 to reach 10,400 in 2020 (National Strategy for Palliative Care Workgroup, 2011).

Singaporeans are living longer but at the same time, reproducing at a lower rate. Life expectancy at birth has increased from 65.8 years old in 1970 to 82.7 years old in 2015 (Department of Statistics, 2016). Together with a below replacement fertility rate of 1.2 (Department of Statistics Singapore, 2018), the old-age support ratio is expected to drop from 5.1 to 2.1 working adults to 1 elderly person in 2030 (National Population and Talent Division, 2013), creating significant pressure on the society to ensure that adequate resources are available to support a much older population in the future. With rapid reduction in family sizes in Singapore, and increases in the proportion of single-person households with an elderly person (Ministry of Social and Family Development, 2015), it became questionable whether families of the future will be able to care for an elderly individual in need. To support family caregivers, almost half of all elderly persons are being cared for, by a foreign domestic worker (FDW) in the home (A. Chan, Ostbye, Malhotra, & Hu, 2014). Today, nursing homes cater only for 2% of the total elderly population in Singapore (Ansah et al., 2013).

2.1.2 Caregiving and death culture.

With individuals of Chinese ethnicity forming the majority of the population, there is strong subscription to the principle of filial piety, which is premised upon the belief that children are beholden to their parents for their birth and must make reparations by obeying them and taking care of them (Kiong, 2004). Through socialisation, the moral obligation to care for one's elderly parents, is upheld not only by the Chinese but also by Malays and other ethnic groups (J. Tan & Chin, 2011). With the passing of the “Maintenance of Parents Act” in 1995, this obligation also became a legal one, as parents aged 60 years and over, can seek maintenance from their children (J. Tan & Chin, 2011). Therefore, it is unsurprising that most aged care occurs at home (Mehta, 2006) rather than in aged care facilities.

Clearly distinct from Western societies where the individual decision making is sacrosanct in relation to healthcare (Peter A. Singer & Bowman, 2002), societies such as Singapore are perceived to give the family or the community greater priority in such discussions. It is widely assumed that familial preferences will supplant individual needs and wishes of the patient. This is often true (J. Tan & Chin, 2011), but among English-speaking Singaporeans, it has also been observed that the need to safeguard one’s identity and autonomy is as important as abiding by familial interests (Alsuwaigh & Krishna, 2015). Tensions do exist as individuals attempt to balance the welfare of the individual with that of the family (C. H. Tan, 1989). Singapore stands apart being an Asian country that is strongly influenced by Western culture where the people have a strong desire for independence together with a collectivist mentality (Li, Ngin, & Teo, 2008).

Based on findings from a qualitative study that elicited the views of 78 physicians in Singapore, it was found that religious beliefs strongly assisted Buddhists, Christians and Muslims to come to terms with death and dying (J. Tan & Chin, 2011). However, for Chinese individuals who subscribe to a syncretic version of Chinese religions that integrates ancestral worship with elements of Taoism, Buddhism and Confucianism; death is often a taboo topic. It is also considered inauspicious to be physically near someone who is dying (Kiong, 2004; J. Tan & Chin, 2011) and until the 1960s, the terminally ill were still being sent to “death houses” (Hack, 2000), to be apart from their families so as not to pollute the living environment when they die (Kiong, 2004). This is a common practice among the low- and middle-income

Chinese who were unable to afford the cost of exorcising the house of spirits (The Singapore Free Press, 1948).

This contrasts with those who subscribe to the Islamic faith. In Singapore, they mainly come from the Malay ethnic group. For them, it is consistent with the Islamic tradition for the person to die at home. It is expected that friends and relatives will make their last visits, and to offer prayers for the dying individual. It is also a time when forgiveness is sought for previous grievances and transgressions against each other (Gatrad, 1994; Sarhill, LeGrand, Islambouli, Davis, & Walsh, 2001; Sheikh, 1998).

2.2 Organisation of health and social care sector

In 2016, the Ministerial Committee on Ageing published the "Action Plan for Successful Ageing", which was based on a public consultative effort with more than 4,000 Singaporeans and grassroot leaders (Ministry of Health, 2016a). A SGD 3 billion national plan was launched to enable to improve the well-being, health, and financial adequacy of the elderly population (Ministerial Committee on Ageing, 2015). This also included health and social care initiatives and changes to the transport and housing infrastructure to support elderly individuals to continue to reside in their homes and be among their communities as they age.

Besides the family, the health and social care sector also plays an essential role in meeting one's healthcare needs and preferences. In Singapore, primary and specialist care, and inpatient care are being provided by both public and private sector providers (Ministry of Health, 2017a). Together, the public healthcare sector caters for 80% of specialist and inpatient care needs of the population whereas the primary care clinics provide approximately 20% of all primary care services consumed. Residential, and community- and home-based continuing care services are mostly provided for by not-for-profit voluntary welfare organisations (VWOs) (National Strategy for Palliative Care Workgroup, 2011). Palliative care services are currently provided by public hospitals, selected nursing homes, and inpatient hospices. Home-based palliative care services are also being offered. Social care services such as befriending, meals-on-wheels, personal care services and escort services are being provided by VWOs as well.

2.2.1 Restructuring to prepare for an ageing population

In the last two decades, there have been tremendous efforts to restructure the organisation of public health care services to better serve the needs of the rapidly ageing population. In 2000, individually-run hospitals, national medical centres and primary care clinics were grouped together first as two clusters to encourage greater efficiency and coordination of care. In the late 2000s, they were reorganised to form six regional groupings; each anchored by a major hospital with the objective of providing vertically integrated care to geographically defined population. Again in 2017, the six groups merged to form three regional health clusters (Figure 2.1) to cover the western, central and eastern part of the island (Ministry of Health, 2017d). Each group aims to provide a comprehensive suite of services, including health promotion and disease prevention, primary and specialist care services. These health clusters work closely with privately-owned general practitioner clinics, VWO-run community hospitals, and aged care providers, to coordinate and provide services that do not come under their remit (W. S. Lim, Wong, Leong, Choo, & Pang, 2017; MOH Holdings Pte Ltd, 2015).

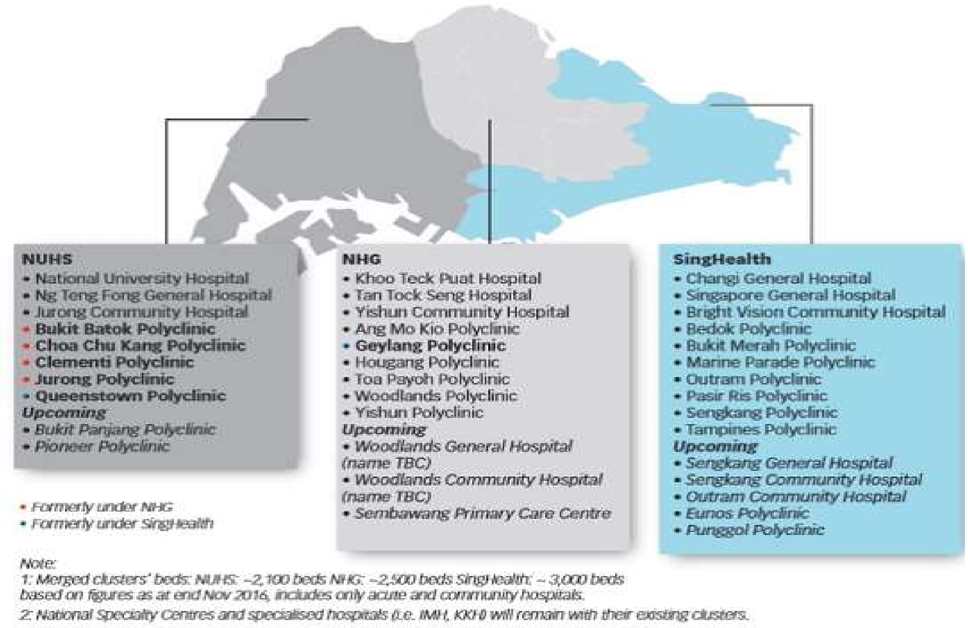


Figure 2.1 Three regional health clusters in Singapore.

Source: Public healthcare system to be regrouped into three clusters. (C. Huang, 2017)

2.2.2 Health and informal care financing

The underlying philosophy of the Singapore health care system views the maintenance of good health and illness prevention to be a collective responsibility that should be shared between the individual, communities, and the government (K. B. Tan et al., 2014). The current government financing of primary and acute care is based on a hybrid system of block grants and case-mix. To maintain affordability of health, the government provides subsidies for the use of acute inpatient services, community hospitals, nursing homes, inpatient hospices, and home care services based on an assessment of the financial means of the patients' household (Haseltine, 2013; Ministry of Health, 2015). A progressive structure was adopted, where individuals from higher-income households receive less subsidies than those from lower-income households.

In supporting the individual to afford healthcare, the government has devised a financing scheme termed as the “3Ms”. Since 1984, under the Medisave policy, every Singaporean resident must put aside a proportion of their monthly salary in a medical savings account. The savings can be used to pay for their personal or immediate family’s healthcare expenses for government-approved inpatient, day surgery and outpatient treatments. Second, MediShield Life, an age-adjusted community rated health insurance policy, was introduced in 2015 to fill in the gaps of a previous scheme. It sought to ensure that all Singaporean residents, regardless of age and pre-existing health conditions, are covered with lifetime health insurance (Lai, 2015). As MediShield Life covers stays in dormitory-style hospital wards, individuals can supplement this by purchasing insurance from private companies for coverage in single- or double-bedded wards, under private integrated shield plans (K. B. Tan et al., 2014). Lastly, Medifund, a medical endowment fund was established in 1993 as a safety net to assist Singaporeans who are face difficulties in affording their medical care, even after drawing upon the above financing schemes (K. B. Tan et al., 2014).

2.2.3 Financing for elder care

Specific to the elderly, financing schemes have been introduced to better support their care. ElderShield, an insurance scheme, was introduced in 2002 to help elderly persons who become severely disabled (K. B. Tan et al., 2014). For those who are not eligible for ElderShield, they are able to tap on the Interim Disability Assistance Programme for the Elderly. To support disabled elderly with long-term care needs, IDAPE provides SGD 150 or SGD 250 per month, depending on the per capita household income, for up to 72- months (Agency for Integrated Care, 2018a).

In 2011, the government also launched the Seniors' Mobility and Enabling Fund, which provides means-tested subsidies for mobility devices, transport and consumables, to enable the elderly to continue to live at home (Agency for Integrated Care, 2013). In 2014, elderly Singaporean citizens born on or before 31 December 1949 were also granted additional subsidies for healthcare services and medication at public healthcare facilities and approved private clinics, under the Pioneer Generation Package. This scheme included free Medisave top-ups by the government, and subsidies on the premiums payable under MediShield Life (Ministry of Health, 2017c).

Besides formal health and social care services, FDWs also provide essential home-based care in Singapore. As each employer is liable to pay a foreign worker levy – a form of tax payable to the government, to lessen the financial burden to families – the government announced in 2004 that concessionary rates will apply, if the FDW were employed to work in households where there are members aged under 12 or over 65 years of age. In 2015, it was announced that, instead of paying SGD 265 per month, eligible families will pay only SGD 60 per month (Ministry of Manpower, 2015).

2.3 Home as the preferred location of death

Although socio-demographic shifts might challenge its feasibility, the Singaporean culture and healthcare policies appear to be largely supportive of the idea of ageing-in-place and caring for one's family members in a home environment (Ministry of Health, 2016a; Toh, 2016). With this, the home is also assumed to be the preferred place of death although literature would suggest that the place of care and the place of death are not synonymous (Agar et al., 2008). The following quotes from the various health ministers exemplify the viewpoint that dying at home is desired.

> “When death is imminent, it is better to die at home in one's own bed, surrounded by loved ones. With portable facilities easily available, it is entirely possible nowadays to ease symptoms at home. We should encourage this and educate our population accordingly.”
>
> George Yeo, Minister for Health, 1994 (Yeo, 1994)

> “After a full and meaningful life, I certainly wish to die at home, among my loved ones, in familiar and peaceful surroundings. We have done a study of where Singaporeans died, mostly (55%) in acute hospitals, 28% died at home but I suspect many more would prefer that too.”
>
> Khaw Boon Wan, Minister for Health, 2007 (Khaw, 2007)

> “Indeed, ‘ageing-in-place’ is the cornerstone of our healthcare policies for our seniors. We want to foster an inclusive and caring community where our elders can age with grace and dignity, and live in a familiar environment that incorporates elder-friendly infrastructures and community-based eldercare services. Ultimately, when the time comes, many of our older people would also wish to die peacefully in their own home, free from pain and surrounded by their families and loved ones.”
>
> Dr Amy Khor, Minister of State for Health, 2012 (Khor, 2012)

2.3.1 Quantification through surveys and focus groups

Currently, the data available does indicate an overall preference towards home as the place of death. In 2014, the Lien Foundation, a Singapore philanthropic house, commissioned a market research firm to conduct a survey to determine attitudes towards death, and the Singaporean public's awareness of hospice and palliative care in Singapore. Through a combined sampling strategy of face-to-face interviews with older Singapore residents (≥50 years old) and an online survey with a younger sample (≤ 49 years old), it was found that 77% of the surveyed individuals would prefer to die at home; and among them, 3 in 4 would still stand by their decision even if there was insufficient support from family, friends and medical professionals (Blackbox Research, 2014). This estimate appeared to place Singaporean preferences close to those expressed by the Taiwanese, North Americans and Western Europeans (Chapter 1).

2.3.2 Use of survey estimates for policy

After being widely quoted in media reports (A. Ho, 2014; Ong, 2017; Tai, 2017) as well as in speeches by health ministers (Chee, 2017; Gan, 2014; Lam, 2017), the figure of 77% has since become part of the public consciousness. It is however unclear regarding the extent to which this estimate of preferences has been incorporated into local health policy decision making. Several methodological issues caution against its use as a definitive policy target.

First, while the study authors had showed that the age, gender and ethnic group profiles of the sample were similar to that of the national population (Blackbox Research, 2014); information on the sampling strategy was insufficient for the readers to ascertain its generalisability to the Singaporean population. Second, in planning for services to cater to those who are currently terminally-ill, policies should also consider the preferences and needs of this specific group. In a small-scale survey conducted with 44 patients diagnosed with cancer, only 52% preferred to die at home, while 42% preferred the hospital (Lee & Pang, 1998). As mentioned in Chapter 1, surveys of this nature, often do not engage individual respondents to cognitively trade-off dying at home against other priorities, which might grow in importance as death draws near.

2.4 Initiatives influencing palliative care

Over the years, government policies have evolved in response to a combination of factors that included population ageing, changing social norms, and the desire to enable a good death. Table 2.1 highlighted specific milestones related to the overall progress of palliative care in Singapore; the enactment and modifications to healthcare financing policies; legislation pertaining to life-sustaining treatments; and the development of specific mechanisms for preference elicitation. The following information was collated based on an unstructured review of the literature, parliamentary speeches, government press releases, government websites, and newspaper reports.

In the pre-independence years, hospitals were often not the first choice of care for the dying. Most individuals were being cared for in one's home or lived in "death houses" until death. Over time, with growing affluence and improved medical care, hospitals became sites of care for the dying. It was not until the late 2000s that the political rhetoric to enable Singaporeans to die at home grew under the stewardship of Health Minister Khaw Boon Wan. However, actual policy changes only occurred in the mid-2010s. Several events potentially precipitated these changes. During the 2010 political elections, the affordability of healthcare and high cost of eldercare became electoral issues (Haseltine, 2013). To address Singaporeans' concerns about healthcare affordability, changes were made in subsequent years to reduce out-of-pocket expenditures on healthcare. Between 2010 and 2014, the publication of several landmark studies (Blackbox Research, 2014; Economist Intelligence Unit, 2010; J. Tan & Chin, 2011), commissioned by the Lien Foundation highlighted several key issues - low level of public awareness about palliative care; presence of significant gaps in palliative care provision and financing; and for the first time, quantified the percentage of Singaporeans who would prefer to receive medical treatments at home, and to remain there until their deaths.

2.4.1 Higher quality of death

From Table 2.1, the provision of palliative care services especially home care services, has grown organically over the years within the charitable sector before the Ministry of Health (MOH) first intervened in the construction of the Dover Park Hospice in the mid-1990s (Yeo, 1994). Since then, the government has sought to train more clinicians in palliative medicine; as well as increase inpatient and home palliative care capacity. With the introduction of palliative medicine in Tan Tock Seng Hospital in 1996, the specialty also became part of mainstream care, and is now available in all public-sector hospitals in Singapore (Lin Goh, 2018) and selected private hospitals.

In 2010, the MOH contracted the Lien Centre for Palliative Care to map out strategies to advance palliative care in consultation with key stakeholders. Their recommendations were accepted by MOH in 2012. This resulted in an increased investment in human resources, expanded palliative care facilities, and clearly defined plans and standard of care. As a result, Singapore rose in an international comparison of quality of death index published by the Economist Intelligence Unit (EIU) (The Economist Intelligence Unit, 2015). In 2015, Singapore was ranked 12th out of 80 countries (The Economist Intelligence Unit, 2015), a significant improvement from its 18th place in the inaugural 2010 report (The Economist Intelligence Unit, 2015).

Table 2.1 Milestones related to elder and palliative care in Singapore

Period	Milestones
1940s – 1960s	• In 1948, there were seven death houses located along Sago Lane; of which two were licensed by the government as "sick receiving houses" (The Singapore Free Press, 1948). • In response to negative foreign press, death houses were shut down in the early 1960s. The government advised the population to admit the dying to hospitals for care (The Straits Times, 1962).
1970s - 1980s	• A proposal put forth to establish a hospice was turned down by MOH (Daryanani, 2017).
1990s	• In 1993, the White Paper "Affordable Healthcare Report" stated that doctors guided by clinical protocols, should not order aggressive treatment not proven clinically or will not improve patients' quality of life (Ministry of Health, 1993) • In 1994, Medisave was allowed to be used for inpatient hospice care (Yeo, 1994) • In 1994, the National Medical Ethics Committee (NMEC) was established to have oversight of and to provide direction for ethical issues in medicine. Advance Medical Directive (AMD) were part of the review, and was recommended in the 1995 report by NMEC (Ministry of Health, 1997) • In 1995, the Singapore Hospice Councl was formally registered with the objective of driving policy, training, fund-raising and public education (Daryanani, 2017). • In 1995, the Dover Park Hospice was opened at an alternative site along Jalan Tan Tock Seng, overcoming protests from students and residents of its initial location beside the Singapore Polytechnic (Lin Goh, 2018). For the first time, MOH covered 80% of the capital cost (Yeo, 1994). • In 1995, the AMD Bill was first introduced, and was widely debated. Public views being submitted to a Select Committee (MOH Holdings Pte Ltd, 2015). The concerns raised included safeguards against euthanasia, proper certification of terminal illness and the right of individuals who had not make directives (Singapore, 1996). In 1996, at its third reading, the Bill was passed. • By 1996, MOH started funding 50% of operational costs of inpatient hospices and disbursing an annual per capita grant to hospice home care patients (Daryanani, 2017). • In 1996, the first hospital-based palliative care service was introduced within the Geriatric Department of Tan Tock Seng Hospital (Lin Goh, 2018). • In 1999, the newly launched National Cancer Centre Singapore (NCCS) started a department of palliative medicine (Lin Goh, 2018).

Table 2.1 Milestones related to elder and palliative care in Singapore

Period	Milestones
2000s	• In 2006, in a reply to a parliamentary question, Mr. Khaw Boon Wan, Minister for Health, said that only 1,328 individuals have signed the AMD by 2005 (Singapore, 2006). • In 2006, NCCS and Flinders University of South Australia signed a Memorandum of Understanding to offer Singapore's first Graduate Certificate in Health (Palliative Care) (National Cancer Centre, 2006). In the same year, palliative care was recognised as a medical subspecialty (Lin Goh, 2018). • In 2007, at the Children Hospice International's 18th Congress, Mr. Khaw Boon Wan, Minister for Health mentioned that in comparison to other countries, more needs to be done in Singapore to give people a 'good death'. He highlighted (a) while most preferred to die at home, 58% died in a hospital; (b) the importance for Singaporeans to talk about end-of-life care preferences, and (c) MOH to study the facilitators and barriers to enabling a home death (Khaw, 2007). • In 2008, non-cancer related home hospice care was introduced under the programme "Holistic Care for Medically Advance Patients" (National Strategy for Palliative Care Workgroup, 2011). • In 2008, the Mental Capacity Act (MCA), was enacted, and subsequently implemented in 2010. It established a framework to guide decisions made by nominated surrogates for individuals who are mentally incapacitated. Surrogates can be nominated formally and legally in a Lasting Powers of Attorney (LPA) document (Menon, 2013). • In 2009, Medisave withdrawals for home care was allowed to enable individuals to tap on their personal medical savings to pay for care that would allow them to spend their last days at home (Ministry of Health, 2009). • In 2009, the National Healthcare Group end-of-life taskforce invited faculty members from the Respecting Choices programme, Wisconsin, US, to conduct an ACP training workshop for healthcare professionals in Singapore (R. L. H. Ng, 2016). Pilot projects were started in Tan Tock Seng Hospital (TTSH) in 2010. • In 2009, the NMEC was tasked to propose an ethical framework for ACP for application in Singapore (National Medical Ethics Committee, 2010).
2010	• The EIU published the inaugural Quality of Death Index, and Singapore ranked 18th out of 40 countries (Economist Intelligence Unit, 2010) • In response to a parliamentary question about ADs, Mr. Khaw Boon Wan, Minister for Health said that MOH was promoting ACP to facilitate individuals to start thinking about and to express their end-of-life preferences. He also mentioned that MOH was committed to growing the healthcare sector's capacity and ability to deliver palliative care in the community to cater to individuals who wished to die at home (Singapore, 2010).

Table 2.1 Milestones related to elder and palliative care in Singapore

Period	Milestones
2011	• MOH launched the Seniors' Mobility and Enabling Fund, which provides means-tested subsidies to acquire mobility devices, transport and consumables that support care at home. The SGD 10 million fund was expanded to SGD 50 million in 2013 (Agency for Integrated Care, 2013). • AIC was task with launching ACP nationally. MOH reserved more than SGD 13 million for the first five years to jump-start the programme (W. C. Ng, 2011). • The report "What Doctors Say about the Care of the Dying" commissioned by the Lien Foundation was published (J. Tan & Chin, 2011). It outlined the state of end-of-life care decision-making in Singapore. • The National Strategy for Palliative Care outlining recommendations to move hospice and palliative care forward, was submitted to MOH (National Strategy for Palliative Care Workgroup, 2011).
2012	• The Lien Foundation launched the "Respectance Fund" to support financially needy patients who wish to die at home (W. Tan, 2012). • An additional SGD 120 per-month grant was introduced to subsidise the foreign worker levy for families to employ FDWs to care for elderly family members at home (Ministry of Manpower, 2015). • Government subsidies for residential, home and centre-based hospice services based on financial means-testing was made available (Ministry of Health, 2015).
2014	• The Lien Foundation commissioned a survey to examine the public's attitudes towards death and dying, and to explore their awareness and views of hospice and palliative care in Singapore. It reported that 77% of Singaporeans wish to die at home. • The National Guidelines for Palliative Care was published, including the following guidelines: "all patients at the end-of-life have access to ACP"; and "care is taken to fulfil the needs of patients in the last days of life, as well as those of their caregivers and families."(Singapore Hospice Council, 2015) • Mr Gan Kim Yong, Minister for Health announced that: (i) the launch of Graduate Diploma in Palliative Medicine by the Chapter of Palliative Medicine Physicians and National University of Singapore; (ii) increase home palliative care capacity to serve 6,000 patients per year by 2020; (iii) increase inpatient hospice beds from 147 to 360 by 2020; (iv) enhance palliative care capability in community hospitals and nursing homes; (v) increase Medisave withdrawal limit for inpatient hospice from SGD 160 to SGD 200 per day; (vi) increase lifetime Medisave withdrawal limit for home palliative care from SGD 1,500 to SGD 2,500 with no limits imposed on terminally-ill patients with cancer and end-stage organ failure; (vii) shift from per visit to per capita subsidy structure for patients on home palliative care; and (viii) promote public awareness about ACP and LPA (Gan, 2014).

Table 2.1 Milestones related to elder and palliative care in Singapore

Period	Milestones
	• Launch of Palliative Care Training Award to support general practitioners to take up the Graduate Diploma in Palliative Care (Khor, 2015)
2015	• In 2015, Singapore ranked 12th out of 80 countries based on EIU's Quality of Death Index (The Economist Intelligence Unit, 2015).
2016	• Amendment of the MCA was passed to (i) introduce the concept of "professional donees" and "professional deputies"; (ii) allow for the revocation of a donee's or deputy's powers by the Court in the event of a significant risk of abuse of the nominating person; and (iii) allow for the suspension of the powers of a donee or deputy by the Court, without the need for an application to have been raised for it.(Singapore, 2016a) • MOH published the "Action Plan for Successful Ageing" after consulting with over 4,000 Singaporeans on their views about ageing well (Ministry of Health, 2016a). As part of this effort, the Home and Community Care Masterplan was also launched to support ageing-in-place (Khor, 2016).
2017	• Mr Gan Kim Yong, Minister for Health announced: (i) a strategic partnership between MOH and SHC to advance palliative care quality, and to raise public's awareness of ACP, AMD and LPA; (ii) expand the coverage of ACP to primary care and outpatient clinics and to extend to 100,000 Singaporeans from 2017 to 2022; and (iii) pilot integrated home palliative care programmes for patients diagnosed with non-malignant conditions by SingHealth and the National Healthcare Group (Gan, 2017)

2.4.2 Better financing for palliative care

The increased provision of palliative care was supported by increased government subsidies for palliative care. Palliative care services offered in hospitals, hospices and at home are funded through a combination of government subvention, Medisave, Medifund and out-of-pocket expenses (National Strategy for Palliative Care Workgroup, 2011). Since 1994, individuals could tap on their Medisave monies for inpatient hospice care, but it was only in 2009 that it could be used for home palliative care, with the policy intention of supporting individuals who wished to "spend their last days in their own homes" (Ministry of Health, 2009). Individuals could utilise up to a maximum of SGD 2,500 per lifetime of Medisave funds for home palliative care and day care services (Ministry of Health, 2017b), with no withdrawal limit for terminally-ill patients either diagnosed with end-stage cancer or advanced organ failure (Ministry of Health, 2018). Adjustments were also made to increase the percentage of means-tested subsidies to make home palliative care more affordable.

Despite the above changes, the non-inclusion of hospice home or inpatient care services in MediShield Life is perceived by commentators to bias healthcare affordability towards hospital care (Law, 2015). Additionally, the historical and continued dependence on funding from the charitable sector (Law, 2015) also brings into question the speed to which the sector is able to respond to the rapid increases in demand. Although government funding has increased in recent years and now accounts for 30-60% of the financial requirements of VWOs (The Economist Intelligence Unit, 2015), perhaps, more is required to impact the overall home death trends in a significant way.

2.4.3 Greater personal and familial autonomy

The above changes occurred against a backdrop of the rapid modernisation of Singaporean society, where there were growing demands from the public for greater autonomy.

AMD in Singapore

However, the government's effort in 1995 to confer legal rights to Singaporeans to refuse life-sustaining treatments was fiercely debated in parliament, where concerns of the public and views of religious leaders were presented by a select committee. Finally, at its third reading, the AMD bill was passed in 1996. The AMD allows individuals to state in advance that they do not want extraordinary life-sustaining treatments to be administered when they become terminally-ill (National Medical Ethics Committee, 2010). These treatments include any medical management or procedure, which only serves to lengthen the dying process when death is near (excluding palliative care).

Among the key concerns raised in 1995/96 was the fear that the AMD represented the start of a slippery slope towards legalising euthanasia (Singapore, 1996), and the certification of the "terminally ill". As such, multiple safeguards were put in place to prevent the potential misuse of the AMD. Although well-intentioned, it has reduced its utility in practice. The safeguards include that: (i) the form must be completed in the presence of a medical practitioner who is able to ensure that the individual is mentally sound and had made the decision voluntarily; (ii) healthcare professionals are not allowed to ask patients about AMDs and are required to enquire through the Registry of AMDs to find out if the patient has signed an AMD; and (iii) a panel comprising three doctors must unanimously certify a patients' terminal illness (Ministry of Health, 2008). Consequently, between 1997 and 2015, only

24,682 Singaporeans made an AMD; out of which, only 10 AMDs were effected during the same timeframe (Singapore, 2016b).

ACP in Singapore

Given the rather low adoption of AMDs internationally, governments in many countries are moving away from a legal approach to one that encourages open communication between the stakeholders involved (Sabatino, 2010). Singapore was no exception. In 2009, the Tan Tock Seng Hospital was the first to pilot ACP, with the intention of encouraging open discussions about future care based on one's personal beliefs, values and experiences. And, in 2011, the National Strategy for Palliative Care workgroup recommended the improvement of public awareness and acceptance of ACP as one of its key goals, with the eventual aim of ensuring that treatments are consistent with patients' preferences.

In that same year, the Agency for Integrated Care (AIC) was tasked by the MOH to launch a national ACP programme, with a budget of SGD 18.1 million over 5-years (I. Chung, 2017). The launch was decidedly quiet, so as not to arouse the same negative sentiments that were created with the AMD Act in 1996 (I. Chung, 2017). The ACP programme, "Living Matters", strongly adapted the processes of the "Respecting Choices" programme in the US (I. Chung, 2017; Hammes & Rooney, 1998). Under the national programme, besides treatment preferences, individuals with advanced illness can also discuss and state their preferred place of care and place of death. Reflecting the collectivist culture in Singapore, family members are encouraged to participate in the ACP decision-making process (I. Chung, 2017).

A comprehensive approach to ACP was developed. As the programme was first launched in the acute care hospitals, members of the staff were trained to facilitate the process through which patients and their families contemplate on the patient's goals, values and beliefs, and to deliberate over their decisions before documenting their preferences about future care. The programme focuses on achieving the objectives of: (i) increasing awareness about ACP among healthcare professionals, community and religious leaders, and the public; (ii) training facilitators to conduct ACP conversations in health and social care organisations; and (iii) developing a national ACP information technology (IT) system (I. Chung, 2017).

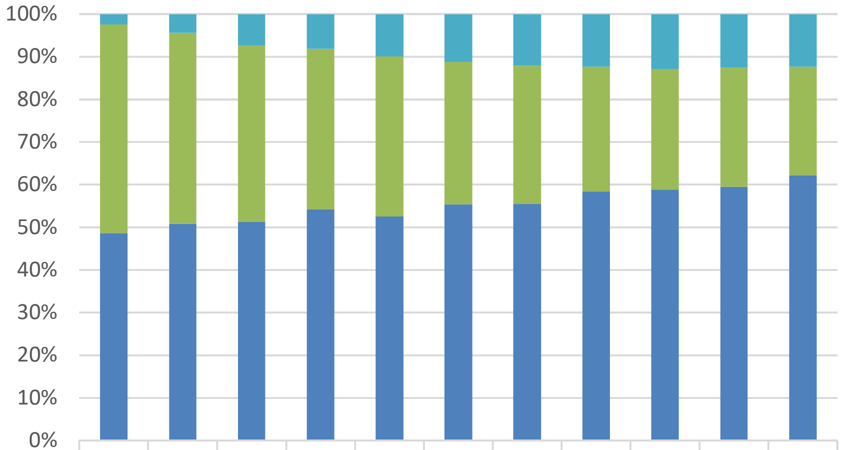
To date, AIC has initiated and supported the training for over 2,000 ACP facilitators (Gan, 2017), and funded the organisation of talks to increase ACP awareness among healthcare professionals working across a range of settings including publicly-funded hospitals, nursing homes, hospice care providers and dialysis centres. VWOs and arts groups are also involved in raising the level of awareness of ACP in the community. In 2017, MOH announced plans to better engage the public by creating more touch points in the community, and to extend ACP facilitation to the outpatient setting (Gan, 2017), as the programme had initially focused on implementing ACP in inpatient care settings.

To obtain more information about ACP, the public is able to do so through a national website (Agency for Integrated Care, 2018b). The website provides users with an online decision-aid that supports the exploration of personal values, beliefs, and preferences for end-of-life care. Brochures and workbooks in the four official languages of Singapore (English, Chinese, Malay, Tamil) can also be downloaded from the website. The website additionally serves as a channel where individuals can share their perspectives about and experiences of ACP.

A national ACP IT system was also launched to allow the facilitators to document the content of the conversations, identified substitute decision makers, and end-of-life care decisions. Frontline clinicians without direct access to the ACP IT system are able to retrieve the content of the forms through their hospital electronic medical records.

2.5 Choosing to examine determinants of home deaths

Even with the multi-pronged approach adopted by the government to facilitate the achievement of preferences for home deaths, the downward trend does not appear to be abating (Figure 2.2). In the last five decades, the rates of home deaths have effectively halved - falling 49% in 1965 to 33% in 1990 to 25% in 2015 (Immigration and Checkpoints Authority Singapore, 2015). Conversely, the share of hospital deaths increased from 49% in 1965 to 62% in 2015.



	1965	1970	1975	1980	1985	1990	1995	2000	2005	2010	2015
🟦 Others (%)	2%	4%	7%	8%	10%	11%	12%	12%	13%	13%	12%
🟩 Residence (%)	49%	45%	41%	38%	37%	33%	32%	29%	28%	28%	25%
🟦 Hospital (%)	49%	51%	51%	54%	53%	55%	56%	58%	59%	60%	62%

Figure 2.2 Death by location, Singapore, 1965 - 2015

Source: Report on the registration of births and deaths, marriages, and persons, 1965 (Registry of Births and Deaths, 1965); Report on the registration of births and deaths and marriages, 1970-1980 (Registry of Births and Deaths, 1970-1980); Report on Registration of Births and Deaths, 1981 – 2003 (Registrar-General of Births and Deaths, 1985-2000); Report on registration of births and deaths, 2005 – 2015 (Immigration and Checkpoints Authority Singapore, 2005-2015)

2. Study context

Despite rich information from North American and Western European countries regarding their experiences in trying to better meet patients' needs and preferences, end-of-life issues can be heavily contextual. More insights into the driving forces, contextual factors, and key processes that could enable the fulfillment of home death preferences is therefore needed. As Singapore was one of the first Asian countries to embark on ACP, it is also timely to examine its implementation, and eventual impact on home deaths.

Chapter 3 Methodological Approach

Abstract

This chapter provides a detailed description and explanation for the adoption of a multiple methods approach for this dissertation. The research involves the conduct of: (i) a retrospective cohort study to identify factors that are linked to the outcome of dying at home, and to profile end-of-life care preferences and determine concordance of care with these preferences; (ii) 14 focus group discussions conducted with 63 healthcare professionals to understand the implementation and conduct of ACP, and factors that have influenced the place of death; and (iii) a quasi-experiment to ascertain the impact of ACP on the place of death. The choices of each of the above study designs, sampling methods, and data analytical approaches adopted in this study are explained. As the researcher plays an integral role in a qualitative research study, the researcher's personal experiences and insights are also described.

3. Research methods

3.1 Introduction

This chapter describes the overarching methodological and analytical approach to address study objectives 1-5. Detailed descriptions of the methods deployed for each objective can be found in Chapters 4-9. All studies are linked to understand the phenomena of home death as a confluence of patient preferences, personal and familial circumstances, and healthcare policies. A multiple methods approach was adopted for the overall thesis, within which, quantitative and qualitative methods were used to address a specific analytic interest.

A quantitative research or deductive approach was adopted, to fulfill the research objectives of describing the profile of end-of-life care preferences in Singaporean patients; enabling the drawing of inferences regarding the influence of individual, clinical and policy-oriented factors on the fulfillment of home death preferences; and assessing the impact of a novel intervention on preference concordance and place of death for individuals with advanced illnesses. Alongside the above, a qualitative approach allowed the examination of place of death preference formation; processes that were involved in the discussion of end-of-life care preferences, and the different configurations of an intervention aimed at facilitating this. Eventually, the results, based on quantitative examination and qualitative exploration, were combined in the discussion chapter, to provide recommendations on how to better meet home death preferences.

The research work described in this dissertation was part of the evaluation of the national ACP programme. The project was commissioned and funded by AIC to better understand the effects of the systematic implementation of ACP across seven public hospitals in Singapore. Dr. Josip Car (main supervisor), and the doctoral candidate jointly conceptualised the overall project and obtained funding for it. The evaluation team comprised researchers from the Lee Kong Chian School of

Medicine, and the School of Social Sciences, Nanyang Technological University, Singapore. Three lead investigators were responsible for the different but interconnected project segments: (i) quantitative impact assessment (doctoral candidate); (ii) qualitative assessment of the implementation process (Dr. Andy Ho), and (iii) economic outcomes modelling (Dr. Low Chan Kee). The work reported in this dissertation are drawn from (i) and (ii).

3.2 Multiple methods

Quantitative research designs, such as experiments, surveys, or modelling of secondary data, are traditionally conducted to address health services research questions. However, this methodological choice limits the inquiry to aspects of the phenomena that are amenable to quantitative methods (Mays & Pope, 1996). The current venture towards a multiple methods approach stemmed from a practical need, as well as a growing curiosity to do research that depicts the richness of contextual narratives, which in turn provides insights beyond what quantitative approaches can offer. In this study, quantitative research was complemented with an in-depth exploration of the contextual factors using a qualitative approach; using data from more than one source and by means of more than one type of analysis (John W Creswell & Clark, 2011; R. B. Johnson & Onwuegbuzie, 2004). This orientated the inquiry towards thinking about the phenomenon of "dying at home" from various perspectives – multiple ways of sensing and participating in the social world (Greene, 2008).

Quantitative (positivist/post-positivist) and qualitative (constructivist/interpretivist) research stem from different philosophical traditions, and it remains controversial whether paradigmatic assumptions are commensurable. In this thesis, the stance of pragmatism was adopted, and it is acknowledged that there are singular, as well as multiple realities, that can be empirically observed (Feilzer, 2009). It centered the research towards providing practical “real-world” solutions in a problem-oriented manner (John W Creswell & Clark, 2011). Rather than focusing on mirroring the reality on home death from a purely positivist or interpretive paradigm, this allows research to be free from these constraints, and create richer insights for health policy-makers, than would be possible from adopting a single paradigm or research methodology.

The optimal approach to support the stated research objectives, is to examine different, but complementary aspects of the same phenomenon. The quantitative and qualitative components were equally weighted, designed, and analysed, concurrently but independently, in a one-phase study (John W Creswell & Clark, 2011). Assumptions belonging to each tradition are importantly different, and the deployment of methods were kept separate (Brewer & Hunter, 1989; Greene, 2008). The mixing only occurred in the final interpretation of the data, by bringing together and triangulating the results from the various coordinated parts. The objectives and methodological approaches used are summarised in Table 3.1.

Table 3.1 Objectives and methods used in this thesis.

Thesis objectives	Study objectives	Strategy of inquiry
1. Explore end-of-life care preferences	Measure the prevalence of preferences including place of death.	Quantitative - Data analysis of retrospective cohort of individuals who had completed their ACP
2. Explore the process of end-of-life care preference elicitation and formation	Understand the experiences of healthcare professionals when eliciting end-of-life care preferences. Understand the formation of patient preferences from the accounts of healthcare professionals.	Qualitative - Semi-structured focus group discussions with healthcare professionals.
3. Explore and determine factors influencing dying at home	Understand contextual factors that influenced meeting of home death preferences.	Qualitative - Semi-structured focus group discussions with healthcare professionals.
	Identify individual, clinical, and health system-level factors influencing home deaths.	Quantitative - Data analysis of national cohort of decedents.
4. Evaluate implementation of ACP to support end-of-life care preference elicitation	Explore implementation models adopted by acute care providers. Explore facilitators and barriers of implementing ACP in acute care hospitals.	Qualitative - Semi-structured focus group discussions with healthcare professionals.
5. Evaluate the impact of ACP on home deaths, and health resource use	Assess the feasibility of using routinely collected data to monitor ACP outcomes.	Quantitative - Data analysis of retrospective cohort.
	Assess the use of life-sustaining treatment, use of acute care services, and place of death between ACP participants and non-participants, differentiated by cancer and non-cancer diagnosis.	Quantitative - Data analysis of retrospective cohort with propensity score matched comparators.

3.3 Quantitative Approach

Quantitative research adopts a positivist standpoint that assumes factual knowledge can be gained reliably through observation or that there is an objective reality that can be measured. The researcher is posited objectively, free from subjective biases, and is able to examine the phenomenon via a “one-way mirror” (Guba & Lincoln, 1994). Its fundamental aim is to determine the relationship between one variable and another. using statistical procedures, with the intent of generalising the results to a larger population. The quantitative approach itself aims to ensure reproducibility of results, by employing research procedures that are repeatable, and using measurement instruments that are valid and reliable. By “valid”, it means that the measurements accurately reflect the underlying concept of interest; and by “reliable”, it means that repeated measurements under the same situations should yield the same results.

3.3.1 Study design

An overarching retrospective cohort study design was adopted for the quantitative studies conducted as part of this thesis. While secondary analysis of existing data is a cost-efficient method for extracting large samples, this effort was dependent on the release of the data from the governmental data owners. It took a year to obtain the relevant ethics and data access approvals and working closely with the data-owners to ascertain data availability, as well as to identify the correct variables for extraction.

First, a prospective survey with a nationally-representative group of individuals would have a plausible alternative study design, that can meet the objective of profiling end-of-life care preferences and to understand the factors that ultimately influenced the place of death. However, to serve our interest in understanding decisions made under real-life circumstances, a retrospective design, using preferences stated as part of ACP, was chosen. Further, to determine which factors are linked to the place of death in a prospective study would have necessitated a protracted and uncertain follow-up period. Like other studies with similar aims, a retrospective design was chosen. Data were linked across multiple national-level databases to provide a holistic picture.

Second, the assessment of the impact of ACP on home deaths was part of a larger national evaluation of the “Living Matters” programme. While the conduct of a randomised controlled trial (RCT) is upheld as the benchmark, it was difficult to overlay a research mechanism over the routine clinical practice of ACP. The pragmatic trial design might have been a good alternative, since it allows the analysis of effects under real-life clinical conditions (Schwartz & Lellouch, 2009; Tunis, Stryer, & Clancy, 2003). This would still require identification using a consistent set of prognostic criteria, to ascertain which individuals are in the advanced stages of their illnesses prior to randomisation (Ford & Norrie, 2016). However, it is uncommon in clinical practice to provide a clear prognosis for patients (R. E. Thomas, Wilson, & Sheps, 2006); and the lack of a single referral or coordinating point for ACP across most sites also posed significant challenges in implementing a pragmatic trial. Therefore, an observational study design was chosen.

The sections below provide an overview of the study population; data sources, linkage process and variables; and a broad description of the statistical methods employed. Specific details about study designs and analyses can be found in the relevant chapters.

3.3.2 Ethics and research governance approval

Ethics approval was obtained from the institutional review boards of Nanyang Technological University [Ref: IRB-2016-03-010] and the National Healthcare Group’s Domain Specific Review Board [Ref: 2016/00739]. (Refer to appendix 2 and appendix 3.) As it was a retrospective database study, informed consent was waived by both boards.

3.3.3 Study populations

The study populations for objectives 1, 3, and 5 are summarised in Figure 3.1.

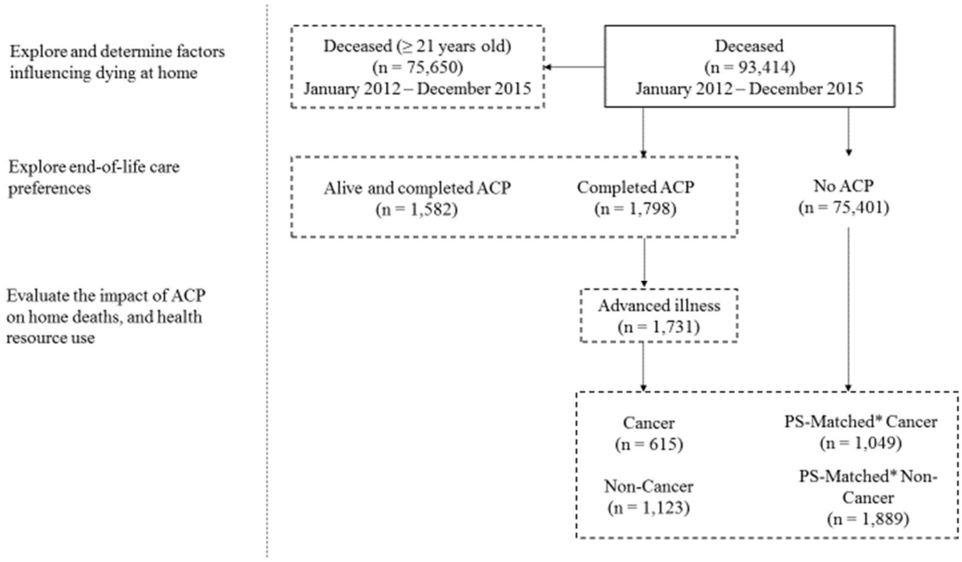


Figure 3.1 Flow chart of study populations for objective 1, 3, and 5.

ACP: Advance Care Planning; PS: propensity score
Boxes bordered with dotted lines reflect the sample used for each objective
*(a) Excluding ACP cases facilitated by social care providers (n=67) as it was not possible to find appropriate matches; (b) A 2:1 matching algorithm using K-nearest neighbor propensity score matching did not give rise to exact number of matched controls

3.3.4 Constructing a comparator group for objective 5

The ability to assert control over intervention assignment clearly limits the reliability of the results of an observational study. However, statistical methods such as propensity score matching (Rosenbaum & Rubin, 1983), can be employed to minimise the extent of confounding bias. In this study, the interest lies in examining the effect of ACP on those who chose to participate in the programme. Therefore, a probability score of membership in the intervention, conditional upon observed covariates, was computed for all observations in the eligible sample.

Traditionally, to adjust for covariate differences, multivariable methods were used in observational studies. There is little evidence that propensity score matching gave rise to estimates that are differently different from the results obtained from more conventional covariate adjustment approaches (Sturmer et al., 2006). However, a propensity score matching method is preferred in this thesis for several reasons. It allows the examination of the extent of overlap between the two groups, in terms of the covariate distribution; and provided greater certainty that the comparison is meaningful if they are similar, because a large difference between the two groups in covariate distribution could imply that the counterfactual would never have occurred in real-life.

Further, by separating the design of the study or intervention assignment from the modelling of the outcomes, it better mirrored the conduct of an RCT, where balance was ascertained between the two groups before estimating the effects of the intervention. Covariate adjustments can be stated a priori. This minimised the inherent bias when conducting a regression analysis, where the analyst has oversight of both the covariates and the outcomes at the same time (Rubin, 2001), rendering the analysis prone to manipulation.

3.3.5 Propensity score deployment strategy

The propensity score can be used to minimise the effects of confounding in a non-randomised study. There are four main methods to deploy it – propensity score matching; stratification based on propensity score; inverse probability of treatment weighting; and using the propensity score as a covariate in a regression (P.C. Austin, 2011). In this study, we have opted to match one participant to two non-participants. This decision was chosen because firstly, the results of the study were intended to inform policy decisions related to ACP. Propensity score matching presented a more intuitive approach that is acceptable to decision-makers, as it better mirrored an RCT design. The large number of potential comparators (>70,000) also gave higher confidence that an individual match would be found. Second, a 1:2 matching was adopted, because this approach was found to improve bias reduction, compared with 1:1 matching (P. C. Austin, 2010; Ming & Rosenbaum, 2000).

3.3.6 Data sources

An anonymised analytical dataset comprising existing information drawn from datasets maintained by MOH, AIC, and TTSH, was first created. Data from TTSH were included to ensure that all completed ACP cases were included in this study[1]. The population, data, and variables extracted from each database, are described and summarised in Table 3.2.

Since the research team was not involved in maintenance of the data used, the quality of the data is ultimately rest on the quality assurance frameworks put in place by the data owners. Regular audits are carried out by the MOH to ensure data accuracy, as the data are used to support government subvention of hospitals, provision of subsidies to eligible patients, and for monitoring health system performance.

---

[1] Tan Tock Seng Hospital operated the ACP programme differently from other hospitals between 2011 and 2015. To minimise resources required to key in all the data into the national ACP IT system, data were captured in hardcopy, and relevant information were entered into an in-house system for tracking end-of-life care preferences.

Table 3.2 Description of data sources and data variables.

Data sources	Population	Description of data	Variables
MOH death data-mart	Deceased individuals	Contains information on all deaths registered with the Ministry of Home Affairs	Age, sex, ethnic group, date of birth, date of death, cause of death, place of death
MOH case mix and subvention database	Individuals attending ED, SOC and hospitalised	Contains information on all attendances at and discharges from public acute care hospitals	ED attendance date, date of hospital admission and discharge including ICD-9-CM and ICD-10-CM diagnosis and procedure codes, ACHI and DRG codes
MOH intermediate and long-term care information system	Individuals admitted to nursing homes, inpatient hospices, using day care, dialysis services, and utilising home medical nursing and palliative care services	Contains information on intermediate and long-term care services eligible for government subsidies	Date of nursing home and hospice admission and discharge; date of day-care, dialysis, home medical, nursing and palliative care service utilisation
National ACP IT system	Individuals completed documentation of ACP preferences	Contains information on end-of-life care decisions documented by health and social care professionals	Age, sex, ethnic group, religion, language spoken, date of publication, substitute decision-maker nomination, life-sustaining treatment decisions, preferred place of care, preferred place of death
TTSH ACP database	Individuals completed documentation of ACP preferences	Contains information on end-of-life care decisions documented by health and social care professionals	Age, sex, date of publication, substitute decision-maker nomination, life-sustaining treatment decisions, preferred place of care, preferred place of death

ACHI: Australian Classification of Health Interventions; ACP: Advance Care Planning; DRG: Diagnosis-Related Group; ED: Emergency department; ICD-9-CM: International Classification of Diseases, 9th version with clinical modification; ICD-10-CM: International Classification of Diseases, 10th version with clinical modification; IT: Information System

3.3.7 Data linkage

All persons residing lawfully in Singapore are issued a unique National Registration Identity Card (NRIC) number by the government. The NRIC is also registered for every healthcare encounter and is used to identify an individual. Therefore, it is possible to obtain a person's information using the NRIC number. To safeguard the confidentiality and privacy of individuals, a project unique identifying number (PUIN) was generated by a third-party vendor for all deceased individuals, based on their NRIC number. This included all deaths registered in Singapore between January 2011 and December 2015. The PUIN was subsequently matched to ACP data from AIC and TTSH, and was used to identify health services utilisation data for each deceased individual across datasets. The data linkage process is represented in Figure 3.2. Researchers subsequently involved in the analysis have no access to the original NRIC numbers.

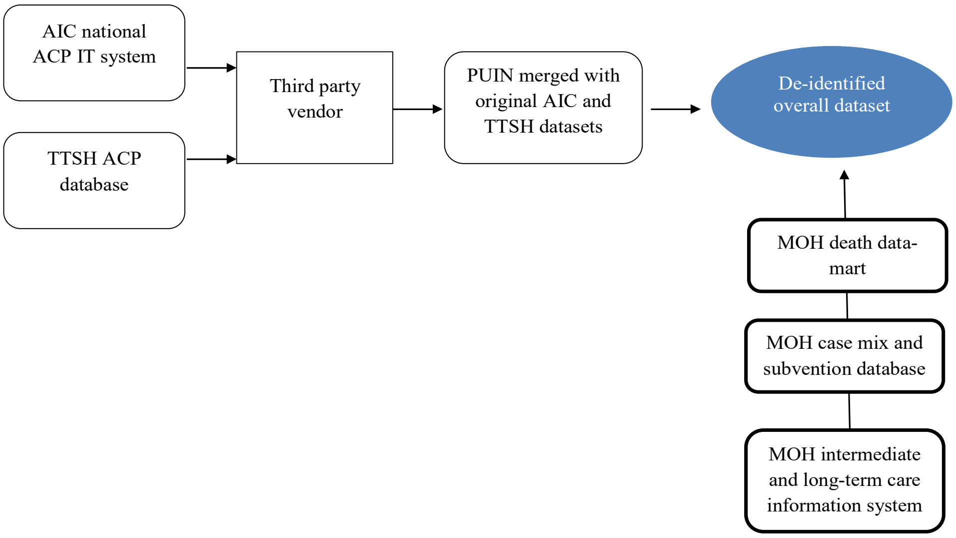


Figure 3.2 Data linkage process.

AIC: Agency for Integrated Care; ACP: Advance Care Planning; TTSH: Tan Tock Seng Hospital; MOH: Ministry of Health; PUIN: Personal Unique Identifying Number

3.3.8 Data analysis

Taking the distribution of the data into account, and the research question to be answered, the most relevant statistical technique was used. While they are fully described in Chapters 4, 6, 8 and 9, the broad approach is described below.

Descriptive statistics, univariate and bivariate analyses

Descriptive statistics and univariate analysis were used to summarise the basic characteristics of the data, using the mean, median, and standard deviation. Frequency distribution tables were created to profile the characteristics of the study samples, to describe the documented end-of-life care preferences and the concordance with the final outcomes. To further describe the empirical relationship between two variables, bivariate analyses were used. Depending on the distributional properties of the variables, the appropriate statistical tests were used. A chi-square test was used to determine whether a statistically significant relationship exists between two categorical variables. For continuous scaled variables which are non-normally distributed, the Mann-Whitney U test, which is non-parametric, was used. The median values, instead of the mean, were compared between the two samples, and therefore it is robust against outliers and skewed distributions.

Multivariable regression models

Due to the distributional properties of the outcome (dependent) variables, generalised linear models (GLMs), which are a class of non-linear regression models, were used. In the case of non-normally distributed data or binary data, a least squares estimation does not provide minimum variance-unbiased estimators for the parameters. Instead, the method of maximum likelihood was used in GLMs in an iterative process to maximise the likelihood function (J. Fox, 2015). GLMs allowed the analyst to (i) specify the conditional distribution of the outcome variable beyond the Gaussian, to include others from the exponential family, such as binomial, Poisson, gamma or negative binomial distributions; (ii) express independent variables as a linear function or linear predictor; and (iii) utilise a linearising link function (identity, logit, log, inverse, inverse-square) to relate the expectation of the outcome variable to the linear predictor (J. Fox, 2015; McCullagh & Nelder, 1989).

Logistic regression, which is a specific type of GLM, was used when the outcome variable is binary or when the distribution is assumed to be binomial (Hosmer Jr, Lemeshow, & Sturdivant, 2013). The logit function was used to link the outcome variable to the linear function of the independent variables. The regression coefficients were expressed as an odds ratio (OR), which can be interpreted to be the odds of an outcome given the exposure to a predictor, compared to the odds of the outcome when the predictor is absent (Menard, 2002).

For count variables, the Poisson distribution was used (J. Fox, 2015). This is useful for modelling non-negative integer values. The Poisson regression assumes the outcome variable has a Poisson distribution. Through a linear combination of independent variables, it is possible to model the logarithm of the expected value of the outcome variable (McCullagh & Nelder, 1989). However, when the data is over-dispersed, the assumption that the conditional variance is equal to the conditional mean is violated. Instead of a Poisson model, a negative Binomial regression model was used. To test for over-dispersion, a likelihood ratio test was used to ascertain whether the Poisson or Negative Binomial distribution modeled the data more accurately. Exponents of the regression coefficients are incident rate ratios, which can be interpreted as multiplicative effects on the expected number of outcomes.

For continuous outcome variables that are non-normally distributed, the ordinary least squares regression is inappropriate and inefficient. In this dissertation, one example included the modelling of the hospital LOS data, which comprised non-negative outcomes, zero outcomes, and positively skewed distributions. A GLM model, with log link and gamma distribution, was used. Exponentiated coefficients are also termed as incident rate ratios, which represents the ratio of expected LOS in the ACP and comparator cohorts. It can be construed as the multiplicative effect of a unit change in an independent variable.

All statistical tests were carried out using STATA version 12 (StataCorp, 2011).

3.4 Qualitative Approach

Given that the intention was also to explore the motivations behind human behaviours, and healthcare processes underlying the social phenomenon of "dying at home", the use of quantitative methods alone was insufficient. The decisions and actions supporting this phenomenon can be complex, and is often influenced by interactions between patients, families, and healthcare professionals, all of whom operate within social structures with prevailing rules of engagement, as well as role expectations.

By "turning the world into a series of representations, including fieldnotes, interviews, conversations, photographs, recordings and memos to the self" (Denzin & Lincoln, 2011), qualitative research aims to understand and interpret the meanings that individuals assign to their experiences of the social world (Mays & Pope, 1996). This worldview is intrinsically inductive and reflective in nature (Omery, 1983); one which allows the rich contemplation of multiple dynamic realities. Therefore, rather than simply determining the proportions of individuals who prefer to die at home and the factors that influence this outcome, qualitative research allows us to explore how preferences for the place of death are formed, and the influences of and interactions between individual perceptions, familial obligation, and activities of healthcare professionals, on the final place of death.

3.4.1 Methodological orientation

An interpretive phenomenological approach was adopted, because it allowed rich descriptions of the process undertaken to organise, implement, and facilitate end-of-life care discussions. This approach allowed the exploration of contextual factors that acted to facilitate or impede "dying at home", as perceived through the interpretative lenses of healthcare professionals, who not only participated in the "work" of ACP, but also brought with them perspectives shaped by personal experiences and cultural contexts (J.W. Creswell, 2007). Instead of adopting a descriptive stance, an interpretive approach (Moustakas, 1994) was used, since "things are not simply in themselves, nor do they exist "out there" independently from us. Their being is always constituted by a "showing themselves to us" and by our way of access to them" (Fuenmayor, 1991).

Other qualitative approaches, such as grounded theory and ethnography, were considered during the design stage of the study. Grounded theory, as an inductive approach, is useful for examining the meaning of lived experiences, and involves continuous identification and incorporation of categories of meaning, to build a contextualised theory (Strauss & Corbin, 1990). However, the iterative theory development process, of formulation, testing and redevelopment of propositions to relate the different categories within the theoretical model, required far more funding and time than was feasible within the scope of this study.

We also explored the possibility of conducting an ethnographic study, which would have allowed for the exploration, description and interpretation of shared experiences situated in the everyday lives of individual persons. Under this approach, the researcher immerses him/herself by participating, observing, and interviewing the participants on their behaviours, use of language and interactions in a shared environment (Harris, 1968). Again, the conduct of an ethnographic was assessed to be too resource-intensive, and the research team encountered varying levels of receptiveness from participating sites to such an approach. Further, the research outputs from an ethnographic study may be less accessible and useful to health policy-makers, due to its storytelling approach (J.W. Creswell, 2007).

3.4.2 Choice of study population and perspective

The qualitative and quantitative segments were designed to offer insights into how the healthcare system can better support the elicitation and achievement of the patient's end-of-life preferences through the effective implementation of ACP. The voices of patients and their family members are undeniably critical but several studies have examined the constituents of a good death (Chetna Malhotra, Chan, Do, Malhotra, & Goh, 2012), and explored the end-of-life care preferences among patients and their caregivers (Finkelstein, Bilger, Flynn, & Malhotra, 2015; C. Malhotra, Farooqui, Kanesvaran, Bilger, & Finkelstein, 2015) in the Singaporean context. Hence, this thesis was scoped to offer a health system perspective.

3.4.3 Interpretive Systemic Framework

This study adopted a qualitative focus group design to support a systemic inquiry into patient preference elicitation and ACP implementation. A health system perspective, as opposed to a patient's perspective, was adopted to gain an insider's perspective of the health system's role in influencing home deaths. Given that the preference elicitation process via ACP involved multiple and differently-trained healthcare professionals, the Interpretive Systemic Framework (ISF) was used to guide the inquiry process.

Combining systems theory and the interpretive paradigm, the ISF is an epistemological approach for the systemic comprehension of organisational structures, through interpreting different perspectives arising from diverse contextual systems (Fuenmayor, 1991). The IFS appropriately allowed for the study of organisational structures, and how different professional groups act and/or interact to bring patient preference elicitation to fruition, and allowed for the examination of their inter-relationships, as well as boundaries between the groups. It highlighted the plurality of “thematic interpretive contexts” (Fuenmayor, 1993) and the different interpretations of reality, from different healthcare professionals belonging to different staff groups, about the social sense of ACP, as situated within the context of acute care hospitals in Singapore.

3.4.4 Declaring personal viewpoints

In the conduct of qualitative research, the researcher plays a different role from that of the objective analyst for quantitative research. By asking questions, making observations, interviewing participants, and interpreting discussions during the focus groups between different stakeholders, the researcher becomes a key instrument within this interpretive process (Altheide & Johnson, 1994). Therefore, it is essential to declare one’s perspective in relation to end-of-life care preference elicitation and dying at home. This brings forth the researcher’s attitudes, belief and perspectives to the reader, and at the same time, creates awareness for oneself to reflect upon how these could have influenced the analytical process, and the interpretation of the research results. This reflexive process also allowed for the conscious seeking of alternative interpretations, alongside the triangulation permitted from working in a team with diverse experiences and perspectives.

The following presents a brief reflection on my personal viewpoints, shaped by several personal and professional events:

- I entered the research assuming home death and the principle of self-determination to be desirable to most patients, while also acknowledging that these may be less important for some individuals, who may be more partial towards familial decision-making, and prefer the level of care that can be provided in a healthcare institution.
- Personally, I have experienced the dilemma that end-of-life decisions could pose to the family. While a relative had earlier communicated her wish to die at home, the family remained deeply divided, between admitting her to the hospital with the view of helping to manage her pain, and honouring her wishes to be cared for and to die at home.
- Professionally, I have been involved in the evaluation of three palliative care programmes, addressing the needs of nursing home residents, adult cancer patients and paediatric patients; two of which had included ACP as a core programme component (C. W. L. Ng, Cheong, Govinda Raj, Teo, & Leong, 2016; W. S. Tan et al., 2016; Teo et al., 2014). Participants in both programmes indicated a strong preference to die at the current site of residence – either in the nursing home or in the patient's own home. The programmes were associated with significant healthcare use and in enabling the patient to die at their preferred locations. While I hold the view that well-designed programmes can be beneficial across a broad patient spectrum, I am also aware that, without good quality and accessible palliative care, formal and informal caregivers in these settings may be unable to support the achievement of these preferences.

3.4.5 Focus group co-facilitators

The focus groups were moderated and observed by the research team, which comprised 6 researchers from the Nanyang Technological University. Andy Ho, Priya Lall and Tan Woan Shin took turns to facilitate and co-facilitate the semi-structured focus groups. Three other researchers – Paul Victor, Wong Lok Hang, and

Oindrila Dutta, recorded the timing of speech by the participants, took note of non-verbal cues, and observed the sessions.

Tan Woan Shin (doctoral candidate) holds both Masters and Bachelor degrees in Economics, was trained in qualitative methods and had previously conducted semi-structured interviews. As a health services researcher who has led the impact evaluation of several end-of-life care programmes, she is familiar with the study context. The two co-facilitators are social scientists. Dr. Andy Ho is an Assistant Professor of Psychology in Nanyang Technological University with more than a decade's experience in conducting death and dying research in Hong Kong and Singapore. He instructs undergraduate courses in qualitative research methodology; has extensive experience leading focus group discussions and is familiar with the study context. Dr. Priya Lall is of British nationality, and was a research fellow with the Lee Kong Chian School of Medicine. She holds a doctorate in social policy and social intervention, is trained in qualitative research methods, and has experience conducting participant interviews related to the prevention of Human Immunodeficiency Virus in South and Southeast Asia.

3.4.6 Ethics and research governance approval

This study was approved by the Institutional Review Board of Nanyang Technological University on 07 July 2016 (Ref. No.: IRB-2016-05-023), and the Domain Specific Review Board of the National Healthcare Group Singapore (Ref. No.: 2016/00603) on 05 August 2016. (Refer to appendix 4 and 5.)

3.4.7 Implementation of the study

Study sites

This study involved a total of seven different sites - five acute general hospitals, one women's and children's hospital, and one specialty centre. All but one acute care hospital, involved in the implementation of ACP under the “Living Matters” programme, participated in the study. Although we made numerous attempts to contact the principle investigator of the last hospital site, we were unable to obtain agreement for participation, before study roll-out.

The final list of participating acute care settings included Changi General Hospital (CGH), KK Women’s and Children’s Hospital (KKH), the National Heart Centre Singapore (NHCS), Khoo Teck Puat Hospital (KTPH), National University Hospital (NUH), Singapore General Hospital (SGH), and TTSH.

Sampling frame and recruitment procedures

Guided by the ISF (Fuenmayor, 1991), the sampling frame was set up to capture the diverse perspectives of participants, who played different roles during the ACP implementation process, and had varying levels of experience in its conduct. Participants were chosen from each of the participating sites to ensure representation of site-specific views and experiences. Purposive sampling such as this is widely used in qualitative research to allow for the identification and selection of participants, who are to provide rich information related to the phenomenon being studied (John W Creswell & Clark, 2011).

Each of the site principal investigators (PIs) from the seven participating hospitals were asked to identify individuals who had completed the ACP facilitator training, conducted by AIC. Ideally, two members, from each of the four professional groups – physicians, medical social workers, nurses and coordinators (employed to carry out administrative and facilitation tasks specific to ACP), should be identified and subdivided based on their level of experience in the programme - defined in terms of the number of facilitated sessions. Respondents who participated in 5 or less conversations were defined as having little involvement in the programme.

Meanwhile, respondents who conducted 5 or more ACP conversations were defined as having a high level of experience in the intervention.

Due to site-specific operationalisation of the programme, not all professional groups were involved in the implementation of ACP. As such, they were not nominated by the site PIs or recruited into the study. In total, the site PIs identified 68 individuals. Subsequently, we sent these participants an advanced email to explain the research aims, informed them about the study eligibility criteria, and that a phone call would be made to make an appointment with them for the focus group discussion (FGD). Consent was obtained from the participants. (Refer to appendix 6 for the informed consent form.)

Table 3.3 Respondent by hospitals by profession.

	CGH	KKH	KTPH	NHCS	NUH	SGH	TTSH	Total
ACP Coordinator	2	0	2	2	2	2	2	12
Doctor	3	1	2	1	2	2	1	12
MSW	3	2	3	4	5	3	4	24
Nurses	4	2	3	0	1	0	5	15
Grand Total	**12**	**5**	**10**	**7**	**10**	**7**	**12**	**63**

ACP: Advance Care Planning; CGH: Changi General Hospital; KKH: KK Women's and Children's Hospital; KTPH: Khoo Teck Puat Hospital; MSW: Medical Social Worker; NHCS: National Heart Centre Singapore; NUH: National University Hospital; SGH: Singapore General Hospital; TTSH: Tan Tock Seng Hospital

Study participants

All individuals contacted consented to participate, but eventually, only 63 (93%) attended the 14 focus group discussions. The composition of the participants was differentiated by hospital, and staff groups (Table 3.3), of which, thirty-seven (59%) participants were considered experienced facilitators. From the table of participant characteristics (Table 3.4), most participants were female (n = 52) with a mean age of 38 years old. The majority were of Chinese ethnicity (87%), and the respondents predominantly identified as Christian (43%); followed by Buddhist/Taoist (30%) and Muslim (11%).

Non-respondents

Five healthcare professionals in the original sampling frame did not attend the FGDs, although they had agreed to participate either via email or telephone. The main reason cited was work exigencies that arose on the day of the scheduled FGD.

Table 3.4 Demographic details for participants.

Variable		Number, n	Percentage, %
Gender	Male	11	17.5
	Female	52	82.5
Age	21 – 30	19	30.2
	31 – 40	24	38.1
	41 – 50	14	22.2
	51 – 60	5	7.9
	60 and above	1	1.6
Ethnic group	Chinese	55	87
	Malay	6	9
	Indian	1	2
	Other	1	2
Religion	Christian/Catholic	27	42.9
	Buddhist/Taoist	20	30.2
	Muslim	7	11.1
	Other	10	15.9

Focus Groups Discussions

A semi-structured interviewing schedule was established based on Proctor et al.'s (Proctor et al., 2011) conceptual taxonomy of implementation outcomes, to generate data on processes involved in the establishment of the ACP programme. They included: 1) acceptability of the ACP programme; 2) programme fidelity; 3) programme feasibility; 4) programme penetration; and 5) programme sustainability. The detailed interview schedule can be found in appendices 7 and 8.

Individuals who agreed to participate in the study were asked to consent in writing, and to engage in a 90-120-minute-long focus group, conducted by the researcher and co-facilitators. The focus groups were conducted in a meeting room in the Lee Kong Chian School of Medicine (Nanyang Technological University, Novena Campus). Each focus group was audiotaped and transcribed verbatim. A focus group format was chosen, instead of individual interviews, for several reasons. First, it was more cost-efficient because the sampling frame spanned across seven different sites, and covered four different groups of healthcare professionals; to conduct one-on-one interviews would require a substantial amount of time. Second, since my objective was to elicit expressions of different opinions and experiences of ACP implementation across the different sites, each FGD involved individuals belonging to the same professional grouping, but from different hospitals. This allowed for richer discussions than would have been possible in a one-to-one interview.

3.4.8 Data analysis

The Framework Analysis approach was used to analyse the data to generate important categories and themes that encapsulate the preference elicitation process in Singaporean acute care hospitals, and to elucidate the elements that have influenced its organisation and implementation, along with factors influencing the meeting of place-of-death preferences. This approach organised data according to themes in a hierarchical manner; and was developed to cater to research that asks a priori determined questions regarding organisational issues, especially complex interventions with interacting processes that involved multiple participants (Gale, Heath, Cameron, Rashid, & Redwood, 2013). While an inductive approach allowing patterns, themes, and categories of analysis to emerge from the data (John W Creswell & Clark, 2011) forms the Framework Analysis approach, a purely inductive method was not used. Instead, the analytical process was also informed deductively with a priori sensitising concepts from the literature (Costa et al., 2016; Gomes & Higginson, 2006; May et al., 2007), to provide a general reference and guidance (Blumer, 1954). These sensitising concepts offered a starting point to see, organise and understand the lived experiences, as they were also ingrained in our personal understanding of the phenomenon (Charmaz, 2003).

Thematic analysis is commonly used as an analytical approach in qualitative research. Thematic analysis helps to search for, and to identify common threads that supports the description of the phenomenon and the research questions of interest. As the themes did not emerge immediately, it involved stepping back to consider the messages of the various participants, and to find underlying commonalities in and between them. It was often an iterative process of coding, linking codes to generate themes, and recoding, as greater clarity is gained in the analyses regarding the similarities and differences in what was being said. These themes often emerged from the data, linking across different FGDs, rather than being explicit concepts brought up by the participants. The coding process is further described in Chapters 5 and 7.

The QSR NViVo qualitative data management software was used for storing, coding, and analysing the data (QSR International Pty Ltd, 2016).

3.4.9 Data saturation

When additional data do not add further information to what is known, we can say that saturation has been reached (Morse, 1991). To operationalise this concept would require the selection of sample, fieldwork and analysis to occur iteratively (Ritchie, Lewis, Nicholls, & Ormston, 2013), which requires a significant investment of time. Due to the time-bound nature of the larger project that that these two studies were situated within, this strategy of assessing data saturation proved infeasible. All 14 FGDs were completed between September and November 2016 and data analysis only started thereafter. Although the Framework Approach does not require data to be saturated (Ritchie et al., 2013), an assessment of new themes emerging from each FGD was nevertheless useful in ensuring the coverage of pertinent concepts in our data. For Chapter 5, no new themes emerged after the fourth FGD and information obtained from the remaining FGDs reflected the same themes. This point was similarly reached at the fifth FGD for Chapter 7.

3.4.10 Ensuring rigour in qualitative research

To establish methodological rigour, an audit trail was kept, investigator triangulation was employed, and member checks were performed.

The study team kept a detailed audit trail documenting our experience throughout the study, which included observations and reflections during the data collection process. Decisions made collectively by the research team, along the iterative process of data collection, analysis, and reporting of findings, were also documented. This allowed for the tracing of steps taken throughout the research, and the reasons underlying any changes made to the research approach.

In this study, triangulation was applied at several levels to ensure trustworthiness of the results (Shenton, 2004). First, we involved a wide range of informants from different professional groups from different hospitals. Individual accounts and perspectives were substantiated by others working in the same hospital. Triangulating across sites minimised the local effects, when exploring the experience of healthcare professionals in conducting end-of-life care discussions. Second, a team approach was adopted in the data analysis and results interpretation process to minimise researcher bias, by taking different perspectives into account (Patton, 1999).

The interpretation of the results was first presented to selected research participants from all seven participating institutions. They found our analysis to be consistent with their observations and experiences. Subsequently, the results were also presented to members of a national-level committee responsible for the implementation of ACP in Singapore, and to the administrative team for this programme. Feedback from these groups also alluded to the reliability of the results.

3.5 Role of the doctoral candidate

As the studies included in this dissertation are part of a larger project, a clear description of the doctoral candidate's role within the multi-disciplinary research team is needed.

For the quantitative studies reported in Chapters 4, 6, 8, and 9, with inputs from the thesis advisory committee, the doctoral candidate conceptualised and designed the overall methodological approach. She led the design and drafting of the statistical plans with inputs from Dr. Ram Bajpai (biostatistician). Geronimo Jimenez (research associate) managed the ethics approval process. The doctoral candidate liaised with representatives from AIC, MOH and TTSH to identify the sources of data relevant to the project; operationalised the variables of interest; mapped the dataflow process across the different institutions, and obtained the necessary approvals to access the data. Dr. Bajpai cleaned and merged the data. Working with Dr. Bajpai, the doctoral candidate coded and analysed the data. She also interpreted and reported the results, and drafted all the chapters, and incorporated comments from the project team as well as the thesis advisory committee.

For the qualitative studies reported in Chapters 5 and 7, the doctoral candidate designed the questions and analytical approach of these chapters, which were incorporated into the wider qualitative assessment of the ACP programme led by Dr. Andy Ho. Paul Victor (research officer) and Wong Lok Hang (research associate) managed the ethics approval process, liaised with representatives from the seven hospitals, coordinated the recruitment of informants, and organised the FGDs. Out of 14 FGDs, Dr. Ho led twelve of them, Dr. Priya Lall (research fellow) and the doctoral candidate led the facilitation of one FGD each. She also co-facilitated 9 of the 14 FGDs. The doctoral candidate transcribed four discussions while Paul Victor, Wong Lok Hang, and Oindrila Dutta (doctoral student), and a private transcription company transcribed the other ten discussions. The doctoral candidate coded and analysed all data relevant to Chapters 5 and 7, and led the discussion with the research team in the analysis and interpretation of the findings. She also drafted the two chapters, and incorporated inputs from the project team as well as the thesis advisory committee.

Chapter 4 A Profile of End-of-Life Care Preferences

Abstract

An ACP programme, “Living Matters”, was launched nation-wide in Singapore in 2011. The programme is accessible to individuals who are healthy, chronically ill, or diagnosed with advanced illnesses. This chapter profiles the end-of-life care preferences of individuals who have formally completed their advance care plans, according to their health statuses.

Eighty-five percent of ACPs were completed in acute hospitals. Most individuals (81.5%) had nominated their immediate family members as substitute decision-makers. Across healthy and chronically ill patients, the majority did not opt for cardiopulmonary resuscitation (CPR) or other life-sustaining measures. Among those with advanced illnesses, 94% preferred not to attempt CPR, but 69% still preferred to receive some form of active medical treatment. Approximately 40% opted for home as the place of care, and the place of death. Those aged 75 years and above were more likely to not opt for CPR; had a stronger preference for comfort measures, as well as to be cared for and to die at home. Females were more likely to opt for full treatment, and to opt for facility-based healthcare.

The majority preferred to not proceed with life-sustaining treatments, but there was still a strong preference to receive some form of limited treatment. Our results indicated a lower preference in this sample of individuals with advanced illnesses as compared with the outcomes of a community-based survey. Better understanding of end-of-life care preferences through ACP can better guide end-of-life care programme planning, and resource allocation decisions.

4. Profile of end-of-life care preferences

4.1 Introduction

Most societies that are experiencing a rapidly ageing population would encounter challenges in providing high quality end-of-life care to its population. In many jurisdictions, an individual could designate a health care decision-maker, and specify decisions regarding life-sustaining treatments in the event of decisional incapacitation, in a legally binding AD. In 1991, the PSDA was enacted in the US, by requiring healthcare institutions to provide information to adult patients about advance health care directives, upon admission to a healthcare facility (Greco, Schulman, Lavizzo-Mourey, & Hansen-Flaschen, 1991). Since then, other countries have joined the movement to empower patients by introducing legislation.

In 1996, the Advance Medical Directive Act was passed in Singapore to safeguard individuals' treatment preferences to forgo extraordinary life-sustaining treatment (Leng & Sy, 1997). An individual can opt to sign an AMD to indicate to one's doctor about his/her wishes with regards to the use of life-sustaining treatment in the event of terminal illness and impending death. Out of the 3.9 million resident population (Department of Statistics, 2016), only 24,682 individuals have completed an AD between 1997 and 2015, of which only ten were effected (Ministry of Health, 2016b). International research has cited legal formalities (Rolnick, Asch, & Halpern, 2017; Sabatino, 2010) and low public awareness (M. Tay, Chia, & Sng, 2010) as impediments towards the completion of advance (medical) directives (Hanson & Rodgman, 1996; Rao, Anderson, Lin, & Laux, 2014).

Due to the shortcomings of setting limits on medical care based on legal means (Rolnick et al., 2017), there has been a shift in policy focus towards supporting ongoing communications about end-of-life preferences between involved parties (Sabatino, 2010) in inpatient, as well as outpatient and community settings (Greco et al., 1991; Rolnick et al., 2017). Effective communication has been identified as key in improving surrogate accuracy regarding end-of-life care (Meeker & Jezewski, 2005), and increasing the level of concordance between received and preferred care (Houben, Spruit, Groenen, et al., 2014). By promoting discussions between patients, their loved ones and healthcare professionals, ACP is thought to better support communication and to align services received by the individuals, with their objectives of their care and their personal preferences (Institute of Medicine, 2015) (Institute of Medicine, 2015)

Research has found ACP to empower patients with a greater peace of mind (L. Murray & Butow, 2016), improve the level of agreement with regards to end-of-life care between patient and surrogate, reduce decisional conflict (Walczak, Butow, Bu, & Clayton, 2016) and improve their satisfaction with care (Weathers et al., 2016). The likelihood of dying at their preferred place was also higher among individuals who had completed an ACP (Martin et al., 2016); the transition between acute and terminal care is often smoother (Oliver, 2005) with earlier referrals to community-based palliative care. ACP was associated with avoiding or reducing unnecessary life-sustaining treatments (Martin et al., 2016; L. Murray & Butow, 2016), increasing the incidence of out-of-hospital and out-of-intensive care, and increasing the probability of dying at home (K. M. Detering, A. D. Hancock, M. C. Reade, & W. Silvester, 2010; Ratner et al., 2001; Schamp & Tenkku, 2006; Teno et al., 2007).

With this perspective, the Singapore government launched a comprehensive national ACP programme, “Living Matters”, in 2011. “Living Matters” is based on the Respecting Choices® programme at the Gundersen Health System in Wisconsin, US Primarily, the programme aims to systematise the elicitation and documentation of medical and care preferences (Gan, 2011); with a longer-term goal of normalising death and dying conversations in the community (Gan, 2014, 2017). Listed amongst populations that are ageing most rapidly in the world, this is a timely effort, as the need to cater for health care, including end-of-life care of the population, is expected to intensify alongside the doubling of the elderly population (Inter-Ministerial Committee, 1999). The ACP programme was launched under the leadership of AIC, an independent corporate entity under the purview of the MOH Holdings. In the first phase of the programme implementation, ACP was initiated in public acute care hospitals and specialist care centres. In 2017, AIC shifted the programme towards a public health stance by expanding the outreach and facilitation services to the community (Gan, 2017).

Research has been conducted locally to profile the end-of-life care preferences across different patients and community-based samples (Blackbox Research, 2014; Finkelstein et al., 2015; Low, Ng, Yap, & Chan, 2000; C. Malhotra et al., 2015) . The data reported in these studies contained the individual responses of their attitudes and preferences, which may not accurately represent real-world decision-making when families or loved ones are also involved. Therefore, in this chapter, we review the demographics and end-of-life care preferences, as documented in an Advance Care Plan. Given that end-of-life care preferences could differ across different health states and over one's life cycle (Ditto, Jacobson, Smucker, Danks, & Fagerlin, 2006), preferences are profiled according to their health status. Additionally, we also examined the effect of age and gender on stated preferences.

4.2 Methods

4.2.1 "Living Matters" ACP programme

Similar to Respecting Choices®, "Living Matters" comprised three integrated components: (1) provision of patient educational materials; (2) trained and certified ACP facilitators who assist individuals with ACP; (3) development of an IT system to enable easily storage, and retrieval of ACP forms (I; Chung, 2013; Moorman, Carr, Kirchhoff, & Hammes, 2012). The programme has adopted a staged approach that considers a person's state of health and allows ACP to be conducted in phases across one's life-time. The conversations can then be individualised based on one's health status, which is broadly categorised as healthy, diagnosed with complex chronic illnesses or diagnosed with advanced illnesses. (Refer to appendices 9-11 for the ACP forms.)

Currently, there is no defined criteria for referral to ACP, and is largely based on clinical judgement and patient readiness to discuss about end-of-life care issues. In practice, a social care or health care professional may facilitate a conversation between the patient, and his/her family members to explore his/her values, beliefs and how this impacts preferences towards medical care at the end-of-life. ACP is not legally binding in Singapore and therefore, there is no need to engage a lawyer for its discussion or documentation (How & Koh, 2015). All participating persons are encouraged to specify an individual who can act as a substitute decision maker to make health care decisions on their behalf in the event of incapacitation. Different questions and standardised forms (Figure 4.1) apply to each of the three health states (healthy, chronically ill, with advanced illness). End-of-life care preferences are documented in an IT system after obtaining the patient's concurrence that they accurately reflect their decisions. These recorded preferences are accessible to different providers across the acute care continuum.

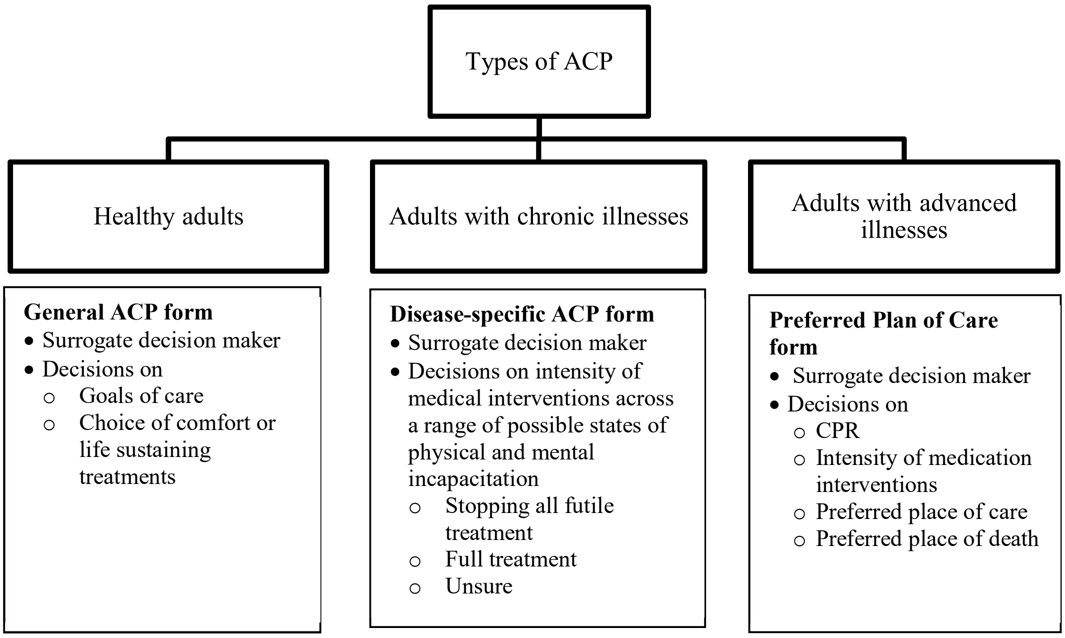


Figure 4.1 Types of ACP and end-of-life care decisions by health status.

4.2.2 Study design and population

A retrospective cohort study was conducted to profile the end-of-life care preferences. Participants included all adults (≥ 21 years old) (n=3,380) who had completed a statement of their preferences as part of a national ACP programme in Singapore. The study timeframe was between January 2011 and December 2015.

4.2.3 Elicited preferences by health status

For healthy adults, they were asked about their preferences related to the goals of care when the probability of recovery or survival is low. The choices provided were: "make comfort the goal of my care and do not prolong my life in this condition" or "continue to provide all necessary life-sustaining treatment until outcomes happen to me which I find unacceptable".

4. Profile of end-of-life care preferences

For individuals with chronic conditions, the wishes documented in an ACP form specifies preferences about CPR during cardiac arrest, and decisions about treatment options if they were to develop serious complications with (i) a low likelihood of survival, or (ii) a high likelihood of survival but might become immobile and unable to communicate, or (iii) a high likelihood of survival but might suffer from permanent cognitive impairment. The choice categories include “all treatment I need to live as long as I can”, “stop all efforts to keep me alive, allow natural death to happen” and “unsure”.

For individuals with advanced illnesses they were asked about their CPR preferences, decisions related to medical intervention (comfort, limited additional interventions, full treatment), place of care, and place of death. Under the current programme, full treatment considers intubation, mechanical ventilation, and cardioversion. Medical management may also include transfer to intensive care if indicated. Limited additional interventions include comfort measures and may also include oral or intravenous medications. While non-invasive ventilation support is acceptable, endotracheal intubation or long-term life support measures, including admission to intensive care units are not. Comfort measures include reasonable measures made to offer food and fluids. Medications, oxygen and other measures may be used as needed for comfort, but it does not include intubation.

For place of medical treatment or care, individuals with advanced illnesses could opt for the home, hospice, nursing home, hospital, a trial of treatment in their homes before considering transfer to a hospital or a hospice, and a trial of treatment in the hospice or nursing home before transfer to a hospital. The documentation also allowed the individual to indicate “no preferences” and “others”. For place of death, individuals are asked where they would wish to be if they were left with 2-3 days of life. They could opt for either the home, hospital, hospice or nursing home, and two or more alternatives such as home or hospital, and home or nursing home or hospital.

4.2.4 Measures and data extraction

We extracted data on ACP participant profiles and preferences from the national ACP IT system, and the Tan Tock Seng Hospital ACP database. There were three different forms, general, disease specific, and the preferred plan of care (PPC) form, to cater to individuals at different health stages (healthy, chronic illness, advanced illness). Data fields related to the nomination of a substitute decision maker(s), preference about the administration of CPR in the event of a cardiac arrest, and end-of-life care preferences were extracted. In addition, for patients diagnosed with terminal illnesses, we extracted their preferences for place of care and death as well.

To ascertain whether the individuals were deceased, the data was linked to death-related data from the National Registry of Birth and Deaths. Every Singaporean resident is issued with a NRIC number. For this study, a project unique identifying number (PUIN) was generated for each NRIC by a third-party vendor, who was not involved in the analysis of the data. The PUIN was then used to link data belonging to each individual person across the datasets.

4.2.5 Data analysis

Descriptive statistics were used to characterise the sample and to summarise the data related to end-of-life care preferences. To examine the independent effects of age and gender on end-of-life care preferences, logistic regression models were used. All statistical tests were conducted using Stata version 12 (StataCorp, 2011).

4.3 Results

A total of 3,380 completed ACP documents were captured in the databases, with approximately 90% completed in acute hospitals. The patient characteristics can be seen in Table 4.1. About 60% of the patients were aged 75 years and above, and there was demographic variation across the three health states, with younger age profiles for those who completed the general (healthy) and disease-specific (chronic illness) forms. Among all individuals who completed the ACP, 53.2% (1798/3380) were deceased as at 31 December 2015, with the highest share for those diagnoised with an advanced illness. The overall median time between ACP completion and death was 7.27 months (95% CI: 6.35-8.18); 63.2% completed ACP within three months prior to death, 52.9% within six months and 42.3% within 12 months.

Table 4.1 Profile of individuals by health status.

Variable		Healthy n (%)	Chronic illness n (%)	Advanced illness n (%)	**Total n (%)**
Age	< 55 years	77 (11.9)	6 (12.2)	142 (5.3)	225 (6.7)
	55–64 years	193 (29.9)	14 (28.6)	259 (9.6)	466 (13.8)
	65–74 years	203 (31.4)	17 (34.7)	445 (16.6)	665 (19.7)
	≥ 75 years	173 (26.8)	12 (25.5)	1,839 (68.5)	2,024 (59.9)
Sex	Female	359 (55.6)	19 (38.8)	1,316 (49.0)	1,694 (50.1)
	Male	265 (41.0)	28 (57.1)	1,335 (49.7)	1,628 (48.2)
	Missing	22 (3.4)	2 (4.1)	34 (1.3)	58 (1.7)
Deceased		57 (8.8)	10 (20.4)	1,731 (64.5)	1,798 (53.2)
Total		646 100.0)	49 (100.0)	2,685 (100.0)	3,380 (100.0)

4.3.1 Documented preferences

Data related to preferences for end-of-life care are represented in Table 4.2. For healthy individuals who had completed the general ACP, 12.2% indicated a preference for life-sustaining treatment. For individuals with chronic illnesses who had completed the disease-specific form, close to 1 in 3 opted for CPR and life-sustaining treatment, even if the likelihood of surviving the complications of the illness were low or if they were to lose their ability to move around or communicate.

However, only 16.3% opted for full treatment if they were to become mentally incapacitated because of their illness.

Table 4.2 End-of-life care preferences for healthy, chronically ill individuals.

Documented preferences	n (%)
Healthy individuals (n = 646)	
Appointment substitute decision maker	581 (89.9)
Comfort measures	560 (86.7)
Life-sustaining treatments	79 (12.2)
Individuals with chronic illnesses (n = 49)	
Appointment 1st substitute decision maker	35 (71.4)
Appointment 2nd substitute decision maker	15 (30.6)
Serious complication with low chance of survival	
Full treatment	16 (32.7)
Stop treatment	31 (63.3)
Serious complication with loss of ability to move around or communicate	
Full treatment	15 (30.6)
Stop treatment	32 (65.3)
Serious complication with mental incapacity	
Full treatment	8 (16.3)
Stop treatment	38 (77.6)
CPR	
Attempt	14 (28.6)
Do not attempt	19 (38.8)
Do not attempt if doctor believes low survival chances	14 (28.6)

ACP: Advance Care Planning; CPR: Cardiopulmonary Resuscitation

For individuals diagnosed with advanced illnesses (Table 4.3), 5.7% opted for CPR and 5.1% opted for full medical intervention. The majority preferred the initiation of a limited trial of treatment, which would be continued with comfort measures if there was no clinical improvement. Approximately 43.6% of individuals preferred to receive treatment in their homes, but 77.4% of these individuals would consider being transferred to an acute hospital after a trial of care at home. Close to 30% stated the hospital as their preferred site of care. For place of death, 40.4% preferred dying at home, and only 14.1% preferred the hospital. One highlight is that although only

4.1% did not state any preference or were unsure about the place of care, 23.0% of respondents did indicate their preferences with regards to the preferred place of death.

Table 4.3 End-of-life care preferences for individuals with advanced illnesses.

Documented preferences	n (%)
Individuals with advanced illnesses (n = 2,685)	
Appointment 1st substitute decision maker	2,526 (94.1)
Appointment 2nd substitute decision maker	1,357 (50.5)
CPR	
Attempt	152 (5.7)
Do not attempt	2,511 (93.5)
Do not attempt if doctor believes low survival chances	22 (0.8)
Medical intervention	
Full treatment	138 (5.1)
Limited additional interventions	1,851 (68.9)
Comfort measures only	677 (25.2)
Unsure	19 (0.7)
Preferred place of care	
Home	265 (9.8)
Hospital	798 (29.7)
Nursing home	166 (6.2)
Hospice	131 (4.9)
Trial of treatment before consider transfer to hospital	
Home	908 (33.8)
Nursing home	269 (10.0)
Hospice	28 (1.0)
Others (no preference, unsure)	110 (4.1)
Missing	10 (0.4)
Preferred place of death	
Patient's home	1,084 (40.4)
Hospital	379 (14.1)
Nursing home	160 (5.9)
Hospice	156 (5.8)
Home or hospital/nursing home/hospice	112 (4.2)
Healthcare institution (hospital or nursing home or hospice)	177 (6.7)
Others (no preference, unsure)	617 (23.0)

ACP: Advance Care Planning; CPR: Cardiopulmonary Resuscitation; PPC: Preferred plan of care

4.3.2 Relationship between patient and substitute decision maker

The share of individuals who had appointed a substitute decision-maker varied across the different health states. The rates of nomination were, however, lower for those who were healthy or chronically ill. For individuals with advanced illnesses who filled out the PPC form, only 8% of individuals did not identify a substitute decision-maker (Table 4.3). From Table 4.4, 78% of individuals nominated their immediate family (spouse, children, grandchildren) to speak on their behalf if they were incapacitated. Only a small percentage nominated non-related persons. Most ACP discussions also took place in the acute care setting.

Table 4.4 Relationship with substitute decision maker.

	Healthy n (%)	Chronic illness n (%)	Advanced illness n (%)	**Total n (%)**
Spouse	185 (28.6)	8 (16.3)	320 (11.9)	513 (15.2)
Child, child-in-law, or grandchild	230 (35.6)	20 (40.8)	1,869 (69.6)	2,119 (62.7)
Other relatives and friends	136 (21.1)	2 (4.1)	266 (9.9)	404 (12.0)
Others (including healthcare professionals)	14 (2.2)	1 (2.0)	10 (0.4)	25 (0.7)
Missing	81 (12.5)	18 (36.7)	220 (8.2)	319 (9.4)
Total	646 (100.0)	49 (100.0)	2,685 (100.0)	3,380 (100.0)

PPC: Preferred plan of care

4.3.3 Relationship between preferred place of care and place of death

Table 4.5 assessed the relationship between place of care and place of death. The results indicated that there was a high level of agreement in preferences related to being cared for at home and dying at home. Other than this, the place of care is not synonymous with where they would like to die at. Close to 1 in 3 individuals who preferred the hospital as the location of care, had also opted for home as the place of death.

Table 4.5 Preferred place of care and preferred place of death.

Place of Death	Place of Care, %						
	Home	Hospital	Hospice	Nursing home	Home to Hospital/ Hospice	Hospice to Nursing home/ Hospital	Others
Home	90.9	31.1	9.9	5.4	57.3	12.1	12.7
Hospital	0.8	30.3	0.0	1.2	9.7	13.7	2.7
Hospice	0.8	3.1	67.9	0.6	2.6	3.3	4.5
Nursing home	0.4	0.4	0.0	70.5	0.2	12.1	0.0
Home or hospital/Nursing home/Hospice	1.9	3.5	1.5	0.0	8.0	2.0	2.7
Healthcare institution	0.4	4.4	4.6	6.6	1.2	30.3	19.1
Others	4.9	26.7	16.0	15.7	20.9	26.7	58.2

4.3.4 Relationship between treatment preferences and patient profile

As age and sex were not correlated with preferences for healthy and chronically ill individuals, the results were excluded. Table 4.6 illustrates the results from a logistic regression to assess the impact of age and sex on the preferences of those with advanced illnesses. Those aged 75 years and above were more likely to not opt for CPR and comfort measures, compared to younger individuals. Care at home or having a trial of care at home was the preferred option for the older age group. Similarly, older people exhibited a stronger likelihood of preferring to die at home.

There were no significant gender differences in preferences for CPR. However, there was a higher likelihood of females opting for full treatment than comfort measures. This is also consistent with the relatively lower odds of choosing home as the site of care and place of death, compared to males.

Table 4.6 Multivariable logistic regression of preferences by age and sex with 2,685 subjects who had completed the PPC form.

Preferred plan of care	Age ≥75 vs. Age <75	Female vs. Male
	Adjusted OR (95% C.I.)	Adjusted OR (95% C.I.)
CPR		
Attempt vs. Do not attempt	0.31 (018-0.54)	1.56 (0.87-2.79)
Medical intervention		
Treatment vs. Comfort measures	0.32 (0.17-0.62)	2.35 (1.18-4.68)
Preferred place of care		
Home & trial at home vs. Others	1.52 (1.23-1.89)	0.69 (0.57-0.84)
Preferred place of death		
Home vs. Others	1.29 (1.03-1.61)	0.70 (0.57-0.85)

Model includes variables: age and sex
CPR: Cardiopulmonary Resuscitation; OR: Odds Ratio; C.I.: Confidence Interval

4.4 Discussion

This is the first study to profile the end-of-life care preferences of individuals who have participated in the national ACP programme in Singapore. The findings offer insights into decisions made under real-life situations, where there is a level of expectation that after having stated a preference, attempts by the individual, his/her family or healthcare professionals will be made to adhere to them. The implications of these decisions may also be more seriously considered, and therefore differ from findings obtained from surveys.

In our study, most individuals nominated their family members to speak on their behalf if they were incapacitated, which is similar to what was observed in other studies (Ang, Zhang, & Lim, 2016). Among healthy and chronically ill patients, the majority did not opt for CPR or other life-sustaining measures. Among those with advanced illness, more than 90% preferred not to attempt CPR, but more than 70% still preferred to receive some form of active medical treatment at the end-of-life, rather than comfort care. In this national sample, approximately 4 in 10 chose to be cared for and to die at home. Other Singaporean studies examined the preferences of nursing home residents (C. W. L. Ng et al., 2016) and those who received care in a day care centre (Low et al., 2000). These studies similarly found that while most individuals did not opt for CPR, they did express a preference to receive some form of active treatment (Low et al., 2000; C. W. L. Ng et al., 2016). ACP is, therefore, an important channel that supports the expression of one's preferences, and to minimise care that is not wished for.

In 2014, the Lien Foundation, a Singapore philanthropic house, commissioned a community-based survey to determine the death attitudes and the level of awareness about hospice and palliative care. The survey reported that 70% and 77% of the surveyed individuals would prefer to be cared for, and to die at home respectively (Blackbox Research, 2014). Preferences for medical treatment at home, and for home deaths were significantly lower in our sample. Public opinions often do not coincide with the views of individuals who are close to the end-of-life (Hoare et al., 2015). The complexity of choices grows as death draws near (Wood & Salter, 2013) when the individual or their families need to trade-off the place of death against other priorities, such as pain and symptom management, and the physical, emotional and financial burden that death at home may bring (Townsend et al., 1990).

We also found that, although the preferred place of care and place of death are related, they are not equivalent. While only a small percentage of individuals did not have strict preferences about where they are being cared for, almost 1 in 4 individuals expressed that they had no preferred place of death. Other studies have similarly indicated that these two dimensions are not equivalent, although healthcare professionals may use them interchangeably in practice (Agar et al., 2008).

4. Profile of end-of-life care preferences

In our study, the time between ACP completion and death was 7.3 months. While there is no objective optimal timing (Geronimo Jimenez et al., in press), this is relatively shorter than the median times (14 - 37 months) reported in literature (Billings & Bernacki, 2014; Hammes & Rooney, 1998). Given that the discussion about preferences should occur before physical or mental incapacitation, earlier initiation can be beneficial to the patients. At the same time, it is important to strike a balance because conducting the ACP conversation too early when preferences are still unstable (Auriemma et al., 2014) could lead to unrealistic choices based on hypothesised scenarios (Billings & Bernacki, 2014). ACP initiation should take into account patient and family receptivity, and ideally, precede major health deterioration that could lead to decisional incapacitation (van der Steen et al., 2014). Different diseases have different pathways of functional declines (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003), which also needs to be considered.

In our sample of patients with advanced illnesses, we found that age was positively associated with preferences to withhold life-sustaining treatments, which was similar to the findings of several studies (Hamel et al., 2000; Hamel et al., 1999). We found that individuals older than 75 years were more likely to opt for the home as the place of care and death; but other studies reported that younger individuals more strongly prefer home as the place of care (Fukui, Yoshiuchi, et al., 2011), or that age did not have a significant effect (C. H. Chen et al., 2014). Cultural differences, in the meaning assigned to the “home” as a place of care and death, or even the availability of alternative palliative care facilities in different countries, could have resulted in the mixed evidence. For instance, due to the availability of inpatient palliative care units in Japan, older individuals had stronger preferences for the patient palliative care unit as the site of care than home (Fukui, Yoshiuchi, et al., 2011). Our finding, that females were less likely to prefer to be cared for and die at home, was similarly reported in other studies (Foreman, Hunt, Luke, & Roder, 2006; Fukui, Fujita, et al., 2011). This could reflect the general longer life expectancy of females compared to males. This reduced likelihood of spousal support at the end-of-life could make home less preferred as an option (Grande et al., 1998).

4.4.1 Policy & practice implications

Currently, efforts to implement ACP are focused on the elderly and the terminally ill. Based on the numbers of completed disease-specific forms, the take-up by chronically ill individuals is very low. While better integration of ACP with chronic disease management efforts or more rapid expansion of ACP to the outpatient and community settings could assist in improving coverage, additional resources would concurrently be needed to assist hospitals to expand coverage to younger adults, and brining ACP conversations forward in the life-cycle of an individual. Building community awareness of, and acceptance towards ACP will be crucial.

Policies should also consider a range of perspectives and preferences, especially of sub-populations that they will most immediately affect. Preferences elicited from surveys can be viewed as an aspirational target that is achievable if practical barriers were eradicated. Additionally, due to the relatively high proportion of individuals who still preferred hospital as the location of care, policy-makers still need to focus on improving the end-of-life care experience in formal healthcare institutions, while also expanding home palliative care capacity to cater to those who preferred home as the first place of care, and place of death.

4.4.2 Study limitations

The sample comprised largely the patients receiving care in the acute care hospitals, and the results may not be generalisable for patients in the community care settings or to other individuals who have elected not to participate in ACP. Individuals who had completed the ACP documentation could be less death-avoidant, and therefore, have different preferences compared to others. Also, as data on ethnic groups and religions were largely absent, these were not reported in this chapter.

4.5 Conclusion

This study identified that most of the individuals in our sample, regardless of health status, preferred not to proceed with life-sustaining treatments across a spectrum of health scenarios. However, individuals with advanced illnesses still preferred to receive some form of active support, e.g. non-invasive ventilation support; or oral and intravenous drug administration. Our results imply that policies should consider not just home-based end-of-life care, but also actively focus on the quality of end-of-life care in hospitals, since many individuals still opt for them as the site of care.

Chapter 5 Preferences for Place of Death and Factors Influencing its Achievement

Abstract

This chapter explores the experiences and perceptions of healthcare professionals in discussing end-of-life care preferences, as well as the facilitators and barriers faced in honouring them.

Rather than being an individual decision, the preference for place of death was negotiated and co-constructed by the patient, family, and healthcare professionals. The life-stage, availability of family support, and cultural beliefs strongly shaped end-of-life care preferences. Discussions about death and dying was viewed as deeply personal, and best conducted with a healthcare professional with whom the patient has a supportive relationship. Having family support, and access to home palliative care, influenced the ability to die at home. However, families also often believed that hospitals provide better care. The lack of continuity of care across settings and inconsistent work protocols may not support paramedics and non-physician healthcare professionals, to act appropriately to meet the home death preferences of patients.

Supporting families at care transition points, and over the end-of-life trajectory, together with ensuring continuity of care and empowerment of healthcare professionals, will further realise place of death preferences.

5. Elicitation of place of death preference and contextual factors

5.1 Introduction

Cultural contexts influence patients' and their families' views and priorities about end of life care (A. Hattori et al., 2005; Ishikawa et al., 2013; Ruhnke et al., 2000). Studies conducted in Canada, Europe, and the US, have found that while dying at home is widely preferred (Canadian Hospice Palliative Care Association, 2013; Barbara Gomes et al., 2012; Leff et al., 2000), patients and caregivers often assign a lower priority to dying at home when asked to rank against other attributes of good end-of-life care such as pain control (Heyland et al., 2006; Steinhauser et al., 2000; Waghorn et al., 2011). Conversely, studies in Japan and Taiwan have highlighted the place of death to be an important consideration for elderly patients (A. Hattori et al., 2005; Shih et al., 2015). and Taiwanese studies have also highlighted the cultural importance of dying at home because it is believed that the soul needs a resting place (Tang, 2000). In Singapore, decisions regarding place of care and death were found to be intimately dependent on the perceived burden on their families (Chetna Malhotra et al., 2012).

With a rapidly ageing of population, the issue of where people prefer to die, is an important item on the Singaporean healthcare agenda. Over the last decade, the Singapore government has invested heavily to expand home palliative care capacity to cater to more patients, including those diagnosed with end-stage organ failure (Gan, 2014, 2017). To reduce out-of-pocket expenditures, the government has also allowed the use of Medisave, a national medical savings account, for home palliation (Gan, 2014). As part of the "Living Matters" programme, a national ACP initiative, healthcare professionals have been trained to assist individuals to reflect upon their personal values and beliefs, leading to decisions about the type and intensity of medical treatments they wish to receive when death is imminent, and the place of care and the place of death (I. Chung, 2017).

Decisions about treatment, and preferences for place of death, are often co-constructed by the patient, the patient's family, and healthcare professionals (Daniel Munday et al., 2009). In societies with a culture of collective decision-making (L. R. K. Krishna, 2012), such decisions often incorporate the views of family members or may even be delegated to them (Hirakawa, Chiang, Hilawe, & Aoyama, 2017; A. Lee & Pang, 1998). For patients, knowing what to expect as the illnesses progress, and being able to articulate their end-of-life priorities, could spur care to be planned to meet their preferences. However, little is known about the process of end-of-life care preference elicitation. This study therefore describes the experiences and perspectives of healthcare professionals in facilitating discussions about future care with the patients and their families in Singapore. We seek to understand factors that have influenced preference formation of the place of death, as well as the facilitators and barriers faced in honouring preferences to die at home.

5.2 Methods

5.2.1 Study design

This study was part of a larger evaluation that explored the views and experiences of healthcare professionals concerning the implementation of ACP. A qualitative focus group design was used. We adopted the ISF (Fuenmayor, 1991) to facilitate our understanding of the social meaning of the preferred place of death, as interpreted by healthcare professionals who played critical roles in eliciting the preferences for place of death from patients and their families and supporting the realisation of these preferences.

5.2.2 Recruitment and sampling

FGD participants were purposefully sampled based on their professional grouping, employing hospitals, and experience in ACP provision (more than five ACP conversations or five or less ACP conversations). Fourteen focus group discussions and dyadic face-to-face interviews were conducted. Sixty-three respondents from the seven public hospitals and specialist medical centres were included, of whom 12 were physicians, 15 nurses, 24 medical social workers (MSWs), and 12 ACP coordinators. The participant profiles are in Table 3.4, Chapter 3.

5.2.3 Focus groups

Questions concerning participants' perspective on patients' preferred place of care and place of death were included in an extended interview schedule that asked participants about their personal views about death and dying, and experiences with implementing ACP in their workplace. (Refer to appendices 7 and 8 for the interview schedules) All interviews were digitally recorded and transcribed verbatim. Each focus group lasted 90-120 minutes. The FGDs were conducted between September and November 2016.

5.2.4 Data analysis procedures

Qualitative content analysis was conducted using the Framework Method (Gale et al., 2013). We adopted an inductive-deductive approach and allowed themes to be developed from the experiences recounted by research participants, as well as deductively from existing literature (Costa et al., 2016; Gomes & Higginson, 2006; Murtagh et al., 2012; Wahid et al., 2017).

Each transcript was first read and reread to increase familiarity with the data. Coding was first carried out by the first author and labelled based on initial impressions on the reasons explaining the preferences for, and the actual place of death. Secondly, codes were grouped into categories that represented similar concepts, and axial coding was conducted to relate categories to each other. Descriptive quotes accompanying themes and sub-themes emerging from the data were then generated. Thirdly, the emergent codes were reviewed by the research team, and consensus was achieved on a set of codes to be applied for the analysis. Quotes from transcripts were finally mapped onto themes and sub-themes in a tabular format. No new themes emerged after the fourth FGD and information obtained from the remaining FGDs reflected the same themes.

Transcripts of FGDs were stored digitally and analysed through QSR NVivo. (QSR International Pty Ltd, 2016) To minimise researcher bias when interpreting the data, field notes and analytical memos were used to support the analysis and interpretation (Lincoln & Guba, 1985). (Refer to appendix 12 for researcher notes and appendix 13 for a screenshot of the coding stripes.) Individual participants were not identified to preserve confidentiality so no one person's story could be put together.

5.3 Results

The analysis revealed 14 themes (Figure 5.1) that described the development of place of death preference, the process of end-of-life care preference elicitation, and factors that influenced the achievement of home deaths. These three aspects interact and influence the actual place of death.

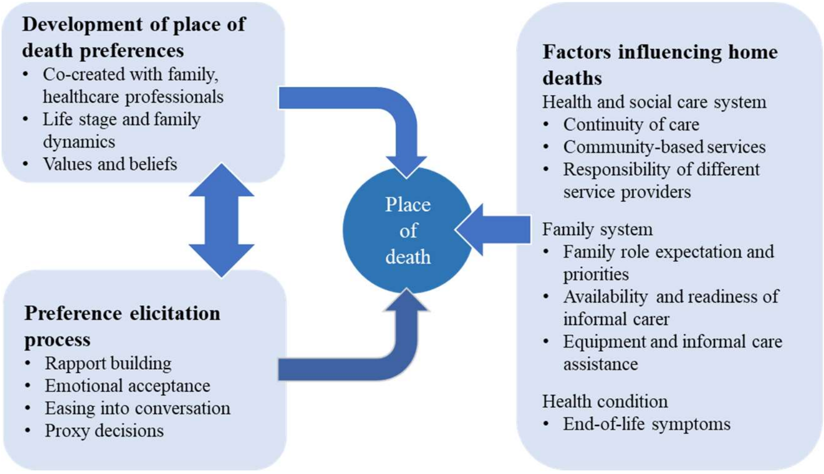


Figure 5.1 Preference elicitation, formation, and completion framework

5.3.1 Development of place of death preference

Rather than being an individual decision, the patient's preference for place of death was often "*co-created with family members and healthcare professionals*" (*theme 1*); taking into consideration the families' ability to cope.

> "The patients have their own decisions, but they also want to hear from their family and hear what their thoughts and together is like, is like a collective kind of decision making. Is because also concern about how they are able to cope, able to manage. So, the patient decision is also somehow based on the family decision, or maybe family has something, but they also want to consider the patient." (ACP Coordinator, Female)

While the ideal place of death is often the home, after being informed of the emotional, logistical, and financial requirements, healthcare professionals mentioned that many patients opted for alternatives.

> "I used to think majority will choose to die at the comfort of their own home, but as of late, I come to realise that it is fifty-fifty. Because most, maybe is also because of my part, I start to educate them that is not easy to manage." (ACP Coordinator, Male)

"*Life-stage and family dynamics*" (*theme 2*) importantly influenced the viability of their decisions. Weak familial ties and dysfunctional dynamics often made home death impractical. Individuals with young children often preferred institutional settings, due to the high amount of emotional distress that dying at home may place on their families. On the other hand, elderly persons preferred to die in the comfort of their own homes. Nonetheless, preferences were dynamic and shifted as life situations and disease conditions evolved over time.

> "There are a handful who are very specific that they don't want to be at home because they want to be in an institution so that they won't be a burden to their family members. And for this group of patients, most of them, they have probably young families. And most of the elderly they (do) want to die at home." (Nurse, Female)

"Values and beliefs" (theme 3) shaped by religions or personal worldviews, influenced their preferred place of death. FGD participants recounted that Malay-Muslim families tended to prefer dying at home to support the carrying out of death rituals important to their religion.

> "For Malays, it seems quite important for them to pass away at home because I think when the patients pass away, they would bring the body back to the house whereby they will wash up the body. So, I am not sure if that is a contributing factor too as to why Malays want to pass away at home, but you generally see them more committed to do that. And I think it's also a time for the family members to come together and say their goodbyes." (MSW, Female)

Others reflected that some individuals of Chinese ethnicity may hold a more pragmatic and economically-driven view that dying at home, is inauspicious, and could lower the value of their residential property.

5. Elicitation of place of death preference and contextual factors

> "But I guess for Chinese, there's this taboo thing like I don't want to have anyone dying at home because like it will scare the children, or like will affect your housing value, things like that." (MSW, Female)

5.3.2 Process of preference elicitation

FGD participants described conversations about preferences to be initiated opportunistically, and *"rapport building" (theme 4)* to be an essential first step.

> "It's very difficult for someone who has met the family or who has met the patient the first time, it can be very difficult to talk about something that is very close to their hearts." (Doctor, Female)

Empathetic listening and sharing of a common language greatly facilitated the discussion that might have touched on sensitive issues. Healthcare professionals used euphemistic terms in describing death to lessen the gravity of the conversations. A member of the staff, or a family member fluent in the language of the patient often acted as a translator, but there was often fear that important information were not conveyed accurately.

FGD participants also mentioned incidences where they were unable to elicit preferences because patients and/or family members were not emotionally unprepared for the poor prognosis or did not want to discuss matters related to the end-of-life. They described a continuous process towards *"emotional acceptance*" (*theme 5*), which can be complicated as some families may prefer not to reveal a poor prognosis to the patient.

5. Elicitation of place of death preference and contextual factors

> "I would think that it's a continuous process that you prepare the patient and their family, and if they do understand what is going on."
> (Nurse, Female)

To initiate a discussion about end-of-life care, healthcare professionals spoke about "*easing into the conversation" (theme 6)*. The facilitators may ask about these preferences directly or skillfully lead into a discussion by suggesting care preparations to elicit a response from the patient, which forms the basis for further discussions about end-of-life care.

> "You will usually tend to explore like, 'Sir, do you have the idea like how your current illness, your current condition?' and he say 'yes'. The next approach will be, 'in terms of your family, do they have an understanding as well? And then if so, who will be the person whom you usually will turn to if let say you want to talk about your illness?'"
> (ACP Coordinator, Male)

In the case of cognitively impaired patients, family members may be approached by healthcare professionals to make *"proxy decisions" (theme 7)* about their care. FGD respondents spoke about the difficulties faced in ensuring that decisions are made in the best interests of the patients. Some elderly patients also relinquish or delegate decision making to their children, or to their physicians. This may also be a response to a healthcare system that does not operate or communicate in a language that they can understand.

> "I think elderly patients you know, they feel that - that you know they may not know enough, their children are more educated, so they feel

> more comfortable when their children take charge." (Medical Social Worker, Female)

5.3.3 Factors facilitating or impeding home deaths

While the home was often perceived as the ideal place of death for some segments of the patient population, several factors have influenced their achievement. Three predominant sub-categories have emerged: the health and social care system, family system, and health condition of the patient.

Health & social care system

"*Continuity of care*" (*theme 8*) supported individuals to die at home. Transitioning between acute care and home required strong facilitation from the inpatient staff to train caregivers, provide emotional support, and guide families on what to expect during the dying process. Palliative care services provided support to the staff in enabling the transition of care to the home setting.

> "Because we have very strong supportive from palliative health team. We have terminal discharge quite often. And we help through our own, we have nursing going to their home, so we walk them through the end. For ours - is really they die at home." (ACP Coordinator, Female)

The *"availability of community-based services"* (*theme 9*) such as home palliative care increased the likelihood of home deaths. However, our findings highlighted a perception that access to hospice services might be limited by capacity and manpower constraints despite an expansion of home palliative care services from 3,800 to 5,500 between 2011 and 2016 (Gan, 2017). Our results further indicated that palliative care services should expand beyond their traditional focus on cancer care to improve access to a wider patient segment. Pilot programmes have been recently initiated to explore new models of home-based palliative care for non-cancer conditions (Gan, 2017).

> "Hospice care itself is stretched. So, they have inclusion criteria, who they want to accept. So, a patient with, an old patient with current acute events may not be accepted by hospice care." (Doctor, Female)

Currently, "*responsibility of different service providers*" (*theme 10*) may not align well towards supporting patients to fulfill their preference to die at home. Families were often unable to locate a general practitioner who could certify the death. In addition, the ambulance services are bound by protocol to convey the patient to the emergency room if there is still a pulse.

> "But most, is true that patient family did mention that they have tried to call the GPs (general practitioners), they do not want to come, and they have left with no choice but to call SCDF (Singapore Civil Defence Force). But if there is pulse, there is this, they will bring back to hospital." (ACP coordinator, Female)

Additionally, in terms of home care provision, hospital care protocol required a physician to sign off on any advice provided to the patient, which hampered the ability of nurses to provide timely advice that could have prevented a hospital death.

> "My nurse practitioner said, "At this moment, the care is still towards the acute care. Until my nurses are empowered, with all the doctors standing behind them, when they call my team, we will still advise go to hospital in case we get into trouble." (Doctor, Female)

5. Elicitation of place of death preference and contextual factors

Family system

"*Family role expectation and priorities*" (*theme 11*) influenced how a family perceived its caregiving responsibilities. Many caregivers of Chinese ethnicity took allowing an elderly parent to die at home as not fulfilling their filial duty, which may lead to them experiencing guilt as a result. They also perceived the hospital to provide the best medical care.

> "I have a few Ah Ma (old lady), Ah Gong (old gentleman), they want to die at home because is a familiar surrounding all that, but the children put the pressure and blame on themselves if we did not do our best. So, it's very cultural." (Medical Social Worker, Female)

Conversely, the Malay-Muslim custom has a different norm, where families often pool resources to support care and death at home. Patients may prioritise being at home as a means of fulfilling the required rituals of Islam, which could surpass the need for better pain and symptom management.

> "A lot of our Muslim patients, they do want to pass away at home...... Even though, you know, for example, they are very symptomatic, they would feel that they can manage. And somehow or the other, they actually do manage. It might not be normally what we deem as a peaceful passing, but to them, the physical being at home outweighs the rest." (Nurse, Female)

Death at home is often preceded by a period where the family needs to provide care. Even with the support of home care services, the "*availability and readiness of informal caregiver*" (*theme 12*) strongly influenced the outcome. Other than providing instrumental support, the emotional readiness and ability to carry out care procedures were essential in allowing the patient to continue to live at home.

> "Some they do have heart to care for patient, but when they see patients, I mean when they see dying, they also get into panic attack, so they may not be able to carry out simple things, like you already teach them, instructed them, however, when the panic comes, they just couldn't, and also they have to deal with their own grief" (ACP Coordinator, Female)

Despite the availability of government subsidy programmes such as the Senior Mobility and Enabling Fund and Foreign Domestic Worker Grant, our findings pointed out that many families may still encounter difficulties in affording "*equipment and informal care assistance"* (*theme 13*) to prepare for and sustain care at home.

> "If you need a full-time caregiver, the only option is to hire a helper, and family has to come up front three thousand dollars to pay for agent fee and everything, there is no way to get help there. Nobody has three thousand, most families do not have that two to four thousand dollars cost, ready to just give it up." (Medical Social Worker, Female)

Health condition

The "*end-of-life symptoms*" (*theme 14*) suffered by an individual may also not allow for care to be carried out at home.

> "There are some group of patients whereby, for example, they are on multiple infusions, and we know that, you know, for example, other

> symptoms can be that they can bleed suddenly, and they can have haemorrhage, so things that are very traumatic for the family, then and if they have young children, then we wouldn't advocate." (Nurse, Female)

At the last stage of life, patients may prioritise being pain-free than to die at home, leading to hospitalisation being the preferred option.

> "I know you said you want to be at home, but if you are not going to be very comfortable at home, let say you need a PCA (Patient Controlled Analgesia) machine which is a, you know, and this cannot be done at home, then what would you prefer? And a lot of people will say I rather be comfortable and I don't care about where." (Doctor, Female)

5.4 Discussion

This study was conducted to understand the process behind place of death preference elicitation, development, and attainment, from the perspective of healthcare professionals. Discussions about values, beliefs, desires and fears about death and dying was viewed as deeply personal, and best to be conducted with a healthcare professional, with whom the patient enjoys a continuing and trusting relationship (Htut, Shahrul, & Poi, 2007; Chetna Malhotra et al., 2012). While healthcare professionals continuously prepared patients and their loved ones for the conversation, some patients may still prefer not to discuss their end-of-life care preferences. The process of elicitation itself required the facilitator to skillfully ease the patient into the conversation by asking about their experiences related to their illnesses and treatment goals (Larson & Tobin, 2000).

The factors found to influence home deaths are broadly aligned with the systematic review findings summarised in Chapter 1. The main themes of health and social factors, family support, and illness-related issues identified were similarly identified by Gomes and Higginson (Gomes & Higginson, 2006), Murtagh et al. (Murtagh et al., 2012) and Costa et al. (Costa et al., 2016). The presence of family support strongly predicted death at home. The level of commitment to meet home death preferences, however, varied between families, and was shaped by their values, priorities, and family dynamics. In the local context, families' financial ability (Chetna Malhotra et al., 2012) to obtain the necessary equipment and assistance strongly affected their ability to care for the individual at home. Timely support from home palliative care also acted to support patients' preferences to die at home (Costa et al., 2016), as caregivers' ability to cope alone, with the level of care required and the inherent unpredictability of the dying processes, often resulted in hospitalisations during the terminal stages of the illness.

Support for informal caregivers, proper discharge planning and continuity of care were emphasised as facilitators of home death in the meta-ethnographic study conducted by Wahid et al. as mentioned in Chapter 1 (Wahid et al., 2017). Our results in this chapter highlighted that the transition from acute care back to the home can be challenging for caregivers if they are not mentally and emotionally prepared for the caregiving process ahead. Such interruptions in care (Naylor, 2002) can be detrimental, and acute care providers, particularly nurses, play an important role in supporting informal caregivers during this stressful time (Penrod, Hupcey, Baney, & Loeb, 2011; Schubart, Kinzie, & Farace, 2008). Further, with different providers acting to fulfill their individual service responsibilities, rather than gearing their protocols and services towards meeting patients' preferences, dying at home in the current healthcare system remains challenging.

5. Elicitation of place of death preference and contextual factors

Effective communication and documentation of the individual's preferences is also a key enabler for supporting wishes to die at home (Wahid et al., 2017). The framework (Figure 1.1) put forth by Gomes and Higginson (Gomes & Higginson, 2006) described how one's individuality influences the place of death. However, in our study, one's life-stage, values, and beliefs appeared to inform the development of the place of death preference rather than the place of death itself. These preferences, whether known or unknown, subsequently interacts with the individual's symptom presentation, family system, and health and social care system to affect the final place of death.

As evidenced in other studies (Beng et al., 2009; Hong et al., 2011; Htut et al., 2007), values built on religious or cultural beliefs and practices played a strong role in influencing place of death decisions. Malay-Muslim families were viewed to prioritise care and death at home, to facilitate the completion of death rituals (Sarhill et al., 2001; Sheikh, 1998). It is a spiritual duty for family and friends to visit the dying person during this time, and to pray for his or her soul (Sheikh, 1998), and for family members (of the same gender) to ritually cleanse and wrap the deceased before burial (Sarhill et al., 2001). In contrast, Chinese individuals often sought to fulfill one's filial obligations by providing resources to meet their parents' care needs, and to procure the best perceived care for them (K. C. Lee et al., 2013) which often resulted in the hospital being the final place of care and death (Reyniers et al., 2016).

The preference for place of death was negotiated and co-constructed between the patients, their family, as well as healthcare professionals. The result was a complex interaction between life-stage, values and beliefs upheld by the patients and their families, as well as practical concerns involved in providing a supportive home environment. Life-stage and the availability of family support have similarly been found in other studies to shape an individual's preferences on the place on death (Choi et al., 2005). The involvement and role of family members in these decisions appeared to distinctly deviate from the observations about North American (Matsumura et al., 2002; Ruhnke et al., 2000) and British populations (Daniel Munday et al., 2009); but were similar to other studies carried out on Asian populations (S.-Y. Cheng et al., 2015; Hirakawa et al., 2017; L. K. Krishna et al., 2014).

5.4.1 Study limitations

The study was conducted with a large group of healthcare providers involved in the delivery of ACP discussions. By sampling this group of individuals, we have obtained a range of views across different professional groups, which provided a system-level perspective of facilitators and impediments of home deaths. Since this group of individuals were early adopters of ACP, they likely provided deeper insights into the end-of-life care, and the place of death preference elicitation process. This however, may not be representative of all individuals working in the acute care sector in Singapore. Future research should also focus on healthcare professionals who are not yet involved in ACP. In addition, a health system perspective, as opposed to a patient's perspective, was adopted, to gain an insider's perspective of the health system's role in influencing home deaths. Future studies should explore patients', as well as family caregivers' perspectives.

5.4.2 Policy and research implications

Our findings suggested that the decision on where to die was often a family decision. Therefore, the preference elicitation process needs to be family-oriented, and conducted by a healthcare professional with whom the patient shares a supportive relationship with. At the same time, to overcome the practical challenges of organising family conferences, technology could be better exploited to involve relevant family members or loved ones, over a series of discussions.

There were also many contributing factors when a home death preference could not be met. Currently, most interventions in Singapore have been designed to address gaps in the health and social care capacity to care for a patient at home (Gan, 2014). However, from a societal perspective, these efforts might reduce the cost of hospital care, but they might shift cost to the patient and the family (Yu, Guerriere, & Coyte, 2015). Often, unpaid caregiver time, the cost of hiring a foreign domestic helper, and also the cost of hiring necessary equipment to support care at home can be substantial. More research needs to be done to quantify the burden distribution of end-of-life care in Singapore, and perhaps, additional policies going beyond the traditional jurisdiction of healthcare financing needs to be enacted to support home deaths.

5.5 Conclusion

Eliciting care preferences has evolved to become a central feature in today's healthcare policies. Although there is a focus on individuals facing imminent death, there is also an impetus to expand ACP beyond this population. We found that the discussion regarding preferences should be best conducted by a healthcare personnel who has or is able to build a strong rapport with the individual. Supporting families emotionally and financially at care transition points as well as over the end-of-life trajectory could meet their needs. Together with this, ensuring care continuity and empowerment of healthcare professionals, will better support the meeting of place of death preferences.

Chapter 6 Individual, Clinical and System Factors Associated with Home Deaths

Abstract

This chapter describes a retrospective cohort study that identified factors associated with home deaths in the adult population. A cohort comprising 75,650 adults (≥21 years old), who had died in Singapore between January 2012 and December 2015, were included in the analytical sample. To assemble the required data variables, five different national databases were linked. A multivariable logistic regression model was used.

Twenty-seven percent of deaths occurred at home. Factors associated with home death included older age, females (OR 1.27, 95% CI 1.22-1.32), Malay ethnicity (OR 1.85, 95% CI 1.76-1.94). Malignant neoplasm (OR 2.40, 95% CI 2.27-2.55), respiratory diseases (OR 2.33, 95% CI 2.17-2.51), and cerebrovascular diseases (OR 1.15, 95% CI 1.08-1.22) as causes of death. Independently, receiving home palliative care, as well as a documented home death preference via ACP, raised the odds of home deaths by 6.9 and 3.6 times respectively. Being admitted to acute hospitals, nursing homes, and hospices decreased the odds of home death.

The results highlight the importance of home-based end-of-life care and ACP, as well as the person and illness-specific factors in contributing to the eventual place of death. Therefore, endeavoring to meet one's preferences at the end-of-life cannot be constrained to being only the responsibilities of the individual or family; it must encompass the resources and determined efforts of the community and society in creating a conducive, compassionate environment that supports people's preferences of how and where they wish to die.

6. Factors influencing place of death

6.1 Introduction

Many middle- and high-income countries are currently facing the challenge of providing quality end-of-life care, and meeting patients' preferences for dying at home. In a systematic review of 210 studies from 34 countries, 75% revealed that most people prefer to die at home. Home death preferences were found to be relatively stable, as only one in five studies reported changes as the patient's disease progressed (Barbara Gomes et al., 2013). Despite a consistent preference for dying at home across these advanced societies, most decedents died in hospitals. Similarly, in Singapore, the rate of home death has been falling, despite a majority of Singaporeans (77%) indicating home death preferences (Blackbox Research, 2014). In fact, 49% of Singaporean decedents died at home in 1965, as compared to 33% in 1990, and 25% in 2015 (Immigration and Checkpoints Authority Singapore, 2015).

The preference to die at home is fundamentally driven by the wish to be surrounded by loved ones in a familiar setting when death approaches (Gilley, 1988). Being at home also allows one to maintain autonomy and control over one's daily life (Peter A Singer et al., 1999), which is an important aspect of dignity that could be compromised in institutional settings where individuals' livelihoods are determined by the healthcare system (A. H. Y. Ho et al., 2015; A. H. Y. Ho & Tan, 2016). Many patients experience a gradual loss of dignity through institutional dependency, and this could further distress them and lower their quality of life as dying approaches (A. A. Wright et al., 2010). At the same time, individuals whose family members received adequate formal or informal end-of-life support, that enabled death at home, reported less intense grieving, both at the time of death and in post-bereavement, as compared to relatives of those who died in the hospital (Gomes et al., 2015).

The place of death is the result of a complex interplay between individual characteristics (socio-demographic), nature of the illness, palliative care policies, and societal perceptions of the desired place of death (Daniel Munday et al., 2009). Governments across higher-income countries have enacted healthcare coverage and financing policies to support treatments and death at home. In the US, the enactment of policies, such as the Medicare hospice benefit in the 1980s and the PSDA in 1990, have raised the proportion of home deaths from 17% in 1980 to 22% in 1998 (Flory et al., 2004). Similar policy efforts (Department of Health, 2008) to reverse the tide of hospital deaths in the UK also saw an increase in the share of home deaths (B. Gomes et al., 2012). In Singapore, the government has adopted a multi-pronged approach to raise the quality of palliative care services, and to expand the capacity and affordability of home-based palliative care services. In 2011, Singapore implemented an ACP programme nationally, which aimed to promote and support discussions between individuals, their families and healthcare providers about future end-of-life care plans (I. Chung, 2017) .

Many studies have examined factors that influenced dying at home. Gomes & Higginson (Gomes & Higginson, 2006) reviewed evidence from 58 studies. Among cancer patients, functional impairment, preference to die at home, having access to home care, high home care intensity, residing with relatives, and having support from the extended family were found to boost the prospect of dying at home. A later study by Costa et al., that extended the review to non-cancer populations (Costa et al., 2016), additionally highlighted the importance of policy-amendable factors, such as the provision of home palliative care by a multidisciplinary team, provision of palliative care services in nursing homes, and timely referrals to palliative care services. While three studies have been conducted in Singapore on the correlates of home death (Beng et al., 2009; Hong et al., 2011; Poulose, Do, & Neo), the factors explored were mostly patient-related and non-modifiable. While Poulose et al. found that earlier referral to an inpatient palliative care service was positively correlated with dying at home, the sample was relatively small and based at a single site (Poulose et al.).

Using data from different national administrative and clinical databases, this study intended to determine individual demographic and clinical factors associated with dying at home, for all who had died in Singapore between 2012 and 2015. It also seeks to ascertain the impact of system factors, such as the national ACP policy on home deaths, as well as to determine the implications of expanding home palliative care services to fulfill home death preferences.

6.2 Methods

This is a retrospective cohort study, which included all individuals who had died between January 2012 and December 2015 in Singapore.

6.2.1 Sources of data

To assemble the required data variables, five different databases were linked (Table 6.1). All data were linked and anonymised using a project unique identifying number, which was generated based on the deceased's National Registration Identity Card number. The final data set contained information on each decedent's date of birth, date of death, sex, ethnic group and place of death; preferred place of death as documented in an ACP; information on each public hospital admission episode, including the date of admission and discharge, as well as diagnoses; and also intermediate and long-term care service utilisation, including home palliative care, inpatient and nursing home admissions.

Table 6.1 Data sources that were linked.

Data sources	Variables
MOH registry of death database	Age, sex, ethnic group, date of birth, date of death, cause of death, place of death
MOH case mix and subvention database	Date of hospital admission and discharge; ICD-9-CM and ICD-10-CM diagnosis codes
MOH intermediate and long-term care information systems	Nursing home admissions; hospice admissions; home palliative care use
National ACP IT system	Patient preferences for home death
TTSH hospital ACP database	Patient preferences for home death

ACP: Advance Care Planning; DRG: Diagnosis-Related Group; ICD-9-CM: International Classification of Diseases, 9th version with clinical modification; ICD-10-CM: International Classification of Diseases, 10th version with clinical modification; IT: Information Technology

6.2.2 Outcome variable

The dependent variable, "home death", was defined as a death that had occurred at a private residential address. Deaths occurring at other sites (hospital, nursing homes, charitable institutions, licensed sick receiving house, and others) were grouped as "non-home death" (Immigration and Checkpoints Authority Singapore, 2015).

6.2.3 Independent variables

Variables found to be significant in the literature (Beng et al., 2009; Costa et al., 2016; Gomes & Higginson, 2006; Hong et al., 2011) were extracted from the above databases, and constructed to define: age group; gender; ethnic group; primary cause of death; and comorbid burden. We have coded the primary causes of death based on the International Classification of Diseases' 9th and 10th codes with clinical modification (ICD9CM, ICD10CM), according to the official local classification (Immigration and Checkpoints Authority Singapore, 2015). Comorbid burden was computed using the Charlson Comorbidity Index (CCI) (Charlson et al., 1986; Quan et al., 2005). Looking back three years from the date of death, principal and secondary diagnosis codes for all hospital admissions incurred by the individual were identified to compute the CCI. The CHARLSON command in Stata was used (Stagg, 2015).

Home-based palliative care was defined and computed as a variable that measured access to a home palliative care service, at least 30 days prior to death. We also included a variable that indicated a documented preference to die at home in an ACP. In addition, since the nursing home, inpatient hospice, and acute hospital care are competing care alternatives, and that individuals who received institutional care are likely to die within those settings, we have also included three additional variables: acute hospital admissions in the last one month of life; nursing home admission; and inpatient hospice admission.

6.2.4 Statistical analysis

First, we carried out bivariate analyses to explore the relationship between home death and the independent variables. A multivariable logit model was then used to investigate the association between the dichotomous dependent variable (home death or not), and independent variables measuring individual (age, sex, ethnic group), clinical (comorbid burden, cause of death), and system factors (home death preference, home palliative care use, nursing home use, hospice use, acute hospital admission). All independent variables were added simultaneously into the logistic regression model.

Traditionally, p-values are used to test the null hypothesis that there are no underlying differences between groups. Due to the large sample size of our study, p-values are predictably small, which will lead us to reject the null hypothesis. even for small differences between groups. Thus, for the bivariate analysis, the differences in proportions were compared. For the logistic regression model, we have chosen to report the OR for each of the independent variables, as well as the corresponding

95% confidence intervals (CIs). The CIs reflected the range of values that the true OR should fall within, as well as provided an indication of the direction and magnitude of the effect (du Prel, Hommel, Röhrig, & Blettner, 2009).

Additionally, with a large data set, we have opted not to rely on the traditional measures of the goodness-of-fit model, such as the Hosmer-Lemeshow (HL), because assessments by deciles have been shown to be unreliable for sample sizes exceeding 25,000. For example, the HL test statistic becomes very sensitive to small departures from the expected distribution (Paul, Pennell, & Lemeshow, 2013). Therefore, to assess the fit of the overall model, we have used the area under the curve (AUC) (Hosmer Jr et al., 2013) to determine whether the fitted model predicted home death adequately. An AUC equal to 0.5 shows that the model performed no better than chance. All statistical analyses were carried out using Stata version 12 (StataCorp, 2011).

6.3 Results

The extracted data set comprised 76,927 people, of which 1,209 were excluded due to their ages being less than 21 years at the point of death, and 68 were excluded due to missing data. The final analytical sample included 75,650 decedents. Among these, 27% died at home, 57% in hospitals, and 16% in long-term care institutions, hospices and other locations. Between 2012 and 2015, the percentage of people who died at home fell, from 27.6% to 25.7%.

6.3.1 Bivariate results

From Table 6.2, compared to those who did not die at home, there was a higher proportion of individuals who were aged older than 75 years and who were female among those who did die at home. Relative to other ethnic groups, a Malay death is more likely to occur at home. Comparing amongst different causes of death, a higher proportion of those who died at home died from malignant neoplasms and cerebrovascular disease, with a lower burden of comorbid conditions. A significantly higher share of those who died at home were not being admitted to any acute or long-term care facilities near the end-of-life. Conversely, a greater proportion of them received palliative care at home or had earlier documented a preference to die at home in an ACP document.

Table 6.2 Profile of 75,650 decedents and bivariate analysis of place of death.

	Total	Home deaths	Non-home deaths	p-value*
INDIVIDUAL FACTORS				
Age (years)				<0.001
21-34	1,760 (2%)	237 (1%)	1,523 (3%)	
35-44	2,283 (3%)	421 (2%)	1,862 (3%)	
45-54	5,606 (7%)	1,117 (6%)	4,489 (8%)	
55-64	11,778 (16%)	2,650 (13%)	9,128 (16%)	
65-74	15,534 (21%)	3,861 (19%)	11,673 (21%)	
75-84	20,770 (27%)	5,944 (29%)	14,826 (27%)	
≥85	17,919 (24%)	6,058 (30%)	11,861 (21%)	
Sex				<0.001
Female	34,541 (46%)	10,532 (52%)	24,009 (43%)	
Male	41,109 (54%)	9,756 (48%)	31,353 (57%)	
Ethnic group				<0.001
Chinese	57,614 (76%)	15,204 (75%)	42,410 (77%)	
Malay	10,550 (14%)	3,613 (18%)	6,937 (13%)	
Indian	5,734 (8%)	1,171 (6%)	4,563 (8%)	
Others	1,752 (2%)	300 (1%)	1,452 (3%)	
CLINICAL FACTORS				
Cause of death				<0.001
Malignant neoplasm	22,813 (30%)	7,434 (37%)	15,379 (28%)	
Heart & hypertensive	16,400 (22%)	3,390 (17%)	13,010 (23%)	
Lung & respiratory	16,338 (22%)	4,047 (20%)	12,291 (22%)	
Cerebrovascular	6,360 (8%)	2,599 (13%)	3,761 (7%)	
Diabetes	1,040 (1%)	464 (2%)	576 (1%)	
Others	12,699 (17%)	2,354 (12%)	10,345 (19%)	
CCI				<0.001
≤ 1	24,731 (33%)	7,653 (38%)	17,078 (31%)	

Table 6.2 Profile of 75,650 decedents and bivariate analysis of place of death.

	Total	Home deaths	Non-home deaths	p-value*
= 2	6,515 (9%)	1,818 (9%)	4,697 (8%)	
≥ 3	44,404 (59%)	10,817 (53%)	33,587 (61%)	
SYSTEM FACTORS				
Nursing home admission	965 (1%)	28 (0%)	937 (2%)	<0.001
Inpatient hospice admission	2,342 (3%)	136 (1%)	2,206 (4%)	<0.001
Acute hospital admission	37,356 (49%)	5,460 (27%)	31,896 (58%)	<0.001
Home death preference	744 (1%)	384 (2%)	360 (1%)	<0.001
Home palliative care use	7,568 (10%)	3,830 (19%)	3,738 (7%)	<0.001

CCI: Charlson Comorbidity Index
*chi-square test was used to assess the differences between groups

6.3.2 Logistic regression results

The results of the univariable and multivariable logistic regression are presented in Table 6.3. Against the reference group (21-34 years old), the 95% confidence intervals of the odds of a home death for other older age groups were greater than 1. The odds of experiencing a home death also increased as age increased. Compared to females, the odds of a home death were lower for males. The odds of a home death among Malays was 1.85 times the odds for non-Malays. Individuals who died of malignant neoplasm, lung disease, and cerebrovascular disease had a higher OR of a home death; whereas individuals who died due to heart diseases were less likely to experience a home death. The odds of a home death for individuals with a CCI score of three or higher was 0.88-times the odds of those with scores that were 1 or below.

Individuals admitted to a nursing home or to an inpatient hospice had very low odds of dying at home. An acute hospital admission in the 30 days prior to death was associated with lower odds of dying at home. On the other hand, compared to the relevant reference groups, the odds of dying at home were significantly higher among home hospice recipients, as well as individuals with a documented home death preference. The AUC was 0.775 (95% CI 0.771- 0.779), indicating the model had fair discriminatory power.

Table 6.3 Univariable and multivariate logistic regression analysis of factors associated with home death.

Variables	Crude OR	95% C.I.	Adjusted OR*	95% C.I.
INDIVIDUAL FACTORS				
Age (years)				
[21-34]	1.00	-	1.00	-
35-44	1.45	1.22 – 1.73	1.45	1.21 - 1.74
45-54	1.60	1.38 – 1.86	1.75	1.49 - 2.05
55-64	1.87	1.62 – 2.15	2.33	2.00 - 2.71
65-74	2.13	1.84 – 2.45	2.85	2.46 - 3.31
75-84	2.58	2.24 – 2.96	3.90	3.36 - 4.52
≥85	3.28	2.85 – 3.78	5.15	4.44 - 5.98
Sex				
[Male]	1.00	-	1.00	-
Female	1.40	1.37 – 1.45	1.26	1.22 - 1.32
Ethnic group				
[Non-Malay]	1.00	-	1.00	-
Malay	1.51	1.45 – 1.58	1.85	1.76 - 1.94
CLINICAL FACTORS				
Cause of death				
[Others]	1.00	-	1.00	-
Malignant neoplasm	1.87	1.78 – 1.97	2.40	2.27 - 2.55
Heart & hypertensive	1.01	0.95 – 1.07	0.80	0.75 - 0.85
Lung & respiratory	2.68	2.51 – 2.86	2.33	2.17 - 2.51
Cerebrovascular	1.28	1.21 – 1.35	1.15	1.08 - 1.22
CCI				
[≤ 1]	1.00	-	1.00	-
= 2	0.86	0.69 - 0.92	1.01	0.94 - 1.08
≥ 3	0.72	0.67 – 0.78	0.88	0.84 - 0.92
SYSTEM FACTORS				
Home death preference				
[No]	1.00	-	1.00	-
Yes	2.95	2.55 – 3.41	3.59	3.04 - 4.24

Table 6.3 Univariable and multivariate logistic regression analysis of factors associated with home death.

Variables	Crude OR	95% C.I.	Adjusted OR*	95% C.I.
Nursing home admission				
[No]	1.00	-	1.00	-
Yes	0.08	0.06 – 0.12	0.07	0.05 - 0.10
Inpatient hospice admission				
[No]	1.00	-	1.00	-
Yes	0.16	0.14 – 0.19	0.07	0.06 – 0.09
Acute hospital admission				
[No]	1.00	-	1.00	-
Yes	0.27	0.26 – 0.28	0.19	0.18 - 0.20
Home palliative care use				
[No]	1.00	-	1.00	-
Yes	3.13	2.99 – 3.28	6.91	6.31 - 7.56

[.]: Reference group; OR: odds ratio; CCI: Charlson Comorbidity Index; C.I.: confidence interval
*adjusted for the year that the death occurred;

6.4 Discussion

This study found that among adult decedents in Singapore, the likelihood of dying at home increased with certain individual and clinical factors, including age, being female, of Malay ethnicity, and lowered comorbid disease burden. Individuals who died from a malignant neoplasm, respiratory diseases, and cerebrovascular diseases were more likely to have died at home. Besides individual and clinical factors, system factors, such as completion of advance statements and home palliative care, also contribute to a higher possibility of home death. On the other hand, admissions to nursing homes, inpatient hospices, and acute hospitals reduce this likelihood, as this usually signified inadequate resources and support to facilitate care and death at home.

Other studies similarly found that older individuals tended to die at home (Beng et al., 2009; Gruneir et al., 2007; Hong et al., 2011; Ikezaki & Ikegami, 2011; Tang et al., 2010; Yun, Lim, Choi, & Rhee, 2006). The last place of residence, which is where the patient resided in and was cared for, is usually also the place of death. This location is often dependent on caregiving norms, and in East Asia, family members are strongly expected to care for the elderly at home (S.-Y. Cheng et al., 2015). This contrasts with countries such as Sweden (Hakanson, Ohlen, Morin, & Cohen, 2015) where the share of elderly home deaths is lower, due to a relatively high proportion of them residing in long-term care residences. In terms of gender influence, our results reiterated the findings from two other Singaporean studies (Beng et al., 2009; Hong et al., 2011) which found home deaths to be more probable among males. This differs from the wider literature on Asian populations (Gu et al., 2007; Tang et al., 2010; Yun, Lim, et al., 2006), but this can be attributed to the higher propensity of hospitalisation for males in Singapore (Niti & Ng, 2003).

Ethnic minorities, with their lower access to primary care (Lackan, Eschbach, Stimpson, Freeman, & Goodwin, 2009) home care (Gomes & Higginson, 2006), and a lower rate of AD completion (Lackan et al., 2009), are less likely to die at home. However, our study, together with others conducted locally (Beng et al., 2009; Hong et al., 2011), found that individuals of Malay ethnicity, which formed 15% of the Singaporean population, had a higher likelihood of home deaths. Since 99% of the Malay population in Singapore are Muslims (Department of Statistics, 2010), Islamic practice related to final religious rites and death rituals could have contributed to this phenomenon (Sarhill et al., 2001; Sheikh, 1998). A study conducted in Malaysia, where 50% of the population is Malay and 60% belong to the Islamic faith, observed similar results (Htut et al., 2007). Nevertheless, the higher utilisation of long-term residential care (C. Chen et al., 2013; E. S. Lim, 2009) by non-Malays could have contributed to lower numbers of home deaths as well. The impact of ethnicity on the place of death goes beyond the socioeconomic disparity argument widely stated in the literature, and warrants further research.

A diagnosis of cancer has been evidenced, in other studies, to be associated with an increased likelihood of a home death; whereas cardiovascular diseases had the opposite impact (Costa et al., 2016). End-of-life care of individuals with multiple comorbid disease conditions tend to be more complex, with frequent admissions to acute care facilities, and a higher likelihood of dying in the hospital (Tang et al., 2010). One plausible explanation is that patients who died of cardiovascular accidents are more likely to present with unexpected acute deterioration or collapse as a terminal event (Penrod et al., 2011). In such situations when family caregivers are caught off-guard, the default action is usually to call for emergency services and readmit the individual.

Unsurprisingly, system factors amenable through policy wield significant influence over the place of death. Singapore has made significant progress towards ensuring a good quality of end-of-life care. The introduction of a national ACP programme, which facilitated individuals to state where they wish to die, was found to be positively associated with dying at home among those who desired a home death. Previous studies (Costa et al., 2016; Gomes & Higginson, 2006) have reported similar results. The statement of a preference acts as a form of goal-setting, and when effectively communicated to family members and healthcare providers, actions could be taken to honour these preferences. Additionally, our study identified access to home palliative care to be positively influence the likelihood of dying at home. This finding concurred with the outcomes of a Cochrane review, which found home palliative care to more than double the chances of dying at home, and that to enable one additional death at home, five additional individuals need to receive home palliative care (B. Gomes et al., 2013).

6.4.1 Strengths and limitations

A key strength of our study lies in linking population-based information about the place of death with national data based on the ACP, and acute and long-term care utilisation. Gomes and Higginson (Gomes & Higginson, 2006), and Costa et al. (Irene J Higginson et al., 2013) have earlier illustrated the importance of social support measures. However, we were unable to incorporate these variables into our model. Future studies should strive to include such variables, since changes to household structures and caregiving norms could significantly influence the place of death.

By exploring the factors associated with home deaths, one might infer that home deaths are assumed to be “more ideal”, but we do recognise that individuals may also prefer to die in other settings. Whilst recognising that place of death preferences vary, examining the correlates of home death and the impact of policies that enable it remains important, due to the attention paid in policy-making to fulfill preferences to die in the comfort of one’s home (Gan, 2014). Future studies should further examine the multiple factors influencing unmet preferences for home deaths, and pay attention to ensuring a high quality of death in an institution.

6.4.2 Implications for practice and policy

Singapore is one of the first Asian countries to have implemented ACP at the national level, with the government aiming to reach out to and initiate ACP conversations with 100,000 Singaporeans (Gan, 2017), expanding the focus of the programme to beyond those diagnosed with advanced illnesses. This may significantly impact the proportion of home deaths in the future, if it is indeed preferred by the population. Beyond Singapore, ACP, as a platform for patients to communicate their end-of-life care preferences with caregivers and healthcare professionals, could support the meeting of home death preferences in other Asian countries. In tandem, our results support the Singapore government's efforts to grow the capacity of home palliative care providers to meet preferences for home death. The number of home palliative care sites increased from 3,800 in 2011 to 5,500 in 2016, with a target of reaching 6,000 by 2020 (Gan, 2017). Greater focus could be placed on developing services for non-cancer populations, such as heart disease, to reduce any differentials currently observed.

6.5 Conclusion

Our study illuminated the importance of home-based palliative care and ACP, as well as the person and illness-specific factors in contributing to the eventual place of death. Our results imply that such policy initiatives could catalyse increases in the number of, and proportion of home deaths in the future. Scaling up these initiatives will help healthcare professionals better understand and support patients' end-of-life preferences if they wish to be at home. Therefore, endeavoring to meet one's preferences at the end-of-life cannot be constrained to just being the responsibility of the individual or family; it must encompass the resources and determined efforts of the community and society in creating a conducive, compassionate environment that supports people's preferences of how and where they wish to die.

Chapter 7 Initiating, Implementing and Integrating ACP: Leading the Transformation of Norms

Abstract

Despite being simply defined as a process to further one's understanding about future medical care, the process of implementing ACP within acute hospital settings can be complex. In this chapter, different ACP service models adopted in Singapore, and the facilitators and barriers to their effective implementation, are described.

A focus group study with thematic analysis was conducted. Four stakeholder groups involved in the implementation of ACP were purposefully sampled. Our sample included 63 participants, 12 physicians, 15 nurses, 24 medical social workers, and 12 ACP coordinators from seven public hospitals and specialist centres.

There are three different acute care models adopted in Singapore, differentiated by leadership approach, target population, delivery process, and job roles. Nine themes that have influenced ACP implementation in an acute care setting were identified. They include: "Transforming norms", "Priority on hospital agenda" "Empowered leaders"; "Shared purpose and goals"; "Differentiation from existing practices"; "Rapid diffusion"; "Preference-supportive culture"; "Responsible resourcing"; and "Accountability and feedback".

To implement ACP effectively in an acute care setting, there needs to be a cultural and behavioural transformation, led by committed and empowered leaders. Organisations that can create a shared purpose built on an ethos of honouring patients' preferences, as well as support this with systematic processes and adequate resourcing, will be more equipped to implement ACP effectively.

7. Implementing ACP

7.1 Introduction

In many countries, including Singapore, an individual could designate a health care decision-maker, and specify decisions regarding life-sustaining treatments, in case of decisional incapacitation in a legally binding AD. However, rates of AD completion are low (Hanson & Rodgman, 1996; Rao et al., 2014), due to the complexities of legal formalities (Rolnick et al., 2017; Sabatino, 2010) and low public awareness (M. Tay et al., 2010). A communications-based approach (Sabatino, 2010) in the form of ACP has evolved, to address the limitations of a legal approach. Today, ACP encompasses a continuing process of discussion about preferences for future care plans, between individuals, their families and care providers (R. L. Sudore, Lum, et al., 2017).

In Singapore, a government-led, national-level ACP programme, named "Living Matters", was initiated in 2011 (I; Chung, 2013). It was modelled after the Respecting Choices® programme, originally developed by the Gunderson Health System in the U.S., which has been evidenced to improve patient-surrogate congruence in end-of-life care decision-making (Song, Kirchhoff, Douglas, Ward, & Hammes, 2005), enhancing compliance with care preferences, and bolstering higher satisfaction with quality of death (Hammes & Rooney, 1998; Hammes, Rooney, & Gundrum, 2010). The objective of Living Matters is to encourage end-of-life care discussion between individuals, families and healthcare providers via: 1) increasing awareness of ACP in the community and among health and social care sectors, through various outreach initiatives; 2) recruiting and training a pool of certified ACP facilitators; and 3) strengthening existing health and social care systems across Singapore to support ACP implementation. Since 2011, more than 2,000 ACP facilitators have been trained (Gan, 2017) and approximately 10,000 ACP conversations have been completed (Foo, 2017). The adoption of Living

Matters has been gradual and varied, due to the diversity in organisational cultures, and operational contexts across public hospitals in Singapore.

Death is often regarded as a failure in a hospital setting, where culturally, clinical training and medical technologies are geared towards stabilising or curing patients of their medical problems (Institute of Medicine, 1997). Implementing ACP therefore requires a significant cultural change, which can be highly complex. Strategies focused on simultaneously impacting patients' awareness, health professional receptivity and competency, as well as reorganising administrative and clinical workflows (Reidy et al., 2017), might be needed. There are many components in the process of ACP. Beyond clarifying, discussing, and documenting end-of-life care preferences; communication of prognoses, establishing clear referral criteria, and ensuring goals of care were met, also form part of ACP. While structured tools and plans of action have been developed to reduce the complexity of implementing ACP (Flo et al., 2016), competing demands in caregiving tasks, coupled with time-pressured clinical workflows, have proven to be major barriers for effective and successful service delivery (Lund et al., 2015).

Many studies have explored ACP by examining the perspective, attitudes, and experiences of various stakeholders of ACP (Beck, McIlfatrick, Hasson, & Leavey, 2015; S. Johnson, Butow, Kerridge, & Tattersall, 2015; Sharp, Moran, Kuhn, & Barclay, 2013), as well as its efficacy (Brinkman-Stoppelenburg et al., 2014; Houben, Spruit, Groenen, et al., 2014); but few studies examined its implementation (Lund et al., 2015) or related sustainability issues. There is also little description from the literature on the leadership approach, organisation of work, and processes undertaken to operationalise the practice of ACP (Flo et al., 2016) within dynamic clinical environments. In this paper, we determined and described the various ACP models adopted in Singapore; and through a critical examination of the perspectives and experiences of healthcare professionals, we identified the facilitators of, and barriers to its effective implementation.

7.2 Methods

7.2.1 Study design

This study is part of a larger project that examined the provision and delivery of Singapore's "Living Matters" ACP programme. A series of focus groups with healthcare professionals was conducted. We adopted the interpretive Systemic Framework (IFS) (Fuenmayor, 1991), which supports the exploration of organisational structures and inter-relationships between stakeholder groups, while at the same time allowing for a systemic comprehension of the implementation process, via the interpretive lens of different stakeholders.

7.2.2 Sampling and recruitment

The sampling frame was designed based on the ISF, and we purposively sampled across four stakeholder groups, including physicians, nurses, medical social workers (MSWs), and ACP coordinators (i.e. allied health workers designated to conduct ACP), and across seven participating hospitals. The inclusion criteria included those aged 21 and above, who had completed the National ACP training program, were involved in ACP provision and delivery within their workplace, and had the ability to communicate in English, as well as to provide informed consent. We recruited sixty-three participants (12 physicians, 15 nurses, 24 medical or social workers, and 12 ACP coordinators).

7.2.3 Focus Groups Discussions

To collect healthcare professionals' narratives and interpretations of ACP implementation, 14 independent focus groups, comprising two to eight participants, were conducted for each stakeholder group, between September and October 2016.

Based on Proctor's conceptual taxonomy of implementation outcomes (Proctor et al., 2011), participants were asked to comment on five major areas, including: 1) acceptability in terms of the healthcare professional's satisfaction with, and direct experience with ACP in their organisations; 2) fidelity refers to the extent to which ACP was carried out according to their training, or as intended by the programme leads in their organisations; 3) feasibility in terms of their views about whether ACP was well-received by patients, their family members and other healthcare professionals; 4) penetration in relation to the extent that ACP is considered part of routine clinical practice; and 5) sustainability regarding their perceptions and belief that the continuation of ACP as part of their daily work. (refer to appendices 7 and 8 for the interview schedules.)

Each FGD lasted approximately 120 minutes. The discussions were recorded, transcribed verbatim and analysed.

7.2.4 Data analysis

Framework Analysis was adopted to analyse the collected data for developing operational models of ACP, and for identifying factors and themes that either facilitated or impeded ACP implementation (Gale et al., 2013). We used the Normalisation Process Theory (NPT) (May & Finch, 2009) as a sensitising device to guide our interpretation of the process of integrating ACP into clinical practice (McEvoy et al., 2014).

Normalisation Process Theory

The NPT provides a conceptual framework, through which we can understand the mechanisms involved in implementing, embedding, and integrating complex health technologies or interventions into routine practice (May & Finch, 2009; May et al., 2007). In NPT, it is proposed that new practices become accepted, and rooted in existing organisational routines when persons either individually or collectively act to actualise and socially sanction them. Continuous investments by individuals and organisations are also required to sustain the new practice, until it fades into the background and becomes part of the everyday business of healthcare provision.

The NPT is made up of four core concepts: creating meaning for the new practice (coherence), how they participate in and sustain it (cognitive participation); sanctioning it (collective action); and evaluating its impact (reflexive monitoring). The use of NPT in our analysis helps to explain the differences in the experiences related by healthcare professionals, in implementing ACP in each of the seven hospitals. These four constructs are further described below:

- Coherence: Participants assign meaning to activities related to a new practice whether individually or collectively.
- Cognitive participation: Participants endorse the new practice and enrol themselves and others to participate in, and/or sustain the processes associated with it.
- Collective action: Participants utilise resources to enact a new practice, with skillsets they have acquired.
- Reflexive monitoring: Participants assess the influence of a new intervention on healthcare processes and outcomes.

These four constructs do not operate in a sequential or linear manner. Instead, they interact with each other and with the wider context and social conventions, in which the new intervention is introduced into (E. Murray et al., 2010)

Data coding

The QSR NVivo software was used for coding, cross-referencing, storing, as well as facilitating the retrieval of data (QSR International Pty Ltd, 2016). Several stages of data coding were performed with the purpose of reducing the data and to distill the most suitable themes to describe the experiential narratives of the FGD participants.

First, we read the transcripts multiple times and coded it line-by-line; summarising and coding the defining elements of the models, as well as the enablers and challenges of ACP implementation. Second, categories, theme and sub-themes were created and refined with the NPT in mind, which were then transferred onto a text document, along with corresponding quotes from the transcripts that illustrate and described them. Third, emergent themes were reviewed and discussed amongst the research team and confirmed via consensus. Finally, we proposed relationships between categories, themes and sub-themes, using supporting quotes from transcripts. (refer to appendix 14 for an example of preliminary results summarised according the NPT constructs.) No new themes emerged after fifth FGD.

To ensure rigor and trustworthiness of the analysis and the interpretation of the results, an audit trail was maintained throughout the study. Regular sessions were held to discuss emergent themes, differing interpretations of the data, and to reach consensus among the research team. All members of the research team agreed on the final theme categorisation and definitions. We also conducted members-checking with the ACP teams from the seven participating hospitals to ensure that site-specific details were accurately captured and reflected.

7.3 Results

The participant profile was reflected in Table 3.4, Chapter 3. Three models emerged due to variations in organisational, clinical, and operational contexts. We identified nine themes that explicated the factors that have facilitated or hindered the initiation, implementation, and integration of ACP in Singaporean hospitals. Factors may be consistent across all models, or they could be model-specific.

7.3.1 Description of practice models

Each model adopted different philosophies of ACP implementation ranging from one that viewed ACP as a community effort to one that adopted a chronic disease approach to target higher-risk hospital-based patients to one that viewed ACP as a social work intervention. These differences led to the development of three practice models distinguished by: (i) target population, (ii) leadership approach, (iii) processes adopted for operationalising ACP (Table 7.1). (refer to appendix 15 for an example on the organisation and ACP processes adopted by one of the seven hospitals)

Table 7.1 Structure and process of ACP by models.

	Model 1	Model 2	Model 3
Hospitals	A, B, C	D	E, F, G
Philosophy	Community	Chronic disease	Medical Social Work
(i) Target population	Community - public, inpatient, outpatient, home care, nursing homes	All patients - inpatient, outpatient	All patients - inpatient, outpatient
(ii) Leadership approach			
Profession of leaders	Physician	Physician	MSW
Initiating department	Palliative / geriatric medicine	Palliative medicine	MSW
(iii) Processes			
Public advocacy	Yes	No	No
Create staff awareness	Yes	Yes	Yes
Defined referral criteria	No	Yes	No
Staff involved in facilitation	Physician, nurse, MSW, coordinator	Physician, coordinator	MSW, coordinator
Coordinators as main facilitators	No	Yes	Yes

The first practice model adopted a hospital-wide, community-based approach, which provides ACP in the hospital, patients' homes as well as nursing homes within a defined geographic area. Consequently, the team also engaged with the community to raise awareness. Efforts were initiated and led by geriatric or palliative care physicians, who subsequently work to enroll physicians from other medical disciplines to participate in ACP.

> "They obviously started it from the geriatrics department. Because it's something that we do it, quite often anyway. I mean in terms of discussing end of life issues, discussing DNR (Do-Not-Resuscitate), that's pretty much on a regular basis for our job scope." (Doctor, Hospital A)

> "I think (the) ACP team themselves have been going to the different medical discipline to explain to them what is ACP…. and giving them (doctors) a chance to question about ACP." (Medical Social Worker, Hospital B)

All doctors, nurses and MSWs formally trained to conduct ACP are expected to facilitate the discussions. Doctors who did not receive formal ACP training would refer patients to ACP coordinators - allied health workers employed specifically for ACP. Clinical judgement, rather than some pre-specified referral criteria, was the dominant approach used to assess patient readiness and suitability to participate in ACP. However, the implementation of such a broad-based strategy was not successful in all instances. Staff from at least one hospital reported a shift towards a discipline-based approach (model 2) midway through implementation.

> “And I have heard, again, I don’t know is unofficial or official, but I have heard that this was not the original intention. Originally when they started out, their intention was that they wanted to get as many staff trained in ACP as possible, so if even there was a situation, that arose, any staff could have an ACP discussion, whether formally or informally.” (Doctor, Hospital C)

Contrasted against a hospital-wide strategy, the second model adopted a disciplinary-based approach (Cardiology, Gastroenterology, Respiratory, Neurology, Renal, Oncology, Infectious Diseases) led by physicians. ACP coordinators are responsible for facilitating ACP discussions, following up with patients, and monitoring the progress of ACP implementation. Junior doctors are also encouraged to co-facilitate the ACP discussion session to explain the medical implications of the various end-of-life care choices. However, for medically complex cases, attending doctors who are trained to conduct ACP may facilitate the sessions themselves. The referral criterion was based on the surprise question "Would you be surprised if this patient died within the next year?" to identify patients with poor prognosis.

> “In my hospital they really put that down in doing step by step. And it's really progressing slowly but for example, take gastro for example, slowly the gastro team will have a leader to head-to really spearhead this ACP new department. Then it goes to the next department. So, we don’t try to just do it hospital wide at once yeah.” (MSW, Hospital D)

> “Encourage the doctors, maybe at least the junior doctors who know the possible complications that may occur to sit in with them. Because the facilitators (coordinators) know the structured framework, but the doctors don’t, and the doctors know the medical bit, so at least they can work and complement each other.” (Doctor, Hospital D)

Led by medical social workers, the third model focuses on ACP for hospital inpatients and outpatients. This model relies heavily on ACP coordinators to promote ACP, and to train healthcare professionals to facilitate ACP discussions. ACP coordinators may actively enroll patients to participate in ACP, but physician referrals remain the *modus operandi*. The referral rate is therefore heavily dependent on the receptiveness of individual physicians who are accommodating, but not actively enrolled into or participating in its implementation.

> “If I am not advocating ACP to patients, I am facilitating ACP discussion, or I will be training doctors or nursing or people from outside to do ACP or to advocate for ACP.” (Coordinator, Hospital E)

> “Most of my department (cardiology), I think it will be helpful for them to know the patient’s point of view, but whether would they go for course (ACP training), they might not see the value of that. They don’t object to having their patient’s approach by the social workers to have this discussion.” (Doctor, Hospital F)

7.3.2 Factors influencing implementation and integration of ACP

(1) Transforming norms

The role of the hospital, as perceived by the public as well as the healthcare profession itself, is one of curation and life-prolongation. The introduction of ACP, in this setting, challenges this conception more than many other healthcare innovations. Healthcare professionals therefore expressed doubts and anxiety about initiating conversations with patients, that are viewed to go against cultural norms, or at odds with the curative intent.

> "If you are talking to any doctor in an acute hospital, it's very clear that to every doctor in the hospital, acute hospital is for cure of patients. The ultimate goal for most patients is cure and is the same with the patients when the patient goes to the acute hospital. He is expecting whatever illness he is….to cure as much as possible. Ya, so is very clear and in fact is good that actually both the healthcare people and the patients are actually on the same page regarding this. And in fact, this is probably the biggest obstacle and the reason for why ACP is difficult to do in an acute hospital." (Doctor, Hospital C)

(2) Priority on hospital agenda

Stakeholders agreed that, for ACP to be integrated successfully, the senior management of each hospital needs to place ACP as a key priority on both policy and practice agendas. There are multiple competing agendas within an acute care setting; for example, ACP was perceived to be "not as urgent as infection control". The lack of investment to create structures, processes and procedures have created problems in the implementation of ACP. Inadequate senior management support also implies that the efforts of early adopters will not be recognised and rewarded, thereby discouraging leaders from stepping forward.

> “Because you know in the acute hospital things are very busy that there is always a lot of fires to fight on all fronts. And ACP is not one of those big-ticket items. Because after all in acute hospital, people go there for a cure, and it’s also right from the start, it has associated ACP to talking about death, which is the antithesis of getting a cure. Ya, so it is competing, this whole thing is going to be competing with a lot of other agendas in the hospital, in one hospital management.” (Doctor, Hospital C)

(3) Empowered leaders

Commitment at the policy level, as well as successful enrollment of senior managers, are essential when introducing a new healthcare intervention. Due to the centrality of physicians in the acute care system, attempts to initiate and legitimise ACP without them will frustrate and heavily compromise the attempt (model 3). Rebalancing internal power dynamics is crucial to empower non-physician leaders, in order to effectively spearhead the implementation of ACP; without which, active physician leadership still remains vital in efforts to integrate an intervention as complex and multidisciplinary as ACP into routine clinical practice.

> “But back in Hospital E, the effort is actually, helmed by the support worker, I think is not by choice, but by instructions. So, I think the doctor to helmed it, to start the conversation right, and the facilitator, follow out through, I think the process will be much easier. But for where I am coming from in my institution, I think we are trained to convince the physician or the healthcare

> team on how good or how beneficial ACP conversation will be. I think it's very tough. Unless there is a mindset shift that they believe that they truly believe ACP conversation will help the patient, then I think the work will be much easier." (Coordinator, Hospital E)

> "I mean if it's only on us to head the whole thing…to expect just MSWs to do the work of ACP, I think that's very tough and challenging." (MSW, Hospital E)

(4) Shared purpose and goals

Most FGD participants agreed that ACP facilitates the articulation of one's values and preferences, and is of value, not just to the patients but also to themselves. Yet, there was a lack of understanding and common agreement about the objectives and expected benefits of ACP. Healthcare professionals perceived ACP to achieve a wide range of goals (Table 7.2), including empowering end-of-life care decision-making, facilitating post-discharge care planning, reducing familial conflicts, guiding the medical team on end-of-life care planning, and rationalising the allocation of healthcare resources. Despite such positive reception towards ACP, one salient challenge lies in convincing physicians to believe that ACP is patient-centred, and not at odds with life preservation. Establishing common agreement about the goals and outcomes of ACP was especially challenging under the third model. Without legitimate power to influence others' behavior, MSWs faced significant challenges effecting this practice innovation.

> "I think, even at the very senior level, there is, not total buy-in, I would say that the buy-in is still very little, there is a lot of

> ambivalence, and sometimes even fear, that we are going down the slippery road.” (Doctor, Hospital G)

Table 7.2 Perceived goals of ACP.

Patient empowerment
"Which is to make sure that, is the voice of the patient what they really want, and what they value.” (Coordinator, Female, Hospital A)

Discharge care planning
“Because the advance care, so they thought is care arrangement for the patient when they go home, how to arrange for the care, that kind of thing.” (Coordinator, Female, Hospital F)

Improve patient-surrogate agreement on course of treatment
"After the discussion, the family actually somehow, I mean, respect patient’s decisions. So, it makes the treatment easier and the communication towards the treatment plan and management easier as well for the whole team." (Nurse, Female, Hospital A)

Guide medical team on preferred care
"There was an example where, there was moral distress in the medical teams. Because it’s a big team, and then different doctors of that team had different opinions of whether to tracheostomised a 23-year-old with leukaemia, relapse leukaemia, or not. And because the patient said that I do not want that although I am 23 years old, but I don’t want it. Then in the end you know there was no longer any moral distress and when the day, the day came where we have to make that decision, it was very clear-cut, because the patient said so.” (Doctor, Female, Hospital D)

Rationalise resource allocation
“Sometimes also is because, probably, the hospital cannot cope with so many patients and we think that if there is really not a good chance for them to live, we will want to document that and then be able to kind of like say that patient wants this, so that is that, you know.” (MSW, Female, Hospital B)

(5) Differentiation from existing practices

Existing practices, such as DNR orders and Extent-of-Care (EOC) orders, contain physicians’ orders about cardiopulmonary resuscitation, and decisions about the management of the patient. With the advent of ACP, it is important to align practices such that decisions about non-resuscitation, as reflected in the ACP, are followed by a physician’s DNR orders. Further differentiation, regarding the objectives, processes, and content of ACP, DNR and EOC, is desirable as FGD participants have opined that the distinction between these three tools is unclear, which some doctors may tend to assume that a completed ACP form is a DNR order. This is especially important when there is rapid diffusion of the new practice, such as hospitals operating with the first model.

> “Sometimes, they (physicians) will ask us to go in and discuss the extent of care states and do not want to further do more for the patient and leave it to the facilitators to deal with that, which is not what ACP is for. It’s for respecting the patient, what they think they want but not for us to go in and help them decide what are the DNR states." (Nurse, Hospital C)

> “Because I have, personally have this experience. Someone, ‘Oh, ACP.’ And then they just take it for DNR…. the ACP – it is not DNR it’s about active (treatment). Then, you know, it is very totally different. So maybe they don’t have a much knowledge.” (Doctor, Hospital A)

(6) Rapid diffusion

Palliative and geriatric medicine are often pioneers in the initiation stage, because end-of-life care discussions are part of usual care within these disciplines. However, a sluggish pace of implementation could entrench ACP as a specialty-specific service, which reinforces the misperception that “ACP equals to palliative care equals to refer to palliative care”. In the third model, the lack of traction in ACP work resulted from the practice being pigeonholed as a "medical social work” issue. Rapid diffusion of the practice beyond the initiating medical discipline or department is essential, and must be supported by clear communication about the intended goals and adequate resourcing.

> “Maybe is an unintended side effect…if you want to start the ACP programme, you must have some department to coordinate it, to oversee it. So, of course, it falls upon the palliative care department. Whether you like it or not, sooner or later, ACP equals to palliative care equals to refer to palliative care. Simply because that department, they started with it becomes it….. is one of those things that, hospital being an organism it can evolve that way." (Doctor, Hospital C)

(7) Preference-supportive culture

Establishing a culture that respects a patients’ end-of-life care preferences can be impactful in sustaining ACP, not just among patients but also healthcare professionals. Although the lack of electronic connectivity with private hospitals and nursing homes has been cited as a reason for breaking continuity of care, culture building goes beyond simply creating an electronic platform for the documentation, storage, and retrieval of ACP documents. Non-medical healthcare professionals repeatedly expressed concerns about the lack of legal or operational safeguards, which left ACP decisions vulnerable to being superseded by physicians. FGD participants were also anxious that physicians might not understand the conditions under which ACP preferences should apply.

> “I’ve heard of scenarios where the patient had an ACP but he or she comes into A&E (accident and emergency) and it’s a life-threatening situation and because ACP is not an AMD, it’s not legal, it’s not actually have to be enforced as well. So, there are

> some cases the doctors would just override it as well because it's based on their own medical judgement and their roles to save lives." (MSW, Hospital C)

> "Once the ACP is done, when the patient comes to ED, there is awareness of ACP and the choice is comfort care, the ED team will also alert our pall med (palliative medicine) team to go to ED to look at the patient. I think at the point, they will also think what is beneficial to the patient. If patient is still, I mean good for treatment, certain infection that is reversible, they will go ahead and do it. So, there is this communication going on." (MSW, Hospital B)

(8) Responsible resourcing

Beyond skills-based training, it was perceived that emotional competency and continued mentoring is needed to prepare and support healthcare professionals to perform the facilitator role. Despite many healthcare professionals being trained and certified, the FGDs did not point to any systematic manner in which they were incorporated into the ACP workflow. Many were simply unable to incorporate ACP in their day-to-day work. It was mentioned that ACP does not integrate well with the role of a ward nurse.

> "So, we can train many of them. But you notice there is only a handful that actually does the facilitation. Because the rest are just not comfortable to carry on with the job. And so, getting the correct people to be the facilitators rather than just push different people from the field in. You have the funding and you can try, can just push people to go through the training. Without really

> giving the emotional support or guidance, that doesn't really help to start with." (Nurse, Hospital C)

In the second and third model, ACP coordinators were specially hired and deployed to facilitate ACP, with the aim of minimising disruption to routine clinical practice. Since coordinators did not have any pre-existing relationship with the patient, they were required to spend additional time and effort on rapport-building. Therefore, responsible resourcing requires leaders to think through the tasks and requirements of the job role, and having the authority to designate and reallocate resources, including manpower, to ensure that the correct staff groups are involved in a timely manner to address patients' concerns.

> "To make it (ACP) meaningful, sometimes you have to foresee potential scenarios, specific to the patient condition. And I think that is where the medical knowledge comes… Whether the ACP facilitator (coordinator) is able to do that. I think it's the referring doctors' responsibility to go through and explain. Hopefully, with time they (coordinators) actually come to understand a bit more and gain some experiences." (Doctor, Hospital D)

(9) Accountability and feedback

Stakeholders have expressed concerns about the need for clearer patient referral criteria; the validity of ACP decisions made by a family proxy for patients who are already incapacitated; and the extent to which their efforts have led to preference-aligned treatments for the patients. On the one hand, there were reservations, primarily expressed by physicians, about the quality of discussions led by ACP coordinators. On the other hand, non-medical staff were wary about the impact of time constraints on the quality of physician-facilitated ACPs. Some participants suggested the establishment of a quality assurance framework, to continuously monitor the quality of facilitation. Specifically, for hospitals that have operationalised the third model, the development of a feedback channel is imperative as there was strong feedback regarding the lack of support from the organisation, and the passive involvement of physicians. These were perceived to impede the growth of ACP as a practice. Without a formal appraisal channel to address these issues, staff might start to doubt the intent of, and the value of persisting with their work to initiate, and enact, ACP.

Formal methods of assessing the outcomes of ACP have taken the form of clinical practice improvement projects, outcomes evaluation pilot, patient surveys, and a university-led randomised controlled trial on the effectiveness of ACP. All hospitals also use the national ACP IT system to track the number of completed conversations. Since improved patient care or goal-concordant care forms the core of the ACP agenda, in order for clinicians to embrace and sustain this practice, the importance of sharing ACP outcomes in an organisation-wide fashion cannot be overemphasised.

> "I think if we can show that it does make a difference. We did a very small (pilot) study, the data that we collected. It really makes a huge difference in terms of number of the (patients) and hospitalisations. And actually, we did do the patients satisfaction, I mean their family input. But, you know, I think fulfilling the wishes of the patient. If we can show our colleagues and the general population at what having ACP, what (are) the benefits and how you can benefit them in the local context. I think it would help." (Doctor, Hospital D)

7.4 Discussion

The current curation-focused culture provides a weak foundation for ACP to flourish. Changing this culture is therefore a challenge that must be confronted by the management of hospitals. Organisations that can persuade physicians, to understand that patients could benefit from the precept “to cure sometimes, to relieve often, to comfort always”, will be the ones that are best able to integrate ACP in routine practice. We demonstrated that the three models of ACP implementation in Singapore - distinguished by leadership approach, target population, delivery process, and job roles – faced different challenges. While none of the models can be singled out as ideal, our findings provide insights on potential strategies that can address each of the nine themes found to influence ACP implementation in acute care settings (Table 7.3).

The senior management of each organisation needs to explicitly promote a common vision of ACP, and put its principles into action. The assignment of implementation leaders needs to recognise that healthcare professionals are socially predisposed to recognise physicians as leaders in a multi-disciplinary service, because of their pivotal role in the medical care of patients (A. Hattori et al., 2005). As such, non-physician leadership could limit the ability to persuade, enroll, and define new procedures in any healthcare organisation (T. H. Lee & Cosgrove, 2014). It becomes even more daunting to assign a non-physician leader to spearhead an innovation such as ACP, which requires a fundamental shift in culture and mindset. In an acute care setting, efforts that did not incorporate efforts to empower non-physicians, or have excluded physicians from a leadership role, were unsurprisingly challenged in the creation of a coherent understanding of ACP, and to spur participation in the new practice. Further, to shift cultural and behavioural norms, the level of resources required for ACP may surpass traditional requirements when introducing a new service.

Table 7.3 Themes and strategies to improve ACP implementation.

Themes	Suggested Strategies
Transforming norms	• Introduce policies and mechanisms (organisational, financial, legal) to support shifting of norms from curative towards providing a good death • Educate public, patients, and healthcare professionals to increase ACP awareness
Priority on hospital agenda	• Emphasise the importance of ACP in relation to other aspects of care by the health ministry
Empowered leaders	• Identify leader(s) who is committed to initiate, expand and sustain the programme • Empower the leader with authority and resources to redesign workflows
Shared purpose and goals	• Articulate the objective of ACP by senior leaders repeatedly • Ensure common understanding by all healthcare professionals • Identify system, patient-centred, and process level goals
Differentiation from existing practices	• Identify all existing practices related end-of-life care decision-making by healthcare professions and/or patients • Align goals and practices and remove duplicative procedures
Rapid diffusion	• Provide resources to support diffusion of ACP (goals, processes, and outcomes) across disciplines • Introduce performance-based measures to assess diffusion, and incentives to encourage participation in ACP
Preference-supportive culture	• Identify points-of-entry into and exit from the hospital, and transitions within the hospital where care can be vulnerable to breakdowns in communication about patients' ACP preferences • Create work processes that safeguards preferences of patients
Responsible resourcing	• Define prerequisite skills-sets for tasks identified for successful implementation of ACP alongside routine clinical care • Identify healthcare professional with longstanding supportive relationship with patient to facilitate ACP
Accountability and feedback	• Establish a performance assessment framework for continuous process improvement but allow for missteps and empower the system to learn from mistakes • Feedback results regarding preference-concordant care at the discipline, and facility level to sustain enrollment and participation in ACP • Incentivise and reward those who do the work

To increase operational clarity, the objective of a new programme needs to be delineated from or aligned with existing practices of end-of-life care decision-making (May & Finch, 2009). With greater diffusion of the new practice, the need to ensure consistency in the understanding of its goals across healthcare professionals is greater. Tasks involved in ACP need to be set up, so that everyone is aware about their role within the process, and understands how to interact effectively with each other. The emergency department, as an entry point into the acute care system, plays a crucial role in supporting and honoring patients' preferences as decisions made could determine the course for the patient's treatment trajectory within the hospital system. Policies and processes must therefore be created across the healthcare continuum to support healthcare professionals, even those not directly involved in ACP activities, to work towards meeting patients' expressed goals and preferences.

Under the second and third models, non-traditional staff members were actively deployed and tasked to integrate ACP into routine clinical practice. While the intention was to minimise workflow disruption, it created other challenges – stakeholders have expressed the need for physicians to be involved in the ACP discussion, as patients often queried about the impact of life-sustaining treatments specific to their disease condition. Other studies have similarly highlighted the vital role of the physician in explaining the aims of ACP, to conduct a medical review, and to communicate with the patients about end-of-life care (Emanuel, Danis, Pearlman, & Singer, 1995; Sankaran et al., 2010). However, given constraints on a physician's time, a more plausible strategy would be to include him or her as part of a multidisciplinary ACP team, and to gather the medical inputs in a timely manner (Emanuel et al., 1995).

Lastly, as a healthcare system, we need to first recognise and agree upon the range of objectives that ACP should achieve (Kolarik, Arnold, Fischer, & Tulsky, 2002). With this, we can then move away from informal assessment to systematic quality assurance and outcome monitoring. This helps to create trust within the system regarding the quality of ACP facilitation, and encourages learning and adaptation (Peters, Adam, Alonge, Agyepong, & Tran, 2013), which are important in creating a virtuous and sustained cycle to motivate participants to persist in the process. Further, if ACP were strongly prioritised, healthcare professionals would be deeply interested in their performance vis-à-vis other colleagues. More might opt to lead the implementation if these improvements are rewarded.

7.4.1 Strengths and limitations

To our knowledge, this is the first study to describe different models of ACP implementation in Singapore. The qualitative design, together with recruitment across a range of healthcare professionals and experiences regarding ACP, allowed insights into their perspectives as well as the complex interactions between actors, processes, and systems during ACP implementation. Respondents were purposively recruited by on-site principle investigators attached to each of the seven acute settings. This allowed us to gather information from key stakeholders involved in the programme, but potential response bias could be a limitation. For future studies, a purposive random sampling strategy could be used. This paper has also presented a provider's perspective, and did not include the views of patients and their nominated substitute decision-makers. Even so, the results provided useful insights on integrating ACPs into clinical settings, as focus group respondents also reflected the challenges faced when interacting with patients. Lastly, as this is a qualitative study, our aim is to provide a rich description of the contextual factors affecting ACP implementation, rather than to offer generalisable observations. Some of these sites might not be at the 'mature' stage of implementation, with evolving processes. Care should be exercised when applying the results to different contexts, especially since the outcomes of social processes are often rife with uncertainties.

7.5 Conclusion

Worldwide, policymakers are increasingly nudging individuals to pre-emptively exercise autonomy over their end-of-life preferences, using ACP as a channel. We learned that, to implement ACP effectively in an acute care setting, there needs to be a cultural and behavioural transformation, led by committed and empowered leaders. Organisations that are able to create a shared purpose built on an ethos of honouring patients' preferences, and to support this with systematic processes and adequate resourcing, will be more equipped to implement ACP effectively.

Chapter 8 Using Routinely Collected Data to Assess Concordance in End-of-Life Care Preferences

Abstract

One of the key outcomes of ACP is whether patients had received medical care that was aligned with their expressed goals and preferences. In this chapter, we illustrate the practicability of using routinely collected healthcare data to ascertain the level of concordance between care received and the stated goals.

In this retrospective cohort study, medical treatments were ascertained using a combination of hospital procedural codes, and diagnosis-related codes. Places of care were obtained by reviewing the sequence of health services utilised, and the place of death was extracted from the national death registry. To ascertain concordance, medical treatment, places of care, and place of death, were compared against the individual's preferences.

The sample include 1,731 decedents (aged 21 years and above) who completed their ACP documentation as part of a national programme. Only individuals diagnosed with advanced illnesses at the point of ACP completion were included. Ninety-eight percent who wished for comfort measures met their preferences. Sixty-five percent of individuals who wished to be cared for at home received care at home. Close to half of the individuals who opted to die at home achieved their wishes.

Administrative data can provide a cost-efficient and powerful method for assessing outcomes for a large population-based national programme. However, this approach is still at an early developmental phase, and needs to be further validated before it can be used at scale.

8. Concordance with ACP preferences

8.1 Introduction

One of the main objectives of ACP is to allow patients to maintain autonomy in relation to current and future healthcare decisions. In 2011, a national programme, called “Living Matters”, was launched in Singapore to meet this specific aim. The programme aimed to ensure systematic conduct of end-of-life care discussions, supported by a consistent documentation of preferences. One of the first to be introduced in Asia, “Living Matters” was adapted from the Respecting Choices® programme in the Gunderson Health System in Wisconsin, US. In the US, the programme was associated with improvements in patient-surrogate congruence (Song et al., 2005); and also resulted in a 98% compliance with treatment preferences of 540 decedents (Hammes & Rooney, 1998).

There have, however, been a surprisingly small number of evaluation studies that have systematically examined whether end-of-life care preferences, stated as part of ACP, have been adhered to. In a systematic review of 55 studies examining the efficacy of ACP (Houben, Spruit, Groenen, et al., 2014), only three studies measured and reported the level of concordance with treatment preferences (K. Detering, A. D. Hancock, M. C. Reade, & W. Silvester, 2010; Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2010; Morrison et al., 2005). Given that the goal of ACP is primarily to "ensure that individuals receive medical care that is consistent with their values, goals and preferences during serious and chronic illness” (R. L. Sudore, Lum, et al., 2017), the paucity of evaluation studies examining whether choices were respected represents a significant gap in current ACP evaluation frameworks.

Among the published studies, ACP was found to be associated with a higher concordance rate of end-of-life care wishes in older persons ((K. Detering et al., 2010), and in individuals diagnosed with congestive heart failure and end-stage renal disease (Kirchhoff et al., 2010). In terms of preferences related to CPR, the results were mixed. Kirchhoff et al. did not find any statistically significant difference (Kirchhoff et al., 2010), while Morrison et al. reported better adherence with CPR preferences when comparing the effects of a multicomponent programme that trained social workers to counsel nursing home residents about end-of-life care decisions against usual care (Morrison et al., 2005). In a hospice study conducted in England, 75% of patients who completed their ACP eventually achieved their choice of place of death (Abel, Pring, Rich, Malik, & Verne, 2013). Conversely, in a US study, individuals (enrolled in a hospice service) who preferred to die at home were more likely to die at home, especially when supported by home hospice care (Jeurkar et al., 2012).

In the aforementioned studies, the occurrence of treatment procedures at the end-of-life were ascertained through medical records review, and supplemented by surveying attending nurses (Morrison et al., 2005) or surrogate family caregivers or decision-makers (Kirchhoff et al., 2010). Other studies examined concordance outcomes associated with DNR (Phua et al., 2011), AD, and end-of-care discussions (Alexi A. Wright et al., 2010) have relied on similar methods. However, such data collection approaches could be time-consuming, and might not be scalable to population-based evaluations. The literature suggests that studies with large sample sizes have primarily examined concordance with only the place of death (Fromme, Zive, Schmidt, Cook, & Tolle, 2014; Hurley et al., 2017). In a recent publication by Turley et al., the authors advocated for, and demonstrated the utility of, defining end-of-life care events based on medication and procedural codes that were captured routinely as part of electronic medical records documentation (Turley, Wang, Meng, Kanter, & Garrido, 2016). This approach allowed a systematic assessment of the level of concordance between documented preferences and actualised end-of-life care treatments.

Since its implementation, the outcomes of "Living Matters" has not been evaluated nationally. Discussions about death and dying are considered taboo with little communication about these preferences between family members. Doctors are also often requested to withhold poor prognosis from patients by their families (J. Tan & Chin, 2011). Little research has been conducted in Asian settings regarding the effectiveness of ACP in promoting adherence with individual treatment preferences. To support a population-based assessment of the outcomes, we aim to explore the use of routinely collected administrative data at the national level, to compare preferences against actualised outcomes. We identified incidences of life-sustaining treatments from inpatient clinical procedural codes and diagnosis-related codes. Hospital, nursing home, and hospice records were used to identify the transitions in care, and data from the national death registry were used to identify the place of death.

8.2 Methods

8.2.1 Study design and population

As mentioned in chapter four, different ACP processes and documentation requirements are applicable to adults who are healthy, diagnosed with complex chronic illnesses, or diagnosed with a life-limiting or advanced illness. This paper focuses on the last group. "Living Matters" was first implemented in acute care hospitals aimed at individuals diagnosed with advanced illnesses. Therefore, there was a sufficiently large sample size that allowed for further analysis. Further, due to the mortality rates within this group (64.5%) as compared against those who are healthy (8.8%) or chronically ill (20.4%), it was possible to compare actual outcomes against the documented preferences.

A retrospective cross-sectional design was adopted to profile the end-of-life preferences of deceased individuals, and to ascertain the extent of concordance between stated preferences and end-of-life care. Individuals who had completed their ACP and died between 2011-2015 were included.

8.2.2 Data source

It can be observed from chapter seven that there are three predominant ways that ACP is being organised and implemented in acute care hospitals in Singapore. However, across the different locations, trained facilitators, who may not necessarily be medically trained, support patients and their families to discuss and document their future choices about health care. The preferences were then documented in an ACP form that specifies preferences about cardiopulmonary resuscitation during cardiopulmonary arrest, and preferences about intubation, mechanical ventilation, cardioversion, and transfer to intensive care. The patient was also asked about their preferred place of medical treatment or care if their medical condition were to deteriorate. Lastly, the preferred place of death (nursing home, acute hospital, home, inpatient hospice, no preference) was also documented. The completed form was then uploaded into the National ACP IT system, and/or the electronic medical records of the individual hospitals.

We extracted ACP participant profile and preference data from the above databases. Other data variables were obtained from the Ministry of Health: acute hospital diagnosis, procedural, and service codes were extracted from administrative databases that captured case mix information from all public-sector hospitals in Singapore; long-term care service usage was extracted from administrative databases that captured information for individuals who received government subsidies for services provided by dialysis centres, day care centres, home care providers, nursing homes and inpatient hospices; and place of death data were extracted from the national death registry. To safeguard data confidentiality, a project-unique identifying number was generated for each NRIC number that identifies every Singapore resident, and was used to link data across datasets.

8.2.3 Preference statements

The ACP document contains information about individual preferences related to the administration of CPR, decisions related to medical intervention (comfort care, limited additional interventions, full treatment), place of care, and place of death. Full treatment takes into account intubation, mechanical ventilation, and cardioversion. Management may also include transfer to intensive care if indicated. Limited additional interventions include comfort measures, and may include oral or intravenous medications. While non-invasive ventilation support is acceptable, endotracheal intubation or long-term life support measures, including admission to intensive care units, are not. Lastly, comfort measures included reasonable measures made to offer food and fluids. Medications, oxygen and other measures may be used as needed for comfort, but this does not include procedures considered under full treatment and limited additional interventions.

Other preferences, however, could reflect sequential options. For the preferred place of medical treatment or care, individuals could opt for home, hospice, nursing home, hospital, and a trial of treatment in their own home or nursing home or hospice, before considering transfer to hospital or hospice. The documentation also allowed the individual to indicate “no preferences” or “others”. We have mapped out 10 permutations within place of care. For place of death in the event of deterioration, individuals could choose their home, the hospital, hospice or nursing home. They could also state two or more alternatives, such as home or hospital, and home or nursing home or hospital. A “no preference” option was also available.

8.2.4 End-of-life care events

To identify incidences of tracheostomy, intubation, mechanical ventilation, non-invasive ventilation, electrical cardioversions, and CPR, we used a combination of ICD-9-CM, Diagnosis-Related Group (DRG), and the Australian Classification of Health Interventions (ACHI) codes. First, two researchers with training in health services research created the initial list of codes, based on a combination of a literature review (Barnato et al., 2009) and checking through the relevant code books. Second, three physician-researchers independently reviewed the list of procedure and diagnosis-related codes for final inclusion. The timeframe used for collating the information were 14-, 30-, and 90-days prior to death. (Refer to appendix 16 for the codes used.) Although the reliability of the coding has not been explored or ascertained, we expect the DRG codes to be reliably coded, since this is monitored by MOH, as part of the annual review of healthcare utilisation and performance (Haseltine, 2013).

To locate the places that care was received, we identified admissions to inpatient acute care facilities, community hospitals, nursing home, and inpatient hospices. Records of utilisation of home care (medical, nursing, palliative care), and day care services were used to determine whether the patient was cared for at home. In addition, if we could identify no formal care service usage, we assumed that the patient was cared for at home. Given that an individual could access and consume different types of services at various sites prior to death, we first ascertained the sequence of health service usage, based on the date of admission or attendance and date of discharge, whichever is applicable for the service type, in the 14-, 30-, and 90-days prior to death.

To identify the actual place of death, the official classification of "residential home", "nursing home and clinic", "public and charitable institutions" (aged care facilities), "licensed sick receiving house" (inpatient hospices), and "others", were extracted.

8.2.5 Concordance mapping

The four ACP preferences (CPR, full treatment, limited additional intervention, comfort measures) were mapped onto eight end-of-life care procedures or treatments (Figure 8.1), which were each coded dichotomously. For each patient, concordance occurred when recorded end-of-life care treatments matched the documented preferences of full treatment, limited additional interventions and comfort care. For example, if the patient had opted for comfort care, but had received tracheostomy and/or mechanical ventilation (MV) and intubation and/or non-invasive ventilation or CPR, this would have been identified and coded as a non-concordant case. For each patient, the date difference between the procedure administration and date of death was also computed, to ascertain concordance at 14-, 30-, and 90-days prior to death. Our mapping algorithm is, however, limited, because a lack of concordance for individuals who opted for full treatment or limited additional intervention could reflect low clinical need, rather than discordance.

To compute the level of agreement for place of care, where preferences could be for a single site, or be conditional for everyone, we mapped the actual care transitions to the preferred place of care, as indicated by the ten identified possible permutations. Concordance is achieved when the preceding-succeeding relationships were met. For example, the location(s) of care would be considered concordant with the preference to receive "a trial of treatment in their homes before considering transfer to a hospital", if the care transition reflected that the patient had received medical, nursing or palliative care at home, before being admitted to an acute hospital. (Refer to appendix 17 for an illustration of the approach.)

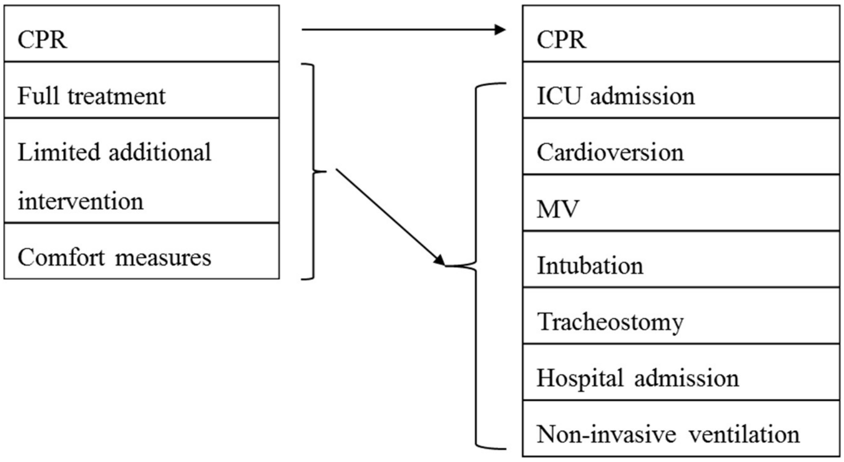


Figure 8.1 Preferences mapped to end-of-life care treatments.

CPR: Cardiopulmonary resuscitation; ICU: Intensive care unit; MV: Mechanical ventilation

For the place of death, concordance was determined by comparing the place of death category with the stated preference. For any preferences that included two or more options, we have considered agreement using a summative approach. For instance, there is concordance with the preference “home or hospital” if the patient had either died at home or in an acute hospital. Data on individuals who had stated “unsure”, “no preference” or “depends on the situation for place of care or place of death” were not considered in the computation of the level of agreement.

All data analyses were carried out using Stata version 12 (StataCorp, 2011).

8.3 Results

8.3.1 Patient demographics and stated preferences

The demographics of the 1,731 decedents are summarised in Table 8.1. Almost two in three persons in this sample were aged 75 years and above. Females account for half of the sample, and individuals of Chinese ethnicity were over-represented in this sample, compared with the national average (83% versus 77%) (Department of Statistics). In terms of preferences, more than 90% opted for "no CPR during cardiac arrest and is not breathing or has no pulse". Only 44 out of 1,731 patients opted for full treatment, with the remaining stating a preference for limited additional interventions or comfort measures. Approximately 46% would prefer to receive care at home or to have a trial of care at home, before considering care in the hospital, and 24% outrightly preferred to be care for in the hospital. For the preferred place of death, approximately 40% expressed a distinct preference to die at home, and about 30% chose an institutional setting (hospital, nursing home, hospice) as their preferred place of death. While only 5% of the sample had no preferences, or were unsure about the place of care, 23% indicated they had no preference, or were unsure about the place of death.

Table 8.1 Demographics and documented PPC preferences of decedents.

Variables	Number (%)
Age group (years)	
< 45	30 (1.7)
45 – 54	75 (4.3)
55 – 64	181 (10.5)
65 – 74	306 (17.7)
≥ 75	1,139 (65.8)
Gender	
Male	902 (52.1)
Ethnic group	
Chinese	1,447 (83.6)
Malay	160 (9.2)
Indian	96 (5.6)
Others	28 (1.6)
CPR	
Attempt	56 (3.2)
Do not attempt	1,661 (96.0)
Unsure	14 (0.8)
Medical treatment	
Full treatment	44 (2.5)
Limited additional intervention	1,160 (67.0)

Table 8.1 Demographics and documented PPC preferences of decedents.

Variables	Number (%)
Comfort care	514 (29.7)
Unsure	13 (0.8)
Preferred place of medical treatment or care	
Home	193 (11.1)
Hospital	407 (23.5)
Hospice	122 (7.0)
Nursing home	129 (7.5)
Trial of treatment at home before transfer to hospital or hospice	458 (26.5)
Trial of treatment before transfer to hospital	
Home	142 (8.2)
Hospice	35 (2.0)
Nursing home	159 (9.2)
Others (no preferences, unsure)	86 (5.0)
Preferred place of death	
Home	680 (39.3)
Hospital	214 (12.4)
Hospice	133 (7.7)
Nursing home	120 (6.9)
Home or hospital	46 (2.7)
Home or hospice	12 (0.7)
Hospital or hospice	27 (1.6)
Hospital or nursing home	73 (4.2)
Hospice or nursing home	10 (0.6)
Other combinations	17 (1.0)
Others (no preferences, unsure)	399 (23.0)

CPR: Cardiopulmonary resuscitation

8.3.2 Agreement between preferences and actual outcomes

Table 8.2 presents the level of agreement, in terms of medical treatment. The level of concordance for individuals who opted to receive comfort measures were close to 98%. The agreement between preferences for CPR, full treatment, and limited additional treatment and actual treatments was very low, but as clinical need or judgement was not ascertained in this retrospective database study, it might not reflect concordance.

Table 8.2 Concordance with medical treatment, by time prior to death.

Preferences	Number	Concordance by time prior to death (%)		
		14-days	30-days	90-days
CPR				
Did not prefer	1,679	100.0	100.0	100.0
Medical interventions				
Prefer full treatment	44	9.1	20.5	31.8
Prefer limited additional treatment	1,160	31.1	55.9	79.5
Prefer comfort measures	514	99.6	98.8	98.1

CPR: Cardiopulmonary resuscitation

The level of agreement between preferred and actual place of care is reflected in Table 8.3. Of the 193 (11%) individuals who wished to be cared for at home, 57-65% received care at home. Among the 458 (26%) patients who wished for a trial at home before admission to the hospital, close to half met their preferences. Four hundred and seven individuals (24%) wished to be cared for in the hospital. The percentage of concordance with hospital care ranged from 68% at 14-days prior to death to 90% at 90-days prior to death. Among individuals who opted to only receive care in an inpatient hospice or to have a trial of care in the hospice before transfer to the hospital, between 35% and 40% received preference-concordant care. Close to 50% of individuals who opted for care in the nursing home or a trial in nursing home before admission to the hospital met their preferences, and the concordance reached 100% if the move occurred towards the timeframe of 90 days before death.

Table 8.3 Place of care concordance, by time prior to death.

Preferred location	Number	Concordance by time prior to death (%)		
		14-days	30-days	90-days
Home	193	65%	63%	57%
Hospital	407	68%	78%	90%
Hospice	122	35%	35%	35%
Nursing home	129	58%	58%	100%
Trial of treatment at home before transfer to hospital or hospice	458	56%	53%	48%
Trial of treatment before transfer to hospital from				
Home	142	59%	53%	49%
Hospice	35	37%	37%	40%
Nursing home	159	50%	51%	100%
Others (no preference, unsure)	86	-	-	-

From Table 8.4, we observe that the overall concordance with place of death preferences is 50%. The rate of concordance was lower for individuals who opted for a single location, compared to those who preferred more than one alternative. Nearly forty percent of the deceased individuals had opted to die at home. Among them, 51% achieved their wishes; whereas 76% of those who opted for home or hospital and home or hospice had their preferences fulfilled. However, a lower level (45%) of concordance was observed among those who wished to die in the hospice or nursing homes.

Table 8.4 Place of death concordance.

Preferred location	Number	Concordance
Single option	1,147	48%
Home	680	51%
Hospital	214	54%
Hospice	133	45%
Nursing home	120	22%
Multiple options	185	57%
Home or hospital	46	83%
Home or hospice	12	50%
Hospital or hospice	27	69%
Hospital or nursing home	73	51%
Hospice or nursing home	10	45%
Others	416	-
Others (Relative's home, healthcare institution, three or more options)	17	-
No preferences or unsure	399	-
Total	**1731**	**50%**

8.4 Discussion

Administrative data, collected at the national level, were used to evaluate whether care received by an individual was in agreement with their goals and preferences. One of the strengths of our approach is its declarative nature, where the mapping of preferences to actual care and the determination of concordance are explicitly defined, rendering the process repeatable. Concordance with the goals of care has been recognised as a key ACP outcome measure by an international consensus study (Rietjens et al., 2017); but the usual methods for ascertaining concordance through medical records review could be costly. When family members or healthcare professionals were surveyed post-bereavement, recall bias might reduce the accuracy and reliability of the outcomes. These methods also do not support outcomes monitoring at the system level. With stronger reliance on electronic medical records, eventually, algorithms can be designed and implemented to determine individual-level concordance.

The level of agreement, in terms of preferences for CPR and comfort measures, was found to be very high among the deceased population who completed their ACP. The treatment concordance for participants who have opted for full or limited additional treatments were relatively lower. Another study found that the rates of intubation and defibrillation/electrical cardioversion among a sample of 683 inpatient decedents was 10.1% in the last 24-hours of life (Phua et al., 2011), which is comparable to the 9.1% who received full treatment (intubation, mechanical ventilation, and cardioversion) in the 14-days prior to death in our study.

In terms of the level of agreement with place of care, there were differences depending on the timeframe of analysis. Invariably, we introduced more episodes of institutional care as the timeframe of analysis moved further away from the time of death. This reduces the concordance with home as one of the preferred place of care, while at the same instance, concordance increases for institutional care. There is no consensus in the literature on the timeframe to consider for the computation of concordance with this set of preferences. Furthermore, to the best of our knowledge, no published studies have examined concordance with the preferred place of care.

Using the location of death recorded in the death certificates, we found that approximately 50% of the sample died at their preferred place of death. The percentage of individuals with a home preference dying at home (51%), is double that of the national share of deaths at home (25%) (Immigration and Checkpoints Authority Singapore, 2015). Our results fell within the range of 33% to 67%, reported by studies conducted in Australia (Agar et al., 2008), Italy (Beccaro et al., 2006), and the US (Bakitas et al., 2008; Fischer, Min, Cervantes, & Kutner, 2013; Tang & McCorkle, 2003). Factors influencing concordance with place of death preferences could be multi-factorial, and often non-modifiable (Costa et al., 2016).

The concordance rate in our study was relatively lower for individuals who favoured hospices or nursing homes as compared to those who preferred other locations. This contrasts with the findings by Agar et al., who found 77% and 64% concordance for palliative care patients who preferred to die in a hospice or aged care facility, respectively. The availability of home care and alternative care facilities within each country or geographical region can influence concordance rates. In Singapore, the projected expansion of home palliative care places, from 5,000 in 2014 to 6,000 in 2020, could support individuals and families to fulfill this wishes to die at home (Gan, 2014). Similar efforts to expand the capacity of nursing homes and hospices will likely increase the concordance with the wishes of patients who prefer these facilities as their place of death (Gan, 2014).

8.4.1 Policy & research implications

There is a substantial research gap pertaining to the measurement and assessment of whether preferences are met. We would recommend future work in this area to improve our understanding of the importance of and the meaning placed by healthcare professionals, patients, and their family members on achieving concordance for each category of preferences. For instance, do they place equal weightage on achieving concordance with medical treatments and place of medical treatment or place of death.

With the anticipated expansion of the ACP programme from the coverage of 10,000 (Gan, 2017) to 25,000 Singaporeans from 2017 to 2020 (Chee, 2017), there needs to be a cost-efficient and reliable method for ascertaining the effects of policy in respecting the wishes of the participants. In this study, we have illustrated administrative data that can support the assessment of population-level concordance with preferences stated in an ACP. This approach can be generalised to other healthcare systems, using similar coding mechanisms. With the advent of electronic medical records, text-mining techniques could be applied to enable a systematic monitoring of outcomes at the population level. However, this must be accompanied with further validation to ascertain the degree of potential misclassification, and over- and under-coding for life-sustaining treatments in the routine coding of data. Additional data including service codes for intravenous medications, antibiotics, and artificially administered nutrition should be included for future studies. In addition, further research is required to facilitate the development of reliable and valid measurement tools, especially in terms of agreement with the preferred place of care (R. L. Sudore, Heyland, et al., 2017).

8.4.2 Study limitations

Potential limitations of this study include the use of administrative data to determine the incidence of life-sustaining treatments. The current method, although useful for determining the extent of concordance for comfort treatment, can be limited in determining concordance for individuals who opted for full and limited additional treatments, because the use of aggressive treatment needs to be clinically indicated. We were also unable to conduct a systematic assessment of clinical relevancy in this study (K. Detering et al., 2010; Kirchhoff et al., 2010).

This approach is still at an early stage of development, and needs to be further validated (Luta et al., 2015). Since we have relied on documented preferences, we were unable to account for shifts in patient preferences that were not documented. Future research could compare the accuracy of relying on administrative database versus other methods of data collection, such as health care professional reports, bereaved family member surveys, and medical records review.

8.5 Conclusion

Routinely-collected data on healthcare service utilisation and place of death can support the assessment of concordance between end-of-life care preferences and actual treatments. Administrative data could provide a cost-efficient and powerful method for assessing the outcomes for a large population-based sample, compared to traditional methods, such as medical records review and key informant interviews. Therefore, further research is required to validate this method to move towards a data-driven approach for ACP outcomes monitoring and assessments.

Chapter 9 A Propensity Score-Matched Evaluation of ACP

Abstract

Comparing individuals who had completed an ACP documentation to a group of non-participants, this chapter assesses the impact of ACP on the likelihood of home deaths, as well as the incidence of life-sustaining treatments. Hospital resource use was also compared.

The intervention group comprised adult decedents (aged ≥21 years) who were diagnosed with advanced illnesses at ACP completion. The comparator group comprised propensity-score matched decedents who did not complete an ACP exercise. Programme effects for decedents with cancer diagnosis, and those without, were separately estimated.

Overall, shares of CPR, MV, and ICU admissions were reduced. ACP was linked to a higher likelihood of dying at home among the non-cancer group (OR: 2.01, 95% CI 1.62-2.50). While no significant differences in the number of hospitalisations and ED attendances were found in the cancer group, significant reductions were observed in the number of hospitalisations (Incident Rate Ratio (IRR): 0.91; 95% C.I. 0.84-0.98) and emergency department (ED) attendances (IRR: 0.89; 95% CI 0.82-0.97) in the non-cancer group. No significant differences in hospital LOS was found.

Discussions about end-of-life care could have encouraged patients, families and healthcare professionals to work towards their stated goals, regarding place of death and the intensity of treatment. Our results indicate that the incremental effect of ACP is dependent on the existing practice of care, and more research is required to understand its causal mechanism vis-à-vis palliative care.

9. Propensity score-matched ACP impact

9.1 Background

The application of aggressive measures, such as artificial ventilation at the end-of-life, has contributed to poorer patient quality of life (Zhang et al., 2009), less ability to cope with grief and loss for family members (A. A. Wright et al., 2010), as well as higher healthcare cost (Calfo et al., 2004). Many seriously ill individuals may not wish to undergo intensive treatments that have low probabilities of extending one's life and, on the contrary, may lower the quality of their last days of life. However, they may not be able to convey their desires at this late stage. Such preferences often remain unknown to the healthcare system or their family members – who may be uncertain whether their decisions are aligned with the patient's values and aspirations. This, in turn, could impose long-lasting negative effects, such as feelings of stress and guilt for substitute decision-makers (Wendler & Rid, 2011). Therefore, to mitigate these challenges, individuals are increasingly choosing to make advance decisions regarding medical treatment, place of treatment, and place of death.

Through the conduct of a succession of conversations, ACP aims to assist individuals, their loved ones and health professionals to deliberate and talk about their medical options in a non-emergency setting. To be carried out successfully, the ACP process should include proper documentation about advance end-of-life care decisions that support care consistent with patients' wishes across different healthcare settings (Hickman, Hammes, Moss, & Tolle, 2005). While ACP has been adopted in countries such as the USA, Australia, Canada, and the UK, where personal autonomy is highly valued, it is a relatively new concept in Asia. Its cultural relevancy has been challenged in societies where talking about death is culturally taboo (Searight & Gafford, 2005), and where familial decisions supersede self-determined ones (L. K. Krishna, Watkinson, & Beng, 2015; Shin et al., 2016; K. Tay et al., 2017). Results of studies conducted on frail adults residing in nursing homes in Hong Kong and Singapore (H. Y. Chan & Pang, 2010; Teo et al., 2014), however, provided preliminary evidence of the potential for ACP to improve communication about care preferences in Asian populations.

In 2011, Singapore became one of the first Asian countries to adopt ACP nationally. The national programme “Living Matters” was modified from the Respecting Choices® programme at the Gundersen Health System in the US (How & Koh, 2015), where it has led to improvements in patient-surrogate congruence regarding end-of-life care decisions (Song et al., 2005), stronger agreement with patients’ preferences, and more satisfaction with end-of-life care (Hammes & Rooney, 1998; Hammes et al., 2010). As one of the world’s most rapidly ageing countries, the number of Singaporeans aged 65 years and above will double by 2030 - from one in eight to one in four (Gan, 2015). As one of the government’s strategies to support successful ageing, “Living Matters” aims to cultivate public consciousness in and acceptance of conversations about death and dying in the population, and to facilitate planning for future medical exigencies (Gan, 2014). Recognising the prominence of the family in decision-making, the local programme also strongly encourages family participation in the conversation.

Research findings suggest that ACP is linked to higher concordance between preferred and received care (Houben, Spruit, Groenen, et al., 2014), better quality of end-of-life care, and higher use of hospice care (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). Although we often encounter a sharp increase in healthcare cost in the final year of one’s life (Calfo et al., 2004; Kelley et al., 2011), the increased spending may not result in a higher quality of care for the patient (Huynh et al., 2013). On the contrary, higher costs stemming from the use of more intensive treatments were linked to a poorer quality of death (Zhang et al., 2009). Better understanding one’s preferences has helped to reduce the use of life-sustaining procedures, and unnecessary intensive care unit (ICU) admissions (Brinkman-

Stoppelenburg et al., 2014; Houben, Spruit, Groenen, et al., 2014). ACP has also been found to increase the chances of achieving a home death (K. Detering et al., 2010; Ratner et al., 2001; Schamp & Tenkku, 2006; Teno et al., 2007).

Using data from a national programme, this study contributes to existing literature by examining the outcomes of ACP in a multicultural Asian country. In this paper, we assessed whether the participants of the ACP programme had a higher likelihood of dying at home, compared to non-participants. In addition, we also assessed the impact of the programme on healthcare utilisation, especially life-sustaining treatments and ICU admissions, which may not confer significant survival or quality of life benefits to the patient, close to the end-of-life. Other outcomes, such as hospital admissions and ED attendances, which are commonly tracked in other studies, will also be examined (Brinkman-Stoppelenburg et al., 2014; Houben, Spruit, Groenen, et al., 2014). We also investigated the heterogeneity in effects across cancer and non-cancer sub-groups to account for differing disease trajectories or disease-related practice patterns that could have influenced the results (Tangka et al., 2015; Zhang et al., 2009).

9.2 Methods

9.2.1 ACP in Singapore

Similar to countries such as the UK (Hayhoe & Howe, 2011), US (Detering & Silveira, 2017), and Taiwan (S. Y. C. Cheng, C.Y.; Chiu, T.Y. , 2016), Singapore first adopted a legislative approach by passing the Advance Medical Directive Act (AMDA), to safeguard individuals' preferences to forgo extraordinary life-sustaining treatment, in 1996 (Leng & Sy, 1997). Since then, paralleling the global movement, emphasising a communications approach of an iterative process of sharing, discussing, and decision-making on end-of-life care goals between individuals, families and healthcare providers (Sabatino, 2010), the "Living Matters" programme was launched in 2011. Just like in the UK (Claire Henry, Seymour, & Ryder, 2007), Singaporeans are able to make a non-legally binding statement of preferences as part of "Living Matters", or opt to complete a legally-binding advance medical directive to indicate refusals of life-sustaining treatments.

"Living Matters" was first implemented across eight different public-sector hospitals, before its subsequent expansion in 2015 to include community-based social care providers. The goal was to raise community awareness of ACP; engage and train facilitators to carry out ACP; and strengthen health and social care systems for ACP implementation. The programme targeted healthy, chronically-ill, and individuals with advanced illnesses. These patients are usually referred for ACP by their attending clinicians. A trained facilitator would conduct the discussion, sometimes in collaboration with the attending physician, with the patient and/or family members. The patient is guided to reflect upon their life experiences, goals, values, and beliefs, and for those who are in advanced stages of their illnesses, they were subsequently asked to make decisions relevant to CPR, extent of medical care, preferred place of care and death in the event of decisional incapacitation. These preferences are documented, uploaded and shared on a national IT platform (R. Y. Chung et al., 2017).

9.2.2 Study design

A retrospective quasi-experimental study design was adopted. The expansion of the ACP programme between 2011 and 2015 created a natural experiment, which allowed the use of a propensity score-matched analysis to examine the outcomes of interest. The intervention group comprised individuals: (i) aged 21 years and over, (ii) had completed the ACP form for those with advanced illnesses, and (iii) died between 2011 and 2015. The comparator group comprised propensity-score matched decedents who did not complete an advance care planning exercise. We separately estimated the programme effects for decedents with a cancer diagnosis, and those without. The diagnosis of cancer was defined using ICD-9-CM and ICD-10-CM codes (refer to appendix 18 for the cancer diagnoses codes) on a three-year lookback on all principal and secondary diagnosis codes for all hospital admissions incurred by the individual.

9.2.3 Data source

To assemble the required data variables, different administrative databases, that captured ACP participant profile and preferences, ED attendances and inpatient stays in public sector hospitals, inpatient and home hospice care utilisation for individuals who qualified for government subsidises, and death-related data from the National Registry of Birth and Deaths, were linked. To safeguard data confidentiality, a project-unique identifying number was generated by a third-party vendor, for each NRIC number that identifies each Singaporean resident, and was used to link data across datasets. (refer to appendix 19 for the steps taken to collate the data.)

9.2.4 Exposure variable

The exposure of interest is the completion of ACP or more specifically, the PPC form intended for those with advanced illnesses between 2011 and 2015. Completion was defined by the publication of a statement of preferences in the national ACP IT system. Non-participants comprised individuals who did not complete the documentation for the statement of preferences.

9.2.5 Outcome variables

The outcomes of interest were: (1) odds of a home death, (2) proportion of CPR, and MV, (3) odds of all-cause ED visits, hospitalisations, and ICU admissions, and (4) number of hospitalisations, number of emergency room visits, and the cumulative LOS. A timeframe needs to be defined for the computation of the outcomes. Given that resource use typically escalates near death, healthcare use was ascertained for specific time-points at 1 month (30 days), 3 months (90 days), and 6 months (180 days) prior to the date of death. The last 6 months of life is the most common period of observation as reported in a systematic review that examined end-of-life health services resource use studies (Langton et al., 2014).

Data capturing all inpatient admissions and outpatient encounters at all public healthcare institutions in Singapore were used. To identify whether there were incidences of CPR, and MV, we used a combination of the ICD-9-CM and ICD-10-CM procedural codes, DRG codes, and the ACHI codes. (Refer to appendix 15 for the codes.) The place of death data was classified as: residential home, nursing homes, charitable institutions (hospices), licensed sick receiving house, and other location, in the national statistics database. In our analysis, we have dichotomised the place of death as "hospital" and "non-hospital".

9.2.6 Covariates

Independent variables used in the computation of propensity score, and as risk-adjustors in the multivariable regression, included socio-demographic variables such as age at the point of death; sex (female, male); ethnic group (Chinese, Malay, Indian, and Others); year of death (2011-2015), and subsidy status (private or subsidised), which acted as a substitute for socioeconomic status, and was defined as the discharge ward status of the most recent acute hospital admission episode, prior to death.

Comorbid burden was computed by looking through the primary and secondary inpatient diagnosis codes for hospital admissions in a three-year lookback period. The CCI (Charlson et al., 1986) was computed for each individual observation. The CCI is a weighted prognostic index based on the number and severity of 19 comorbid conditions. It was initially created to predict the 1-year mortality of internal medicine patients. The medical conditions are weighted 1–6, with total scores ranging from 0–37. We categorised CCI scores into four categories: 0, 1, 2 and ≥ 3. In this study, we have adopted a three-year lookback to compute the CCI in a conservative approach, in case there were individuals who were not admitted in the one-year prior to death (G. Chen, 2014; Kim, 2010).

Other independent variables measuring health resource utilisation included: hospital, which was defined as the site that ACP was completed at for the intervention group and for individuals in the comparator group, it was defined as the hospital with the highest admission frequency in the last 3-years prior to death; specialty department, which was defined as the specialty (geriatric medicine, general medicine, and others) that the patient had been most often admitted to in the 3-years prior to death; previous hospital admission, which was defined as hospital admissions 180- and 365-days before death; and cumulative hospital LOS, which was defined as the total number of bed days for hospitalisation 180- and 365-days before death. The length of time between the discharge date and the admission date reflects the LOS; ED visits reflected attendances 180- and 365-days before death; and home palliative care is defined as admission into a home palliative care service 180- and 365-days before death.

9.2.7 Statistical analysis

Propensity score matching

The intervention and comparator groups were matched using the propensity score method, which computed and matched the groups based on the probability of having completed an ACP, conditional on baseline covariates (Rosenbaum & Rubin, 1983). By matching cases with controls using the propensity scores, we are able to imitate the outcomes of randomisation by ensuring the two groups are similar at the baseline

(P.C. Austin, 2011). The propensity score approach has been adopted by previous studies within the field of palliative care, to examine the impact of a home-based programme and end-of-life conversations on inpatient hospital utilisation (C. Y. Chen et al., 2015; Zhang et al., 2009)

For the cancer and non-cancer sample, the propensity scores were separately derived based on a multivariable logistic regression. We have selected the variables to be included based on the strength of their relationship with the outcomes of interest, rather than with exposure. According to Brookhart et al. (2006), this strategy improves the precision of the estimators by adjusting for chance bias or empirical confounding of the data set (Brookhart et al., 2006). We included age, sex, ethnic group, comorbid burden, hospital, subsidy status, and discharge department. Since previous hospitalisations, ED attendances, and home palliative care use could reflect functional and health decline, in turn influencing both exposure and outcomes, we have also added these variables. The variables were: hospital admission (<2 or ≥2), ED attendance (<2 or ≥2), hospital LOS, and home palliative care use (yes/no) at 365-days before death.

Two comparators were matched to one ACP case, using nearest-neighbour matching. In a Monte Carlo simulation, the mean squared error for a 2:1 match was minimised in 84 percent of the simulations, compared with 68 percent for a 1:1 match (P. C. Austin, 2010). Nearest-neighbour matching, based on a caliper of 0.01 of the standard deviation of the propensity score, was used (Connolly & Gagne, 2016; Rosenbaum & Rubin, 1983). ACP and non-ACP participants with propensity scores that fall within a common support region range were included in the analysis, to ensure comparability of the two groups. The PSMATCH2 software (Leuven & Sianesi, 2003) in Stata 12.0 was used.

Bivariable and multivariable analyses

First, the sample characteristics of the cancer and non-cancer groups was described. For continuous variables, the mean and standard deviation were reported. For categorical variables, the number and corresponding proportions were stated. The differences between ACP participants and non-participants were compared using absolute standardised differences (Peter C. Austin, 2009), where a value of 0.1 or less implies that the level of imbalance between the participant and non-participant groups was negligible (Peter C Austin & Mamdani, 2006). Next, for the propensity score-matched samples, a bivariate analysis was done. For dichotomous outcomes, a chi-square test was used to contrast the proportions between ACP and non-ACP groups. For non-normally distributed continuous variables, we compared the distributions using the Mann-Whitney test.

Second, double-adjustment was conducted by adjusting for age, sex, ethnic group, subsidy status, CCI, home palliative care use, previous hospital admission, and the year of death. All covariates that were included to adjust for differences at baseline were simultaneously added into each multivariable regression model.

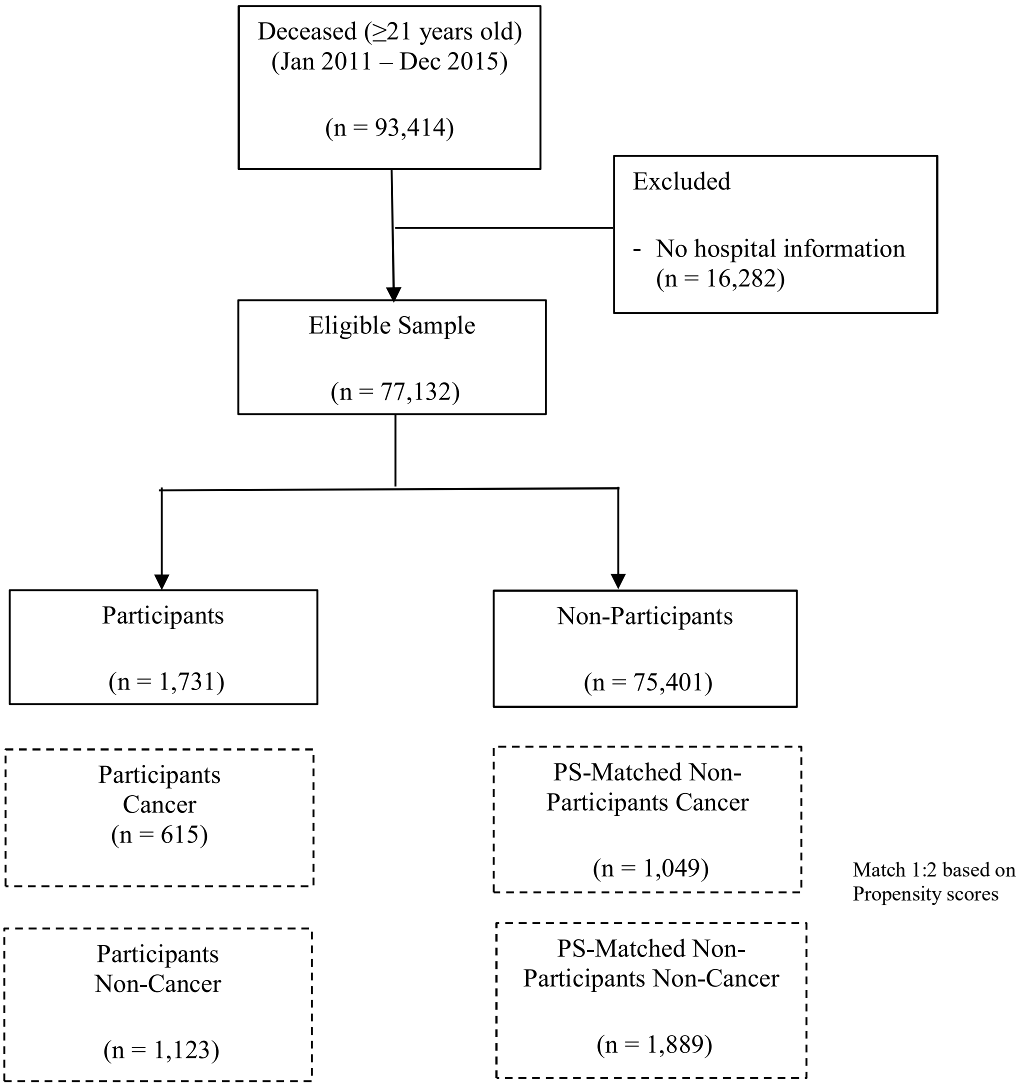
Logistic regression was used to model the impact of ACP on the likelihood of binary outcomes of ICU admissions, ED attendance, and hospitalisation. The odds ratios (OR) and their corresponding 95% confidence intervals (CI) were reported for each association. As mentioned in chapter three, depending on the distribution of the count data (number of hospitalisation and number of ED visits), a GLM model specifying either the Poisson or the Negative Binomial distribution was used. To decide which is more appropriate, a likelihood test was conducted. The adjusted incidence rate ratios (IRR), and the corresponding 95% CI were stated. To compare the health resource use between the intervention and comparator groups, the IRRs were computed as the ratio of the incidence rates at 1 month, 3 months and 6 months before death occurred. GLMs were used for modelling non-normally distributed continuous data, such as length of hospital stay. Although the programme has been implemented in eight different hospitals, a multi-level analysis was not used to address the possibility of nesting, because close to 75% of the cancer and non-cancer samples were derived from two main hospitals.

All statistical tests were carried out using Stata version 12 (StataCorp, 2011).

9.3 Results

9.3.1 Patient characteristics

We identified 1,731 ACP participants and 75,401 potential controls before propensity-score matching. The matched cancer sample comprised 615 ACP participants and 1,049 unique controls, while the matched non-cancer sample comprised 1,123 ACP participants and 1,889 unique controls (Figure 9.1). The characteristics of the unmatched and propensity-score matched samples are shown in Tables 9.1 and 9.2. Compared to the non-cancer ACP participants, the cancer group was younger; a higher percentage was of Chinese ethnicity, had a higher disease burden, with a higher usage of home palliative care. After propensity score matching, patients were well-matched in both cancer and non-cancer groups for all included covariates except for small differences in age and the cumulative LOS in the year prior to death.



Note: (a) Excluding cases from social care (n = 67) as we did not get the appropriate match in the propensity scores; (b) It is not necessary to get exact 2:1 numbers of matched control in K-nearest neighbor propensity score matching analysis.

Figure 9.1 Patient flow diagram for evaluation of ACP.

Table 9.1 Baseline profile of cancer decedents in ACP and control group before and after propensity score matching.

	Unmatched Participants	Unmatched Controls	Matched Participants	Matched Controls	Unmatched Standardised differences	Matched Standardised differences
Number	615	27534	615	1123		
Age, years, mean (sd)	71.87 (13.6)	70.32 (13.1)	71.87 (13.6)	71.62 (13.0)	1.554	0.213
Male, no. (%)	379 (61.6)	15347 (55.7)	379 (61.6)	689 (61.4)	0.059	0.002
Race, no. (%)						
Chinese	989 (88.1)	22888 (83.1)	989 (88.1)	545 (88.6)	0.055	0.009
Malay	70 (6.2)	3032 (11.0)	70 (6.2)	39 (6.3)	-0.047	0.002
Indian	48 (4.3)	1301 (4.7)	48 (4.3)	22 (3.6)	-0.011	-0.011
Others	16 (1.4)	313 (1.2)	16 (1.4)	9 (1.5)		
Comorbidity, no. (%)						
CCI: ≤1	-	-	-	-	-	-
CCI: =2	36 (5.9)	2243 (8.2)	36 (5.9)	62 (5.5)		
CCI: ≥3	579 (94.1)	25291 (91.8)	579 (94.2)	1061 (94.5)	0.023	-0.004
Subsidised status, no. (%)	543 (88.3)	22637 (82.2)	543 (88.3)	983 (87.5)	0.061	0.005
Hospitalisations (≥2), 1-year prior to death, no. (%)	503 (81.8)	20109 (73.0)	503 (81.8)	927 (82.6)	0.088	-0.014
LOS, 1-year prior to death, mean (sd)	47.87 (38.4)	32.13 (30.8)	47.87 (38.4)	46.01 (42.9)	15.742	1.072
ED admissions (≥2), 1-year prior to death	470 (76.4)	18143 (65.9)	470 (76.4)	844 (75.2)	0.105	0.008
Medical department, no. (%)						
Geriatric	140 (22.8)	1723 (6.3)	140 (22.8)	236 (21.0)	0.165	0.005
General Medicine	210 (34.2)	8531 (31.0)	210 (34.2)	366 (32.6)	0.032	0.017
Others	265 (43.0)	17280 (62.8)	265 (43.1)	521 (46.4)		
Home palliative care, 1-year prior to death, no. (%)	248 (40.3)	8396 (30.5)	248 (40.3)	440 (39.2)	0.098	-0.001

CCI: Charlson Comorbidity Index; ED: Emergency Department; LOS: Length of Stay; sd: standard deviation

Table 9.2 Baseline profile of non-cancer decedents in ACP and control group before and after propensity score matching.

	Unmatched Participants	Unmatched Controls	Matched Participants	Matched Controls	Unmatched Standardised differences	Matched Standardised differences
Number	1049	47777	1049	1889		
Age, years, mean (sd)	81.85 (12.28)	76.54 (14.11)	81.85 (12.28)	81.48 (12.01)	5.307	0.131
Male, no. (%)	489 (46.62)	24815 (51.94)	489 (46.62)	901 (47.70)	-0.053	-0.013
Race, no. (%)						
Chinese	857 (81.70)	35877 (75.09)	857 (81.70)	1545 (81.79)	0.066	-0.002
Malay	108 (10.30)	7486 (15.67)	108 (10.30)	197 (10.43)	-0.054	-0.002
Indian	66 (6.29)	3792 (7.94)	66 (6.29)	120 (6.35)	-0.016	0.002
Others	18 (1.72)	622 (1.30)	18 (1.72)	27 (1.43)		
Comorbidity, no. (%)						
CCI: ≤1	476 (25.20)	14379 (30.10)	476 (25.20)	240 (22.88)		
CCI: =2	187 (9.90)	5848 (12.24)	187 (9.90)	108 (10.30)	-0.019	0.003
CCI: ≥3	1226 (64.90)	27550 (57.66)	1226 (64.90)	701 (66.83)	0.092	0.015
Subsidised status, no. (%)	1681 (88.99)	42719 (89.41)	1681 (88.99)	934 (89.04)	-0.016	0.004
Hospitalisations (≥2), 1-year prior to death, no. (%)	813 (77.50)	24528 (51.34)	813 (77.50)	1425 (75.44)	0.262	0.009
LOS, 1-year prior to death, mean (sd)	48.13 (43.57)	27.28 (35.18)	48.13 (43.57)	46.75 (49.47)	20.856	-0.480
ED admissions (≥2), 1-year prior to death	841 (80.17)	28071 (58.75)	841 (80.17)	1473 (77.98)	0.214	0.011
Medical department, no. (%)						
Geriatric	567 (30.02)	6351 (13.29)	567 (30.02)	316 (30.12)	0.168	-0.010
General medicine	997 (52.78)	24013 (50.26)	997 (52.78)	567 (54.05)	0.038	0.016
Others	325 (17.20)	17413 (36.45)	325 (17.20)	166 (15.82)		
Home palliative care, 1-year prior to death, no. (%)	102 (9.72)	1354 (2.83)	102 (9.72)	168 (8.89)	0.069	-0.003

s.d: standard deviation; CCI: Charlson Comorbid Index; LOS: Length of Stay

9.3.2 Bivariate analyses

Compared to non-participants, the place of death was significantly different between the ACP and non-ACP groups (Table 9.3). The percentage of home deaths was substantially higher among ACP participants in the non-cancer sample, but relatively similar in the cancer group. Deaths in the hospices were significantly higher among cancer and non-cancer ACP participants, but it is worthy taking note that almost 1 in 3 individuals with cancer who had completed their ACP died in a hospice, compared with 1 in 8 for ACP participants in the non-cancer group.

Table 9.3 Comparison of place of death between ACP and control group.

Place of death	Cancer Sample			Non-Cancer Sample		
	Participants (n = 615)	Controls (n = 1,123)	p-value	Participants (n = 1,049)	Controls (n = 1,889)	p-value
Home	181 (29.4)	310 (27.6)	<0.001	334 (31.8)	416 (22.0)	<0.001
Hospitals	233 (37.9)	586 (52.2)		516 (49.2)	1,294 (68.5)	
Hospice	185 (30.1)	195 (17.4)		129 (12.3)	106 (5.6)	
Others	16 (2.6)	32 (2.9)		70 (6.7)	73 (3.9)	

The unadjusted results comparing the incidence and units of healthcare use between the ACP and non-ACP groups are reflected in Table 9.4 and 9.5. In both the cancer and non-cancer samples, the ACP group had a significantly reduced proportion of patients who had received CPR, MV, or was admitted to the ICU across the three time-points. For the cancer sample, although the incidences of hospitalisation or, ED attendance were significantly lower at 1 and 3 months prior to death, no differences were detected at 6-months. On the average, the number of ED visits were significantly lower in the ACP group at 1-month prior to death but the number of hospitalisations and cumulative LOS were not. For the non-cancer sample, the incidence of hospitalisation and ED visits were significantly lower only at 1-month prior to death for the ACP group. There was a reduction in the mean number of hospitalisation and ED visits, but the cumulative average LOS did not differ significantly between the two groups.

Table 9.4 Unadjusted health services utilisation and place of death, cancer sample.

Outcome	Measure	Participants	Controls	p-value
1-month before death				
CPR (yes)	no., %	0 (0.00)	14 (1.25)	0.005
MV (yes)	no., %	5 (0.81)	46 (4.10)	0.000
ICU admission (yes)	no., %	7 (1.14)	44 (3.92)	0.001
Hospitalisation (yes)	no., %	342 (55.61)	680 (60.55)	0.045
ED attendances (yes)	no., %	284 (46.18)	626 (55.74)	<0.001
No. of hospitalisations	mean, sd	0.72 (0.03)	0.78 (0.02)	0.081
No. of ED visits	mean, sd	0.60 (0.03)	0.69 (0.02)	0.001
Cumulative LOS	mean, sd	7.40 (0.35)	7.86 (0.26)	0.169
3-months before death				
CPR (yes)	no., %	0 (0.00)	17 (1.51)	0.002
MV (yes)	no., %	11 (1.79)	59 (5.25)	<0.001
ICU admission (yes)	no., %	19 (3.09)	63 (5.61)	0.018
Hospitalisation (yes)	no., %	505 (82.11)	971 (86.47)	0.015
ED attendances (yes)	no., %	473 (76.91)	907 (80.77)	<0.001
No. of hospitalisations	mean, sd	1.69 (0.06)	1.72 (0.04)	0.447
No. of ED visits	mean, sd	1.45 (0.05)	1.51 (0.04)	0.189
Cumulative LOS	mean, sd	21.21 (0.71)	21.23 (0.56)	0.554
6-months before death				
CPR (yes)	no., %	0 (0.00)	19 (1.69)	0.001
MV (yes)	no., %	20 (3.25)	73 (6.50)	0.004
ICU admission (yes)	no., %	33 (5.37)	99 (8.82)	0.009
Hospitalisation (yes)	no., %	585 (95.12)	1069 (95.19)	0.948
ED attendances (yes)	no., %	564 (91.71)	1026 (91.36)	0.805
No. of hospitalisations	mean, sd	2.73 (0.10)	2.55 (0.06)	0.368
No. of ED visits	mean, sd	2.32 (0.08)	2.24 (0.05)	0.864
Cumulative LOS	mean, sd	35.26 (1.14)	33.07 (0.87)	0.011

CPR: Cardiopulmonary Resuscitation; MV: Mechanical Ventilation; ED: Emergency department; LOS: Length of stay; sd: standard deviation

* chi-square test for categorical variables; t-test for continuous variables

Table 9.5 Unadjusted health services utilisation and place of death, non-cancer sample.

Outcome	Measure	Participants	Controls	p-value
1-month before death				
CPR (yes)	no., %	1 (0.09)	43 (2.28)	<0.001
MV (yes)	no., %	14 (1.34)	171 (9.05)	<0.001
ICU admission (yes)	no., %	12 (1.14)	145 (7.68)	<0.001
Hospitalisation (yes)	no., %	583 (55.58)	1185 (62.73)	<0.001
ED attendances (yes)	no., %	602 (57.39)	1250 (66.17)	<0.001
No. of hospitalisations	mean, sd	0.69 (0.02)	0.76 (0.02)	0.001
No. of ED visits	mean, sd	0.73 (0.02)	0.83 (0.02)	<0.001
Cumulative LOS	mean, sd	7.21 (0.26)	7.11 (0.19)	0.310
3-months before death				
CPR (yes)	no., %	2 (0.19)	44 (2.33)	<0.001
MV (yes)	no., %	24 (2.29)	218 (11.54)	<0.001
ICU admission (yes)	no., %	26 (2.48)	212 (11.22)	<0.001
Hospitalisation (yes)	no., %	858 (81.79)	1565 (82.85)	0.471
ED attendances (yes)	no., %	866 (82.56)	1605 (84.97)	0.087
No. of hospitalisations	mean, sd	1.57 (0.04)	1.43 (0.03)	0.104
No. of ED visits	mean, sd	1.62 (0.04)	1.53 (0.03)	0.253
Cumulative LOS	mean, sd	21.0 (0.59)	19.1 (0.44)	0.002
6-months before death				
CPR (yes)	no., %	2 (0.19)	48 (2.54)	<0.001
MV (yes)	no., %	33 (3.15)	241 (12.76)	<0.001
ICU admission (yes)	no., %	40 (3.81)	243 (12.86)	<0.001
Hospitalisation (yes)	no., %	951 (90.66)	1692 (89.57)	0.348
ED attendances (yes)	no., %	956 (91.13)	1734 (91.80)	0.537
No. of hospitalisations	mean, sd	2.39 (0.06)	2.14 (0.04)	<0.001
No. of ED visits	mean, sd	2.48 (0.06)	2.28 (0.05)	<0.001
Cumulative LOS	mean, sd	33.4 (0.89)	31.01 (0.74)	<0.001

CPR: Cardiopulmonary Resuscitation; MV: Mechanical Ventilation; ED: Emergency department; LOS: Length of stay; sd.: standard deviation

* chi-square test for categorical variables; t-test for continuous variables

9.3.3 Multivariable analyses

Cancer sample

Relative to the comparator group, ACP did not result in any statistically significant impact on the odds of home deaths (OR: 1.27, 95% CI 0.97-1.65). The likelihood (Table 9.6) and number of intensive care admissions (Table 9.7) were significantly lower in the ACP group. The logistic regression results indicate that ACP was significantly associated with a lower likelihood of hospital admissions and ED attendances (Table 9.6). However, when we examined the regression results related to the number of occurrences (Table 9.7), no significant between-group differences were observed.

Table 9.6 Effect of ACP on the likelihood of hospitalisations, ED visits, ICU admissions.

	1-month before death		3-months before death		6-months before death	
Cancer	Adjusted OR	95% C.I.	Adjusted OR	95% C.I.	Adjusted OR	95% C.I.
Hospitalisations	0.82	0.65-1.02	0.73	0.54-0.99	0.96	0.57-1.59
ED attendances	0.70	0.56-0.87	0.89	0.68-1.16	1.16	0.79-1.72
ICU admissions	0.24	0.10-0.55	0.46	0.26-0.80	0.52	0.33-0.81
	1-month before death		3-months before death		6-months before death	
Non-cancer	Adjusted OR	95% C.I.	Adjusted OR	95% C.I.	AOR	95% C.I.
Hospitalisations	0.79	0.67-0.94	0.96	0.77-1.19	1.15	0.86-1.53
ED attendances	0.70	0.60-0.84	0.86	0.68-1.08	0.96	0.71-1.31
ICU admissions	0.13	0.07-0.24	0.17	0.11-0.27	0.24	0.16-0.34

ED: Emergency Department, C.I.: Confidence Interval; ICU: Intensive Care Unit; OR: Odds Ratio

Adjusted for: age, gender, ethnic group, home palliative care use, CCI, subsidy status, year of death

Logistic Regression; adjusted OR less than 1 indicates lower chances of ED attendances or hospitalisation for the ACP group relative to the comparator group

Table 9.7 Effect of ACP on the no. of hospitalisations[†], ED visits[†], ICU admissions[†] and cumulative LOS[#].

	1-month before death		3-months before death		6-months before death	
Cancer	IRR	95% C.I.	IRR	95% C.I.	IRR	95% C.I.
Hospitalisations	0.92	0.85-1.01	0.95	0.91-1.00	0.99	0.97-1.02
ED attendances	0.89	0.79-1.00	0.99	0.91-1.08	1.07	0.99-1.16
ICU admissions	0.28	0.13-0.61	0.48	0.29-0.78	0.53	0.36-0.78
LOS	0.95	0.83-1.08	1.04	0.95-1.13	1.11	1.02-1.21
Non-cancer	1-month before death		3-months before death		6-months before death	
	IRR	95% C.I.	IRR	95% C.I.	IRR	95% C.I.
Hospitalisations	0.91	0.84-0.98	0.99	0.95-1.03	1.01	0.99-1.04
ED attendances	0.89	0.82-0.97	1.08	1.01-1.16	1.11	1.04-1.19
ICU admissions	0.15	0.08-0.27	0.21	0.14-0.32	0.30	0.21-0.42
LOS	1.03	0.94-1.14	1.12	1.03-1.21	1.13	1.04-1.22

ED: Emergency Department, C.I.: Confidence Interval; ICU: Intensive Care Unit; OR: Odds Ratio; LOS: Length of Stay
C.I.: Confidence Interval; IRR: Incidence Rate Ratio; RR: Risk Ratio; LOS: Length of Stay
Adjusted for: age, gender, ethnic group, home palliative care use, CCI, subsidy status, year of death
† Poisson Regression/Negative Binomial Regression; incidence rate ratio less than 1 indicates lower incidence rate of ED attendances or hospitalisation for the ACP group relative to the comparator group
# GLM with the logit link function and gamma distribution; risk ratio less than 1 indicates shorter hospital LOS or lower total healthcare cost for the ACP group relative to the comparator group

Non-cancer sample

Contrary to the results for the cancer sample, the odds of ACP participants dying at home was double that of non-participants (OR: 2.01, 95% CI 1.62-2.50). The likelihood (Table 9.6) and number of intensive care admissions were significantly lower in the ACP group. Compared to the results obtained from the cancer sample, the magnitude of reduction in intensive care admissions was larger in the non-cancer sample. The logistic regression results indicated a significant lowering of the likelihood of hospital admissions and ED attendances in the last month before death. The results were also significant when we look at the actual number of occurrences.

There was a 9% reduction in the number of hospitalisations, and the number of ED attendances were lowered by 11% at 1 month prior to death. No significant differences were detected in the prior timeframes. The cumulative LOS did not significantly diverge between the two groups.

9.4 Discussion

In this study, ACP was defined as a professionally facilitated conversation to discuss, and elicit patients' preferences about future medical care that has been systematically implemented across Singapore. We found that systematically implementing ACP was associated with a higher likelihood of home deaths for the non-cancer group. Overall, ACP was linked to a lower utilisation of life-sustaining treatments, including CPR, MV, and being admitted to the ICU. The results pertaining to the associated impact of ACP on acute care resource use was, however, mixed. In the cancer sample, no significant differences between the ACP group and the comparator group were found. In the non-cancer sample, ACP was associated with lower hospitalisations and ED attendances in the 30 days prior to death but the LOS did not differ significantly.

Having an open discussion about one's wishes pertaining to the use of life-sustaining medical treatments in the event of terminal sickness, as well as one's preferred place of death, can act to galvanise support and set forth a series of actions from family members and healthcare professionals to assist the patient to meet his/her goals. The associated higher incidence of home deaths found in our study was similarly reported in other studies (K. Detering et al., 2010; Ratner et al., 2001; Schamp & Tenkku, 2006; Teno et al., 2007). In a recent systematic review, ACP was also found to be correlated with lower utilisation of life-sustaining treatments (Brinkman-Stoppelenburg et al., 2014).

Despite significant reductions in the incidence of life-sustaining treatments, we observed no difference in hospital length-of-stay, in both the cancer and non-cancer samples. Few experimental studies have examined the impact of ACP on healthcare use (J. Dixon et al., 2015). One of these was the landmark SUPPORT trial, which sought to improve end-of-life decision-making by deploying specially-trained nurses to elicit preferences, facilitate ACP and to improve communication between patients and their physicians. The trial, however, failed to detect any significant reductions in healthcare use (Connors et al., 1995). Another RCT found ACP to have reduced the use of intensive care, but there was no significant impact on hospital readmissions (Gade et al., 2008). Other studies that found significant declines in hospitalisations and hospital LOS have been conducted on nursing home residents (Caplan, Meller, Squires, Chan, & Willett, 2006; Levy, Morris, & Kramer, 2008; Molloy et al., 2000; Teo et al., 2014).

9.4.1 Methodological considerations

The recent framework on ACP outcomes, derived from a 52-member Delphi expert panel (R. L. Sudore, Heyland, et al., 2017), included the palliative care services as a moderator between ACP and goals of care, and care utilisation. Unsurprisingly, in a meta-analysis that drew upon data extracted from seven primary studies, home palliative care was found to double the likelihood of dying at home, for individuals with advanced illnesses (B. Gomes et al., 2013), and in a separate systematic review to reduce hospitalisations, although the studies were judged to have a high risk of bias (Kavalieratos et al., 2016). Despite this knowledge, most studies examining ACP effectiveness did not include consideration of the confounding influence of palliative care on health resource outcomes (Molloy et al., 2000; Morrison et al., 2005). To address palliative care as a potential confounder, we have included home palliative care use in the last year of life as a variable in the construction of propensity scores.

From the qualitative results that examined the implementation of ACP in Chapter 7, we observe that process variations exist across hospitals, which might influence the outcomes. Some might argue a hierarchical (multilevel) model should have been used. While this would allow the segregation of the variability across individuals from the variability between hospitals (Leyland & Goldstein, 2001), as a rule of thumb, at least 50 groups to power the analysis (Maas & Hox, 2005). At the time of analysis, our sample size was too small to allow for a multi-level analysis because only 8 hospitals had implemented ACP, and 75% of the observations were contributed by two of the earliest adopters of ACP. Therefore, instead of opting for a multi-level model, we had included hospitals as a variable in propensity score construction, and ascertained that balance in this covariate was achieved across both groups. As more and more health and social care providers support and provide ACP facilitation services, hierarchical modelling could indeed be a useful technique for future analyses.

In our matched sample, approximately 40% of the cancer patients and 9% of those without a cancer diagnosis, in both the intervention and control groups, received home palliative care in the last year of life. This mirrors the development of palliative care in many jurisdictions, including Singapore, where it was initiated to address the care required by cancer patients, with little coverage for non-cancer illnesses (National Strategy for Palliative Care Workgroup, 2011). Discussing goals of care is a cornerstone of palliative care (Bruera & Hui, 2010), which implies that, while the control group did not complete a ACP form, an end-of-life care discussion about preferences could have occurred. The relatively higher percentage of cancer patients who had received home palliative care could have attenuated the incremental impact of ACP on acute care utilisation. Conversely, palliative care development is still in its early phases in Singapore for non-cancer patients. Therefore, having a conversation that ends with a systematic documentation of end-of-life care preferences could have conferred significant reductions in acute care use during the last month of life. Due to greater uncertainty about the trajectories of non-cancer diseases, the attempts to try to meet the care preferences of the patients could only occur when it became clear that the patient is at the end-of-life, where curative care was no longer relevant.

9.4.2 Practice and policy implications

A systematically-implemented and professionally-facilitated ACP can facilitate greater coverage of end-of-life care discussions, especially among the non-cancer group. The results of this study contributed information to support policy-makers in their decisions to expand the outreach and coverage of the ACP programme nationwide. With approximately 20,000 deaths per year in Singapore, of which 6 in 10 are related to chronic illnesses (cancer, heart disease, diabetes, cerebrovascular diseases, renal diseases etc.) (Immigration and Checkpoints Authority Singapore, 2015), the coverage of this programme can be further expanded. In 2017, the government announced the intention to reach out to and initiate ACP conversations with 100,000 Singaporeans (Gan, 2017). Our results suggest that this could support the achievement of a higher quality of life and death for individuals who wish for less intensive forms of treatment.

Examining the impact of ACP on acute care utilisation inevitably raises ethical concerns. Despite this, increases or decreases in resource usage are an unintended consequence of a society's attempt to better meet end-of-life care preferences, and should still be reported and examined. Perhaps clinical audits should be conducted to ensure ACP is focused on eliciting patients' preferences for care, without undue influence to ration healthcare use (Klingler, in der Schmitten, & Marckmann, 2016). Policy-makers could also place greater emphasis on measuring and monitoring other important outcomes, such as satisfaction with care, quality of communication, and quality of care, to allay any fears that might arise.

9.4.3 Future research

The causal pathway between advance care planning, hospice or palliative care, and acute care resource utilisation has not been adequately described in the literature. Exploration of this in future research could attribute the effects more appropriately, to either palliative care or advance care planning. In some instances, ACP is part of a larger palliative care intervention (Levy et al., 2008; Teo et al., 2014), and tends to increase referrals to, and the use of hospice and palliative care (Brinkman-Stoppelenburg et al., 2014). Identifying mechanisms of intervention effects, through the commissioning of pragmatic trials on important outcomes, including health resource utilisation, is an important future area of research. Additionally, research conducted outside of North American settings will be valuable to support policy-makers, as the momentum of ACP implementation grows.

9.4.4 Strengths and limitations

Our study contributes to the literature about ACP by distinguishing its impact on cancer and non-cancer patients. This is also one of the few studies that attempted to isolate the impact of ACP independently of palliative care. In this study, we have also examined the consequences of ACP in terms of the incidence of home deaths, life-sustaining treatment, and acute care utilisation.

Due to the nation-wide implementation of ACP, we have conducted a propensity-score matched evaluation of the programme using a retrospectively determined cohort. This study design limits inferences about causation, and we are also unable to rule out the possibility that unobserved covariates could have influenced the results. Additionally, in adopting a retrospective analytical strategy, we do face the criticism that arguably, if the intervention of interest is life-extending, we might not have captured the additional related cost. However, survival benefits are not associated with the conduct of ACP alone. Additionally, other studies have shown that the look-back approach closely mirrors the results of a look-forward study (Fisher et al., 2003; Skinner, Staiger, & Fisher, 2010).

9.5 Conclusion

Singapore is one of the first Asian countries to introduce ACP, which was founded on the ideals of promoting personal autonomy. Discussions about end-of-life care could have focused patients, families and healthcare professionals towards meeting their stated goals, regarding place of death and the use and intensity of treatment. However, differences in access to palliative care for cancer and non-cancer patients in the local context (also likely in other countries), could have created divergent results regarding its impact on acute care resource use between the two groups. Our results indicate that the incremental effect is dependent on existing practices of end-of-life care, and more research is required to understand its causal mechanism vis-à-vis palliative care.

Chapter 10 Discussion and Concluding Remarks

Abstract

This chapter summarises and discusses the main findings of the dissertation. Plausible reasons, explaining the finding that only 40% of this study sample preferred to die at home, are presented. The potential effect of improving access to home palliative care, facilitating end-of-life care preference elicitation, and ensuring continuity of care in the case of dying at home, are discussed. To increase concordance with home death wishes, enhancing preference elicitation through ACP alone might be insufficient, without larger shifts in organisational and societal norms to proactively support its achievement. Key strengths and limitations of this dissertation are highlighted; practice and policy recommendations are also offered to better support the meeting of place of death preferences. This work has contributed to the understanding of end-of-life care preferences in Singapore; and offered insights into the conduct and effects of ACP in an Asian country.

10.1 Introduction

This chapter consists of six parts. When examining the elicitation of end-of-life care preferences and the influences of place of death, the use of a multiple-methods approach has led to the identification of a multitude of factors, including a detailed evaluation of the ACP programme in Singapore. First, a summary of the main findings of the dissertation is included, before linking the various findings from the earlier studies to provide an overall discussion on how the preferred place of death can be realised. Through a re-examination of the results, synthesising and sense-making insights that extend beyond the limits of previously stated findings were derived. Second, reflecting on the research work that has been done, the overall strengths and limitations of this study are discussed. Third, the potential applications and impacts of the findings on healthcare practices and policies are discussed, which then leads to suggestions about policy and practice changes, as well as aspects of research that should be further explored. Personal reflections about the research was briefly mentioned before finally ending the chapter with concluding remarks for the overall dissertation.

10.2 Discussion of key findings

A point-by-point summary is presented below, before embarking on a discussion of the findings and insights of the earlier chapters, according to the main themes.

- In our study of a national ACP register of patients with documented end-of-life care preferences, only 40% of those diagnosed with an advanced illness had opted for home as the place of death. There was also a general sense that institutional care was unavoidable at the end-of-life.
- These preferences were found to be shaped by one’s life-stage, availability of family support, and personal beliefs and values. Rather than being a wholly autonomous decision made by the patient, inputs from family members and

healthcare professionals strongly influenced one’s decisions regarding end-of-life care.

- Multiple factors (inter)act to contribute to the final place of death. To honour preferences for home death would be a challenging policy aspiration, as many of the influencing factors are non-modifiable, such as socio-demography, one’s financial ability, and the extent of support and commitment from one’s social network to meet his/her wish.
- Policy-amenable factors included greater care continuity within the wider health care system, including support from home palliative care. Having previously stated a home death preference in an ACP document was also strongly associated with a higher likelihood of dying at home. Our results indicated that 51% of decedents with a stated home preference died at home, which exceeds the national figure of 25% of home deaths.
- To expand the outreach of ACP, attention should be paid towards changing public mindsets on conversations surrounding death and dying; and shifting the healthcare culture to one that values and provides care that maximises patients’ quality and quantity of life. Our results indicated that provider organisations who created a shared purpose, built on the ethos of honouring patients’ preferences, staffed by empathetic healthcare professionals with good communication skills, and developed systematic processes with adequate resourcing, were more equipped to implement ACP.
- ACP discussions about end-of-life care could have focused patients, families and healthcare professionals towards meeting stated goals, regarding place of death and treatment intensity. ACP was also linked to reduced utilisation of life-sustaining treatments. For non-cancer patients – who rarely had access to palliative care – the likelihood of dying at home was increased.

10.2.1 Co-creation of preferences

Home is widely assumed to be the "ideal" location for where death should occur. In our study, among a sample of 2,685 individuals (3% of all deaths in Singapore) who had documented their care preferences as part of a national ACP programme, only 40% chose "home" as their preferred location of death. The share of individuals who opted for home was significantly lower than the figure of 77% reported in a 2014 community survey on death attitudes (Blackbox Research, 2014). In the same survey, respondents were asked to consider the situation where there is a lack of support from family members, friends or healthcare professionals. This brought the share of home death preferences down to 58% (Blackbox Research, 2014). The divergence between real-life versus hypothetical decision-making could have contributed to the differences in results.

Surveys often require individuals to respond to a single question about their preferred place of death, based on a hypothetical end-of-life scenario (Barbara Gomes et al., 2013) without having to trade-off against other priorities or account for other than one's personal concerns. Therefore, choices elicited through a survey could reflect what is preferred under more "ideal" circumstances. Since an illness impacts the individual biologically as well as socially (Siminoff, 2013), the survey process may not mirror real-life decision-making processes well (Hoare et al., 2015). Given that the value of autonomy is culturally dependent (Winzelberg, Hanson, & Tulsky, 2005), our study found that family dynamics and role expectations featured strongly in the process of decision-making regarding end-of-life care preferences (Broom & Kirby, 2013).

For those who are estranged from their families, dying at home is not a viable choice. For others, the stated preference for place of death was formed through a process of negotiation between one's personal desires and those of his/her family, which are often intertwined, rather than independent (Borgstrom, 2015). Preferences can also be said to be moderated by the amount of burden perceived to be manageable by family caregivers in the home space. As evidenced in other studies (Beng et al., 2009; Hong et al., 2011; Htut et al., 2007), values built on religious and cultural beliefs and practices contributed to decisions on where one would wish to die.

Rather than being passive facilitators of the preference elicitation process, healthcare professionals can actively influence decisions about end-of-life care through their interactions with the patient and their families. Their professional opinion about the family's ability to fulfill the patient's wish to die at home often resulted in a co-constructed "preference", rather than one that is fully autonomous (Daniel Munday et al., 2009). Given that both the qualitative and quantitative study segments were based on healthcare professionals and patient samples derived from acute care settings, the results may reflect care perceptions dominant in this population. Families and healthcare professionals tacitly acknowledge that care should occur in or be shifted to the hospital, if not well-managed at home. This outlook was likewise reflected in patients' documented preferences. While only 24% of individuals diagnosed with advanced illnesses opted to be cared in the hospitals, another 46% opted for the hospital as a second care site, if care at their first-choice sites turned out to be impractical or sub-optimal.

10.2.2 Levers for change

The current local policy discourse assumes home to be the preferred place of death for the majority. The role of the healthcare sector in supporting patients' choices to die in a familiar environment, surrounded by friends and family, is heavily emphasised. Thus far, experiences from countries, such as the UK and the US, indicated that despite significant changes at the national level in legislation, healthcare financing policies and strategies for end-of-life care, the overall impact on the share of home deaths has been relatively small.

A myriad of factors can influence the final place of death. The results are broadly consistent with Gomes and Higginson's theoretical framework of factors influencing place of death mentioned in Chapter 1. In this dissertation, besides non-modifiable person- and family-level factors, several practice- and policy-modifiable factors have influenced the probability of dying at home. Being a recipient of home palliative care (Costa et al., 2016), and having a documented home death preference in an advance care plan (Josie Dixon et al., 2016), are independently and strongly correlated with a higher likelihood of dying at home. Access to home palliative care has repeatedly been found to strongly influence the place of death. In a Cochrane review, home palliative care was found to more than double the chances of achieving a home death (B. Gomes et al., 2013).

Care delivered at home is dependent on the triadic relationship between the patient, informal caregiver, and the home palliative care professional (McGann, 2011). Having a family caregiver who is able to, and willing to care for the individual, increased the likelihood of dying at home (Costa et al., 2016; Gomes & Higginson, 2006). Those without willing and capable family members often received care in formal healthcare settings. Besides physical and nursing care, family caregivers are intimately involved in the coordination of services across health and social care services, to ensure continuity of care, and to provide emotional support for the dying (Kristjanson & Aoun, 2004). Support from formal networks of care, including home palliative care, is crucial in preventing caregiver burnout and aiding the improvement of their emotional well-being (Horsfall, Leonard, Noonan, & Rosenberg, 2013; Stajduhar, Martin, Barwich, & Fyles, 2008).

Above and beyond home palliative care, the completion of an ACP significantly impacts where one eventually dies. In our comparative effectiveness analysis (Chapter 9), participation in and completion of ACP was correlated with an increased likelihood of dying at home amongst non-cancer patients. When end-of-life care preferences become known, family members and healthcare professionals often act to facilitate their achievement. Despite the fact that ACP is widely thought to support wishes to die at home, there have been few trial-based assessments of its impact (Brinkman-Stoppelenburg et al., 2014). The publication of trial protocols examining the impact of ACP on cancer (Stephanie Johnson et al., 2016), chronic obstructive pulmonary disease (Houben, Spruit, Wouters, et al., 2014), and heart failure patients (C. Malhotra et al., 2016), indicates that new evidence will be added to the discourse in the near future.

It is common for patients to transit across multiple sites of care in the last months of life (S. Y. Wang et al., 2017). The lack of continuity of care appears to compromise the healthcare system's ability to support deaths at home (Wahid et al., 2017). These challenges occur predominantly at intersections between the home and the hospital, as well as between care providers. Poor discharge planning, poor inter-provider coordination and communication, and slow acquisition and high cost of equipment necessary for home-based care, act as barriers against home deaths (Wahid et al., 2017). However, opportunities to improve the quality of care are also present at these intersections. For instance, the timely provision of information and skills training can equip a caregiver with the knowledge to perform basic nursing care in the home. Emotional support from healthcare professionals can also help caregivers to mentally adjust to the realities of home-based caregiving.

10.2.3 Viewing ACP in a wider context

As the work of eliciting and meeting patient preferences is embedded within a wider healthcare ecosystem, the introduction and integration of ACP within routine care processes can be construed as part of a wider paradigmatic shift in the medical model of care. By promoting ACP as a mechanism to get to know individuals and their preferences, it is implicitly assumed that the model of care is person- and relationship-centred. However, the healthcare system in Singapore has not yet fully embraced the biopsychosocial model of medical care (Engel, 1977) - one that promotes active patient participation in clinical decision-making. The attempt to integrate ACP in a curation-focused environment, where physicians are still perceived to be the best persons to decide on the appropriate treatments for the patient (E. Fox, 1997), has been challenging.

Conversations about end-of-life care are deeply personal. Having a healthcare professional familiar to the patient can provide comfort and ensure a trusting environment for the initiation and conduct of an ACP discussion (Covinsky et al., 2000). The lack of relational continuity, revealed in this study, implies that healthcare professionals involved in the care of the patient often do not have a consistent appreciation and understanding of the individual patient's needs (Haggerty et al., 2003). Moreover, the conversation itself is often wrapped up in the routine of curative care, and echoes pre-existing physician-patient communication patterns. In certain cultures such as Singapore (J. Tan & Chin, 2011), families may also prefer to withhold prognostic information from the patient (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Kwak & Haley, 2005). In so doing, it is difficult for healthcare professionals to initiate end-of-life care discussions when the patient is unaware of his/her prognosis.

The results of SUPPORT, the largest trial conducted on end-of-life care, illustrate that isolated interventions designed and implemented with the purpose of improving shared decision-making (Connors et al., 1995) do not lead to better care quality. Instead, systematic changes in mindsets and practices, at the societal and health systems level, are essential for improving end-of-life care (Covinsky et al., 2000). Our results echo these findings, and at the same time, underscore the importance for policy-makers to focus on reframing the physician-patient relationship, from one of paternalism to one that acknowledges patients and their families as partners in healthcare decision-making.

10.3 Strengths and limitations

The strengths and limitations of each study have been presented and briefly discussed in Chapters 4-9. This section consequently focuses on the most important methodological considerations and discusses their strengths and limitations with the perspective of informing the interpretation of the findings, and future research.

10.3.1 Multiple methods

Preference generation and spaces where death occurs often reflect social processes that cannot be satisfactorily explored and understood from a purely quantitative perspective. Through the adoption of a multiple-methods approach, rich quantitative and qualitative data were triangulated to validate our observations about the phenomenon of home death. Findings from the two qualitative studies added insights regarding contextual factors that could not be measured quantitatively in a meaningful manner. Various factors that influenced place of death preferences and its actualisation were examined. This included organisational dynamics and the work involved in implementing ACP.

Results from both the quantitative and qualitative studies reported in Chapters 5 and 6 were generally complementary. Receiving palliative care at home was found to increase the likelihood of home death but health and social care factors interact with family and the individual's health condition to influence whether one is able to receive this care at home. While the quantitative results implied that expanding access to home palliative care could increase the likelihood of dying at home, the qualitative findings highlighted that more focus should be placed on non-cancer illnesses and on frail elderly persons who are not yet well-supported by home palliative care services.

Healthcare professionals recounted that inpatient care was often perceived to be of a higher quality. From this viewpoint, hospitalising an elderly parent fulfils one's filial duty. With its defined role and physical presence, the hospital is also easy to access in the current context where community resources and protocols buttressing care between care providers are lacking in inconsistency to support dying at home. This supported the results from the quantitative study (Chapter 6) where hospitalisation in the last few months of life was significantly associated with a reduced chance of dying at home.

The qualitative data also allowed a more in-depth exploration of gaps not captured in the quantitative study on factors influencing place of death. As routine databases used in this study did not contain information on the level of family support, instrumental or financial, we were unable to examine its relationship with death at home. The qualitative results further illustrated how time and financial constraints as well as emotional unpreparedness of the family can influence the probability of dying at home.

The quantitative results illustrated that ACP was linked to a higher likelihood of dying at home. With the quantitative results alone, it was difficult to appreciate the complexities involved in implementing and integrating ACP in routine clinical care so as to expand its coverage. The qualitative findings in Chapter 7, provided a rich description of the work enacted within the acute care setting. Beyond the work of facilitating a discussion about end-of-life care, the concept and practice of ACP challenges the cultural and hospital norms that it is situated within.

10.3.2 Use of linked national databases

A key strength of this dissertation was the use of large study samples, made possible by tapping on existing administrative databases. While there is immense value in using these sources of data, there are limitations in using data collected for other purposes (e.g. billing, reimbursement) in this research.

Definition of home deaths

In this dissertation, “home death” was defined as a death that had occurred in a private residence. We did not distinguish between whether the death had occurred at the individual’s home, at a family member’s home or elsewhere. This could be an important distinction, as the value of dying in one’s home is correlated with being in a familiar environment where one is comfortable, having control over one’s routine, and being able to share the last moments with their loved ones (Milligan et al., 2016).

This definition of “home death” also did not distinguish between individuals who were cared for and had died at home, and those who were terminally discharged from the hospital to the home when death was near. While the preference to die at home would have been fulfilled in both cases, the latter does not meet the assumption upheld by policy-makers, that individuals prefer to be cared for and to die in a familiar environment surrounded by loved ones. Future studies could include this distinction as terminal discharge, which is a common practice in Taiwan (Y. C. Huang et al., 2009) and Singapore (Beng et al., 2009), as mentioned in Chapter 1 and 2.

Routinely collected data

By accessing and linking records stored across multiple administrative databases, it allowed the examination of the influence of factors related to place of death, such as admissions to aged care facilities and home death preferences, which were not previously examined (Beng et al., 2009; Hong et al., 2011; Poulose et al., 2013). This approach, however, limited the analysis to readily-captured data, and we were unable to include pertinent predictor variables, such as the availability of family support or burden, which were known to influence the place of death (Costa et al., 2016; Gomes & Higginson, 2006; Wahid et al., 2017). While we were unable to quantify the relationship in this study, results from our qualitative study did point to the importance of the family network in supporting deaths at home.

Difficulties have been encountered in defining and measuring whether care delivered indeed met patients' preferred goals of care (R. L. Sudore, Heyland, et al., 2017). Many studies have ascertained concordance through medical records review or surveying of key informants. These are, however, not efficient methods for monitoring population-based outcomes. For the place of death, information is usually available from the national death registers, which allowed for the determination of concordance for large samples (Fromme et al., 2014; Hurley et al., 2017). In this research, a map, linking individual preferences with health outcomes, health service use and place of death, allowed for the assessment of concordance. This approach helped to minimise the level of subjectivity and recall bias involved when using mortality follow-back surveys (R. L. Sudore, Heyland, et al., 2017).

Other studies have likewise utilised routinely-collected data (diagnosis codes, service use codes etc.) to ascertain care continuity (Sharma, Freeman, Zhang, & Goodwin, 2009), care intensity (L. Wang, Piet, Kenworthy, & Dy, 2015), and also concordance with end-of-life care preferences (Turley et al., 2016). Administrative data was found to yield valid and reliable results when assessing the place of death as a quality indicator (Grunfeld et al., 2006). Nonetheless, in the assessment of other outcomes, further validation is required before we have confidence to deploy it in a sustained manner, for population-wide tracking of ACP outcomes.

10.3.3 Observational study design and internal validity

One of the key drawbacks of a retrospective observational design is that the study is unavoidably subjected to several methodological challenges. Confounding bias arises when factors that concurrently affect ACP participation and the outcomes of interest are not adequately addressed. This potentially compromised its internal validity, as we are unable to attribute the observed effects to the participation in ACP alone (Rothman, Greenland, & Lash, 2008). To minimise the effects of confounding bias, propensity score matching was used to construct a comparator group with similar covariate distributions as the ACP group.

Underlying the propensity score method is the assumption that all potential confounders are measured and included in its construction (P.C. Austin, 2011). In using retrospectively-collected data, important confounders might however be omitted. For instance, although the individual's socioeconomic status or functional status might be associated with ACP participation and its outcomes, such data was not available in our assembled dataset. As such, proxy variables were constructed. Hospital ward subsidy status was used to proxy socioeconomic status, as individuals who opted for dormitory style wards tend to differ from those who opted for single rooms, in terms of income. To proxy for functional status, the number of previous hospitalisations was used, because repeated admissions is indicative of functional decline (Ehlenbach et al., 2010; Gill, Allore, Holford, & Guo, 2004).

10.3.4 Qualitative research

The qualitative research segment of this study yielded rich data from a relatively large group of expert informants (n=63), who described the decision-making process in the context of end-of-life care; and how different factors interacted with complex organisational structures and processes to meet one's wish to die at home. A key criticism of this approach was the absence of the patients' and family caregivers' voice and perspective in this analysis. This is certainly a valid concern, and while we had explored these perspectives in the wider evaluation of ACP that this study was part of, the reporting and analysis of the findings fell outside the scope of this dissertation.

Inherent in qualitative research is the potentiality to introduce one's biases into the analysis and interpretation of the results. First, this was addressed by working within a multi-disciplinary team, where my co-researchers were involved in the facilitation, data coding and interpretation processes. The team-based approach served to minimise the influence of personal biases. Second, rather than interpreting the focus group responses through my own lens, constant clarifications were sought throughout the FGDs to elicit the interpretation of what was being said from the respondents themselves. Third, the results were also presented and discussed with my supervisors and clinical mentor, who were not directly involved in the conduct of the study, and were able to view my results within the wider societal context and clinical practice in Singapore.

Although the goal of qualitative research is not to produce generalisable knowledge, there is often interest in understanding its value to the wider context - how applicable the findings are to contexts and situations outside the current study context (Given, 2008). Within the qualitative research paradigm, this concept is referred to as transferability (Guba & Lincoln, 1994). The results, although context-derived, have given rise to a series of concepts that are related to the achievement of a home death, and a set of strategies for the successful implementation of ACP, which are arguably transferrable to other populations and settings. To allow the reader to judge whether the results are applicable to their context, a comprehensive description of the local context was also provided in Chapter 2.

10.4 Main practice and policy implications

This section draws upon evidence from the dissertation and the literature, to provide recommendations regarding shifts in practice and policy that could contribute towards a better understanding and meeting of place of death preferences.

10.4.1 Ageing and dying in place

As mentioned in Chapter 2, to better support successful ageing of the Singaporean population, a national action plan was drawn up in 2016. The direction of policies and programmes currently underway to promote ageing-in-place could potentially support preferences for home death, through the building of home and community care capacity. Pilot programmes initiated by MOH and other governmental agencies include the training of foreign domestic workers to provide care for elderly persons at home before the start of their employment; and the bundling of health and social care services to provide person-centred care (Khor, 2016). Beyond investments in manpower and skills-building, the results of this dissertation highlight the importance of having policies and processes that are geared towards supporting deaths at home. This could include efforts to ensure a single appointed healthcare professional is responsible for the patient's care, including ACP. Having care continuity will better support the elicitation and meeting of place of death preferences.

10.4.2 Changing mindsets and practice for ACP to flourish

Singapore is one of the first Asian countries to have implemented ACP at the national level. Given that ACP is an important tool for preference elicitation, additional investments towards changing public mindsets and death attitudes would be required to extend its outreach and impact. Since the launch of the 'Living Matters' programme in late 2011, approximately 10,000 individuals have completed formal ACPs (Foo, 2017). To further investments in the promotion of ACP, the health ministry announced plans in 2017 to reach out to 100,000 Singaporeans (Gan, 2017) and to facilitate ACP conversations for 25,000 individuals in outpatient settings, such as specialist and primary care clinics, over the next 4 years (Chee, 2017).

To successfully integrate ACP, it is important to establish congruency between the objectives of ACP and the practice norms of its implementation sites (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004). In our study context, ACP was often perceived to be at odds with the perceived overarching goal of curation (Vanderhaeghen, Bossuyt, Opdebeeck, Menten, & Rober, 2017) by both physicians and patients. Therefore, for the practice of ACP to be sustained, we would recommend for a gradual shift in practice culture away from life prolongation, to one that ensures maximal quality of life for the patients. Further, in line with the newly-announced plans, policy-makers should consider how ACP aligns with the service goals and practice norms within outpatient settings. Normalising these conversations as part of planning for future care (Rebecca L. Sudore & Fried, 2010), rather than focusing on end-of-life care, could help increase programme traction. To do so, care may also need to gradually shift from one that is episodic in nature to one that better encourages a longer-term perspective towards maintenance of health, and caters for the changing needs of patients and families.

10.4.3 Holding space for contemplation and discussion

As mentioned earlier, family dynamics strongly determine the outcome of ACP discussions. Preference elicitation and end-of-life care management, therefore, must be supported by healthcare professionals who are able to navigate between the patient's perspective and the family context, and consider the patient and the carer(s) as a single unit (Brink & Frise Smith, 2008). Being able to listen empathetically, provide gentle guidance, and yet provide emotional space to allow contemplation without judgement, does not come naturally to healthcare professionals. Medical, nursing and allied health curricula should give attention to building up communication and interpersonal skills training. Better trained professionals will be more equipped to support patients to play a more active role in discussions and decisions related to their treatment and self-care plans. In doing so, the positive effects will naturally extend to preferences and decisions about end-of-life care.

10.4.4 Aligning practices and policies

The dissertation results highlight several operational issues within the health and legal environment that have hindered dying at home. However, new business and technological innovations such as SPEEDOC (S. Tan, 2018), a home medical mobile application that is aimed at increasing access to house call services, could ameliorate difficulties faced when trying to locate private general practitioners who are willing to certify a death that had occurred at home. Information about new services should be made readily accessible to the public as well as individuals who had expressed a preferred location of care or death.

Further, since the ACP is not a legal document, providers, including hospital staff, are not legally bound to adhere to the statement of preferences. To better support the achievement of home deaths, care protocols must be aligned across the continuum of care with the clear designation of responsibilities. For example, ambulance officers follow a strict protocol, which require them to resuscitate patient when they are called in, regardless of patient's ACP. In the US, Physician Orders for Life-Sustaining Treatments (POLST) have been initiated to allow emergency service personnel to provide comfort measures, without having to transfer the individual to the hospital (Kendra, Rubin, & Halpern, 2016). Similar interventions could be explored to bridge this current gap in protocol.

10.4.5 Good deaths regardless of location

A significant and increasing share of deaths (62%) occur in the hospitals. Other researchers have argued that the attention on the place of death has shifted the social discourse away from the experience of dying (Pollock & Wilson, 2015) to an overemphasis on the place of death. Given that a substantial share of individuals still prefer the hospital as the site of end-of-life care, hospitals must continue to be viable sites where dying patients and their families are able to receive high-quality care (Pollock, 2015). First, rather than simply focusing on the location, it would be useful to examine whether alternative care sites could offer the same value that people attach to dying at home. The creation of a "family atmosphere" may address the loneliness or discomfort associated with dying in institutional settings (McGann, 2011). Second, going forward, systematic monitoring and evaluations should be conducted to validate the assumption that the home space allows for a more dignified and better death.

10.5 Recommendations for policy and practice

The following recommendations are derived from the findings of this dissertation and seek to support future efforts to elicit and better meet end-of-life care preferences in Singapore.

10.5.1 Align policies to support dying-in-place

Policymakers should work with stakeholders to review current policies and practices that impede dying-in-place. Riding on efforts to facilitate ageing-in-place, there is a need to relook at ambulance protocols, transition points between care settings, financial support for family caregivers, and home care support for individuals without familial support. Relevant information about how to prepare for dying and death at home should be easily accessible. Currently, there is a paucity of publicly available information that caters to individuals from different socioeconomic, cultural and religious backgrounds.

To increase families' and friends' level of confidence in supporting an individual to die at home. The healthcare system must look into systematically training caregivers on practical nursing skills to support care at home (Bee, Barnes, & Luker, 2009) to improve their readiness for care. Given that home palliative care reassures family members by being present, and in the provision of skilled home care (Sarmento, Gysels, Higginson, & Gomes, 2017); such services should be strongly promoted in Singapore especially among individuals who wished to die at home.

10.5.2 Expand public awareness about ACP and palliative care

Mindsets and death attitudes can be changed through a multi-modal advocacy and educational strategy to create a productive ground for ACP and palliative care to grow. Greater outreach efforts in the community, to normalise conversations about end-of-life will help shift public attitudes and encourage more people to start discussing their end-of-life care preferences with their loved ones.

10.5.3 Improve organisation and implementation of ACP

Institutions should identify leaders who have the authority to lead to accelerate the pace of programme buy-in. Developing a culture that respects patients' preference will naturally create a virtuous and self-sustaining implementation cycle. A clearer articulation of the health system, as well as the patient-centred goals of ACP, will guide the development of activities necessary to achieve them. Currently, different institutions have adopted implementation models tailored to their context. The implementation process will be better guided if a set of commonly agreed goals could be developed at the national level, and communicated effectively to all staff involved in the work of ACP.

10.5.4 Redesigning communication skills training

To enhance clinician-patient communication (beyond ACP), communications skills training for doctors, nurses and allied health professionals should promote cognitive, practical, as well as emotional competence at the pre- and post-registration phases. Continuous and periodic refresher courses should also be developed, and be introduced as part of continuing education.

10.6 Recommendations for future research

Future research can provide support to several pertinent aspects/questions that fell outside the scope of this thesis. We acknowledge that the data from the current study was obtained from an early-stage implementation of an ACP programme, and therefore can be limited in representing a full range of preferences across different diseases and health states. As the coverage of the programme expands in the future, we recommend further quantitative and qualitative investigation of public attitudes towards and preferences (or indifference) for place of death, to advance our understanding of these preferences. In particular, we would recommend that the analysis differentiates according to diseases, health status, ethnic groups, religions and socioeconomic status. A longitudinal examination will further allow the examination of the effects of illness trajectory on place of death preferences.

We have also based the analysis and reporting of the qualitative findings, regarding preference elicitation and factors influencing the place of death, based on accounts from healthcare professionals. Future studies should ascertain the experiences and perspective of patients, as well as bereaved family members of individuals who died at their preferred place (home, hospital, hospice, aged care facility) and those who did not. This will extend the current discussion to include the impacts of preference (non-)fulfilment, and provide further insights on factors that have influenced their ability to cope with end-of-life caregiving, especially in the home setting. Future studies can also assess the relationship between patient and family well-being with place of death; and concurrently investigate the distribution of cost from a societal perspective. Combining the two aspects will facilitate an economic assessment on the place of death.

The dissertation findings also pointed out that there were differences in the impact of ACP on cancer and non-cancer patients. We did not carry out further sub-group analysis as the sample sizes were not sufficiently large in this study. Future studies could extend the analysis for those with end-organ failure, cognitive disorders, and elderly who are frail. The care-path from diagnosis until death can also be mapped out and modelled to identify gaps in care approaches or services, which could be bridged to better support home deaths.

To ascertain the validity of our approach of mapping preferences to outcomes using diagnosis codes, service codes and address of death, we need to further compare our approach against other data collection methods, including mortality follow-back surveys and medical notes review. These different approaches can also be explored, to be used in combination. The framework can further be expanded to incorporate unstructured data, obtained from the mining of medical case notes. However, to date, the use of such data for research is still highly restricted in Singapore.

Different modelling techniques can be explored in future research. First, we have utilised a simple logistic regression model to examine factors that were significantly associated with dying at home. To take this further, we can use techniques such as structural equation models to establish the causal relationships between the variables, to test the framework for place of death that was established in Chapter 1. Second, in the analysis of the outcomes of the ACP programme, we did not employ this technique in this study, because two hospitals accounted for close to 75% of the observations, being among the first out of eight public hospitals to implement ACP. Future research could consider the use of hierarchical models to account for the effects of individuals clustered within each hospital.

10.7 Reflections on ethical challenges

Within the framework of ACP discussions, it is supposed that individuals would want to decide pre-emptively what care he or she wishes to receive, and where to receive this care, and where to die. Given that 23% of the final sample did not indicate their preferred place of death, the results suggest that individuals may not be so concerned about the physical location of death, and perhaps were more concerned about how they will be cared for. The exercise of preference elicitation also fundamentally assumes ‘choice’ at the end of life is possible. In Chapter 5, the results brought forth the implausibility of home as the place of death for some segments of the population. Healthcare professionals who participated in the FGDs also raised the question of whether it is right for them to present “choices”, which increases expectations but cannot guarantee that the individual’s preferences will be met. Other participants mentioned feeling that they have failed to protect the patient’s interest as the ACP is not a legal document and in serious medical situations, the decision still resided with the doctor.

These difficult issues must be addressed compassionately in the communication between the medical team, patients, and their family. The direct application of the “choices” as a checklist of preferences must be avoided. Rather, the role of an ACP facilitator is to support discussions around choices that do exist and to assist individuals to come to terms with the fact that other options are not achievable. Observing and reflecting upon these challenges also supported the crafting of a set of practice and policy recommendations that are sensitive to these issues in this thesis.

In the absence of universally available and affordable home care and timely access to equipment, a home death, may also not be a realisable option and may expose the patient, family members and even home care providers to the risks of poor or even unsafe care. In the context of Singapore where a significant proportion of healthcare is being paid for out-of-pocket, financial considerations exert significant influence on end-of-life care choices. Policies advocating ageing-in-place and dying-in-place may inadvertently increase the cost to the community and the family. A financial sacrifice or leave from paid employment may be required to support care at home. With a rapidly ageing population and sharp increases in old-age dependency ratio, preferences for end-of-life care have to be carefully balanced with what the family can manage.

10.8 Reflections on research's impact on researcher

Having worked as a health economist for eight years before embarking on this learning journey, it was not certain what this journey might bring. But, it did begin with an open mind. While the research initially set out to examine how to better honour, and to increase the numbers and the share of home deaths, there was a quick realisation that these preferences or choices are much more complicated than media reports or even research literature might suggest. This led to a reconsideration of the direction and methodological approach of this research. Armed with the belief that research methodologies and tools should be appropriately selected for answering the questions, qualitative research methodologies were incorporated into this research. This truly expanded my repertoire of research skills beyond quantitative methodologies, and provided richer insights into understanding the phenomenon of dying at home using an integrative approach.

In the conduct of the focus group discussions, I was astounded by the generosity of the research participants in the giving of their time, and their candid sharing of experiences, insights and ideas related to end-of-life care. Personally, this created meaning for the research process; as did the reflexive nature of the method. Working closely with a team trained in qualitative research methodologies also supported my training in this approach. I participated actively in the larger project - from project management to project implementation and finally the analysis and interpretation of the data.

The differences between the qualitative and quantitative approach were sometimes difficult to navigate, requiring different ways of skills and ways of perceiving the world. Nonetheless, I truly feel that my work is richer for having adopted a multiple-methods approach. There remains more work to be done to further this line of inquiry, requiring both quantitative and qualitative approaches, and have been outlined earlier.

10.9 Contribution of the research

By bringing robust quantitative and qualitative results together, this dissertation brought nuance to the discussion around the development, elicitation and attainment of place of death preferences. The results reinforced the association between individual, illness-related, and system-level factors with variations in place of death outlined in the theoretical framework by Gomes and Higginson (Gomes & Higginson, 2006). Further, the dissertation illustrated that while demographic profile, personal values and beliefs may influence the final place of death directly, these aspects also interact to shape the type of end-of-life care preferences that one may hold - which may be expressed in an end-of-life care conversation or may remain unspoken and/or unknown. In Gomes and Higginson's model, this relationship was not described. End-of-life care preferences are also co-created and not just the family members but also influenced by information and inputs provided by the healthcare professionals. This offers opportunities to further advance our current conceptualisation of modifiable and non-modifiable elements that might drive home deaths in the future.

The research work also contributes to the theoretical front by highlighting how curative medical culture in the acute care hospitals in Singapore, coupled with fragmented care processes, and the high cost of home-based care have acted as a barrier towards home death. The reviewed literature further suggested that health policy, legislative advancements, and culture influences preferences for, and the final place of death. Therefore, future conceptualisation of place of death should consider not only that different factors interlink and interact but also recognise that they are contained within, and sculpted by healthcare and societal norms.

This dissertation explored a topic that is of significant policy interest, in Singapore and internationally. This is the first study to have quantified actual decisions about the preferred place of death, in a relatively large clinical sample in Singapore. Other published studies have adopted a survey design to elicit preferences as part of research (Finkelstein et al., 2015; A. Lee & Pang, 1998; C. Malhotra et al., 2015). Combining evidence from the literature and the empirical results from our quantitative and qualitative inquiries, this research furthered our understanding of the process by which factors associated with the place of death influenced the fulfilment of home death preferences.

As ACP has not yet been widely adopted in Asia, these results are also among the first to report on the implementation of ACP outside of the North American and Western European context, and its impact on home deaths. The study also adds to literature by proposing and illustrating the feasibility of using routinely collected data to assess the achievement of preference-concordant care. This includes the level of concordance with the preferred place of care, which is often unmeasured or unreported in other evaluation studies.

While other studies have examined the impact across mixed populations (K. Detering et al., 2010), little was known about effect heterogeneity across illnesses. This study has added to the literature by examining the effects of ACP on cancer and non-cancer populations, which demonstrates that future research on ACP should explore potential heterogeneity in treatment effects across sub-groups.

10.10 Concluding remarks

In high-income societies, dying at home has long been touted as an achievement that most people aspire to. This is also a common assumption in Singapore. To address the steep decline in the proportion of deaths at home over the last five decades, we learnt that a multi-pronged effort, including improvements in the organisation, coordination, and delivery of health services, is required. The findings from this study challenged the popular viewpoint that home is the most preferred place of death. Less than half of the sample, comprising individuals with advanced illnesses, had opted for home as the preferred place of death.

To fulfil one's wish, articulation is the first step. ACP appears to fill in the gaps in end-of-life care discussions, and has the potential to lead the transformation of care culture towards one that is focused on maximising quality of life, in harmony with an individual's needs and preferences. The observed positive effects of ACP in supporting home deaths raised exciting possibilities of the benefits that an expansion of these services could bring. The use of rigorous qualitative methods nonetheless highlighted the challenges that we face in introducing ACP in a society where talking about death is taboo, and where the healthcare system is strongly geared towards curation. But, with greater insights gained in this study, we can move into the future with greater confidence to redesign clinical work processes with the perspective of respecting choices.

This study brought forth many issues that have potentially wide-ranging consequences for policy-makers who wish to promote home deaths. Asian countries, who are considering the introduction of ACP to better support preference elicitation, may also find the results of relevance.

This study has also adopted a health-system perspective in building the evidence on how to better meet preferences for home deaths. Going forward, the assessment of wider societal and economic impacts of place of death, and the incorporation of the voices of patients and their families, will be crucial in further narrowing the information gap to support policy-making.

Chapter 11 References

Abel, J., Pring, A., Rich, A., Malik, T., & Verne, J. (2013). The impact of advance care planning of place of death, a hospice retrospective cohort study. *BMJ supportive & palliative care, 3*(2), 168-173. doi:10.1136/bmjspcare-2012-000327

Agar, M., Currow, D. C., Shelby-James, T. M., Plummer, J., Sanderson, C., & Abernethy, A. P. (2008). Preference for place of care and place of death in palliative care: are these different questions? *Palliat Med, 22*(7), 787-795. doi:10.1177/0269216308092287

Agency for Integrated Care. (2013). Factsheet Seniors Mobility and Enabling Fund (SMF). Retrieved from https://www.aic.sg/sites/aicassets/AssetGallery/Factsheets/Factsheet%20%20-%20SMF2.pdf

Agency for Integrated Care. (2018a). Interim Disability Assistance Programme for the Elderly (IDAPE). Retrieved from https://www.silverpages.sg/financial-assistance/Interim%20Disability%20Assistance%20Scheme%20For%20the%20Elderly%20(IDAPE)

Agency for Integrated Care. (2018b). Living Matters - Advance Care Planning. Retrieved from www.livingmatters.sg

Ali, M., Capel, M., Jones, G., & Gazi, T. (2015). The importance of identifying preferred place of death. *BMJ Support Palliat Care*. doi:10.1136/bmjspcare-2015-000878

Alsolamy, S. (2014). Islamic views on artificial nutrition and hydration in terminally ill patients. *Bioethics, 28*(2), 96-99. doi:10.1111/j.1467-8519.2012.01996.x

Alsuwaigh, R., & Krishna, L. K. R. (2015). How do English-speaking cancer patients conceptualise personhood. *Ann Acad Med Singapore, 44*, 207-217.

Altheide, D. L., & Johnson, J. M. (1994). Criteria for assessing interpretive validity in qualitative research.

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter? *Journal of health and social behavior*, 1-10.

Ang, G. C., Zhang, D., & Lim, K. H. J. (2016). Differences in attitudes to end-of-life care among patients, relatives and healthcare professionals. *Singapore Medical Journal, 57*(1), 22-28. doi:10.11622/smedj.2016008

Ansah, J. P., Matchar, D. B., Love, S. R., Malhotra, R., Do, Y. K., Chan, A., & Eberlein, R. (2013). Simulating the Impact of Long Term Care Policy on Family Eldercare Hours. *Health services research, 48*(2pt2), 773-791. doi:10.1111/1475-6773.12030

Ariès, P. (1975). *Western attitudes toward death: from the Middle Ages to the present* (Vol. 3): JHU Press.

Arnold, E., Finucane, A. M., & Oxenham, D. (2015). Preferred place of death for patients referred to a specialist palliative care service. *BMJ Support Palliat Care, 5*(3), 294-296. doi:10.1136/bmjspcare-2012-000338

Asai, M. O., & Kameoka, V. A. (2005). The influence of Sekentei on family caregiving and underutilization of social services among Japanese caregivers. *Soc Work, 50*(2), 111-118. doi:10.10.1093/sw/50.2.111

Asai, M. O., & Kameoka, V. A. (2007). Sekentei and family caregiving of elders among the Japanese: development and psychometric evaluation of the sekentei scale. *J Gerontol B Psychol Sci Soc Sci, 62*(3), S179-183. doi:10.1093/geronb/62.3.S179

Auriemma, C. L., Nguyen, C. A., Bronheim, R., Kent, S., Nadiger, S., Pardo, D., & Halpern, S. D. (2014). Stability of end-of-life preferences: a systematic review of the evidence. *JAMA Intern Med, 174*(7), 1085-1092. doi:10.1001/jamainternmed.2014.1183

Austin, P. C. (2009). Using the Standardized Difference to Compare the Prevalence of a Binary Variable Between Two Groups in Observational Research. *Communications in Statistics - Simulation and Computation, 38*(6), 1228-1234. doi:10.1080/03610910902859574

Austin, P. C. (2010). Statistical criteria for selecting the optimal number of untreated subjects matched to each treated subject when using many-to-one matching on the propensity score. *Am J Epidemiol, 172*(9), 1092-1097. doi:10.1093/aje/kwq224

Austin, P. C. (2011). An introduction to propensity score methods for reducing the effects of confounding in observational studies. *Multivariate behavioral research, 46*(3), 399-424. doi:10.1080/00273171.2011.568786

Austin, P. C., & Mamdani, M. M. (2006). A comparison of propensity score methods: a case-study estimating the effectiveness of post-AMI statin use. *Statistics in Medicine, 25*(12), 2084-2106. doi:10.1002/sim.2328

Bakitas, M., Ahles, T. A., Skalla, K., Brokaw, F. C., Byock, I., Hanscom, B., . . . Hegel, M. T. (2008). Proxy perspectives regarding end-of-life care for persons with cancer. *Cancer, 112*(8), 1854-1861. doi:10.1002/cncr.23381

Barclay, S., & Arthur, A. (2008). Place of death — how much does it matter?: The priority is to improve end-of-life care in all settings. *The British Journal of General Practice, 58*(549), 229-231. doi:10.3399/bjgp08X279724

Barnato, A. E., Farrell, M. H., Chang, C.-C. H., Lave, J. R., Roberts, M. S., & Angus, D. C. (2009). Development and Validation of Hospital "End-of-Life" Treatment Intensity Measures. *Medical care, 47*(10), 1098-1105. doi:10.1097/MLR.0b013e3181993191

Beccaro, M., Costantini, M., Giorgi Rossi, P., Miccinesi, G., Grimaldi, M., & Bruzzi, P. (2006). Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). *J Epidemiol Community Health, 60*(5), 412-416. doi:10.1136/jech.2005.043646

Beck, E. R., McIlfatrick, S., Hasson, F., & Leavey, G. (2015). Health care professionals' perspectives of advance care planning for people with dementia living in long-term care settings: A narrative review of the literature. *Dementia (London)*. doi:10.1177/1471301215604997

Bee, P. E., Barnes, P., & Luker, K. A. (2009). A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs, 18*(10), 1379-1393. doi:10.1111/j.1365-2702.2008.02405.x

Beng, A. K., Fong, C. W., Shum, E., Goh, C. R., Goh, K. T., & Chew, S. K. (2009). Where the elderly die: the influence of socio-demographic factors and cause of death on people dying at home. *Ann Acad Med Singapore, 38*(8), 676-683.

Billings, J. A., & Bernacki, R. (2014). Strategic targeting of advance care planning interventions: the Goldilocks phenomenon. *JAMA Intern Med, 174*(4), 620-624. doi:10.1001/jamainternmed.2013.14384

Bischoff, K. E., Sudore, R., Miao, Y., Boscardin, W. J., & Smith, A. K. (2013). Advance care planning and the quality of end-of-life care in older adults. *J Am Geriatr Soc, 61*(2), 209-214. doi:10.1111/jgs.12105

Blackbox Research. (2014). Lien Foundation Survey on Death Attitudes. Retrieved from http://lienfoundation.org/sites/default/files/Death%20survey%20Presser%20Final%20-%20Combined_0.pdf

Blackhall, L. J., Murphy, S. T., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and attitudes toward patient autonomy. *Jama, 274*(10), 820-825. doi:10.1001/jama.1995.03530100060035

Blumer, H. (1954). What is wrong with social theory? *American sociological review, 19*(1), 3-10. doi:10.2307/2088165

Borgstrom, E. (2015). Advance care planning: between tools and relational end-of-life care? *BMJ supportive & palliative care, 5*(3), 216-217. doi:10.1136/bmjspcare-2015-000979

Boyd, K. J. (1994). Hospice home care in the United Kingdom. *Ann Acad Med Singapore, 23*(2), 271-274.

Brazil, K., Bedard, M., & Willison, K. (2002). Factors associated with home death for individuals who receive home support services: a retrospective cohort study. *BMC Palliative Care, 1*(1), 2. doi:10.1186/1472-684x-1-2

Brewer, J., & Hunter, A. (1989). *Multimethod research: A synthesis of styles*: Sage Publications, Inc.

Brink, P., & Frise Smith, T. (2008). Determinants of home death in palliative home care: using the interRAI palliative care to assess end-of-life care. *Am J Hosp Palliat Care, 25*(4), 263-270. doi:10.1177/1049909108319261

Brinkman-Stoppelenburg, A., Rietjens, J. A., & van der Heide, A. (2014). The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med, 28*(8), 1000-1025. doi:10.1177/0269216314526272

Bronfenbrenner, U. (1979). *The ecology of human development*: Harvard university press.

Brookhart, M. A., Schneeweiss, S., Rothman, K. J., Glynn, R. J., Avorn, J., & Sturmer, T. (2006). Variable selection for propensity score models. *Am J Epidemiol, 163*. doi:10.1093/aje/kwj149

Broom, A., & Kirby, E. (2013). The end of life and the family: hospice patients' views on dying as relational. *Sociol Health Illn, 35*(4), 499-513. doi:10.1111/j.1467-9566.2012.01497.x

Brown, M. A., & Stetz, K. (1999). The labor of caregiving: a theoretical model of caregiving during potentially fatal illness. *Qual Health Res, 9*(2), 182-197. doi:10.1177/104973299129121776

Bruera, E., & Hui, D. (2010). Integrating Supportive and Palliative Care in the Trajectory of Cancer: Establishing Goals and Models of Care. *Journal of Clinical Oncology, 28*(25), 4013-4017. doi:10.1200/jco.2010.29.5618

Brumley, R., Enguidanos, S., Jamison, P., Seitz, R., Morgenstern, N., Saito, S., . . . Gonzalez, J. (2007). Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc, 55*(7), 993-1000. doi:10.1111/j.1532-5415.2007.01234.x

Burge, F., Lawson, B., & Johnston, G. (2003). Trends in the place of death of cancer patients, 1992–1997. *CMAJ: Canadian Medical Association Journal, 168*(3), 265-270.

Calfo, S., Smith, J., & Zezza, M. (2004). Last year of life study. *Centers for Medicare and Medicade Services, Baltimore, MD.*

Canadian Hospice Palliative Care Association. (2013). *What Canadians Say: The Way Forward Survey Report*. Retrieved from

Cantwell, P., Turco, S., Brenneis, C., Hanson, J., Neumann, C. M., & Bruera, E. (2000). Predictors of home death in palliative care cancer patients. *J Palliat Care, 16*(1), 23-28.

Caplan, G., Meller, A., Squires, B., Chan, S., & Willett, W. (2006). Advance care planning and hospital in the nursing home. *Age Ageing, 35*. doi:10.1093/ageing/afl063

Carlsson, M. E., & Rollison, B. (2003). A comparison of patients dying at home and patients dying at a hospice: sociodemographic factors and caregivers' experiences. *Palliat Support Care, 1*(1), 33-39. doi:10.1017/S1478951503030098

Cassel, C. K., & Field, M. J. (1997). *Approaching death: Improving care at the end of life*: National Academies Press.

Chai, H. Z., Krishna, L. K., & Wong, V. H. (2014). Feeding: what it means to patients and caregivers and how these views influence Singaporean Chinese caregivers' decisions to continue feeding at the end of life. *Am J Hosp Palliat Care, 31*(2), 166-171. doi:10.1177/1049909113480883

Chan, A., Ostbye, T., Malhotra, R., & Hu, A. J. (2014). *The Survey on Informal Caregiving: Summary Report* Singapore: Ministry of Community Youth and Sports Retrieved from http://app.msf.gov.sg/Portals/0/Informal%20Caregiver%20Survey%20Summary%20Report%20%28upload%29.pdf.

Chan, H. Y., & Pang, S. M. (2010). Let me talk--an advance care planning programme for frail nursing home residents. *J Clin Nurs, 19*(21-22), 3073-3084. doi:10.1111/j.1365-2702.2010.03353.x

Charlson, M. E., Sax, F. L., MacKenzie, C. R., Fields, S. D., Braham, R. L., & Douglas, R. G. (1986). Assessing illness severity: does clinical judgment work? *Journal of chronic diseases, 39*(6), 439-452.

Charmaz, K. (2003). Grounded theory: Objectivist and constructivist methods. In. K. Denzin & YS Lincoln (Eds.), Strategies of qualitative inquiry (pp. 249–291). In: Thousand Oaks, CA: Sage.

Chee, H. T. (2017). Speech by Minister of State for Health, Mr Chee Hong Tat, at the MOH Committee of Supply Debate 2017 [Press release]. Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2017/speech-by-minister-of-state-for-health--mr-chee-hong-tat--at-the.html

Chen, C., Naidoo, N., Er, B., Cheong, A., Fong, N. P., Tay, C. Y., . . . Koh, G. C. H. (2013). Factors Associated with Nursing Home Placement of All Patients Admitted for Inpatient Rehabilitation in Singapore Community Hospitals from 1996 to 2005: A Disease Stratified Analysis. *PLOS ONE, 8*(12), e82697. doi:10.1371/journal.pone.0082697

Chen, C. H., Lin, Y. C., Liu, L. N., & Tang, S. T. (2014). Determinants of preference for home death among terminally ill patients with cancer in Taiwan: a cross-sectional survey study. *J Nurs Res, 22*(1), 37-44. doi:10.1097/jnr.0000000000000016

Chen, C. Y., Thorsteinsdottir, B., Cha, S. S., Hanson, G. J., Peterson, S. M., Rahman, P. A., . . . Takahashi, P. Y. (2015). Health care outcomes and advance care planning in older adults who receive home-based palliative care: a pilot cohort study. *J Palliat Med, 18*(1), 38-44. doi:10.1089/jpm.2014.0150

Chen, G. (2014). *Influence of using different databases and lookback intervals to define comorbidity for patients with newly diagnosed hypertension*. Paper presented at the International Health Data Linkage Conference, Canada. http://www.ihdlnconference2014.org/abstract/Chen

Chen, R. (2016). A Personal Journey in Taiwan's Hospice Palliative Care Movement. *BAOJ Pall Medicine, 2*, 019.

Cheng, H. W., Li, C. W., Chan, K. Y., Ho, R., & Sham, M. K. (2014). Bringing palliative care into geriatrics in a Chinese culture society--results of a collaborative model between palliative medicine and geriatrics unit in Hong Kong. *J Am Geriatr Soc, 62*(4), 779-781. doi:10.1111/jgs.12760

Cheng, S.-Y., Suh, S.-Y., Morita, T., Oyama, Y., Chiu, T.-Y., Koh, S. J., . . . Tsuneto, S. (2015). A Cross-Cultural Study on Behaviors When Death Is Approaching in East Asian Countries: What Are the Physician-Perceived Common Beliefs and Practices? *Medicine, 94*(39), e1573. doi:10.1097/MD.0000000000001573

Cheng, S. Y. C., C.Y.; Chiu, T.Y. . (2016). Advances of hospice palliative care in Taiwan. *Korean J Hosp Palliat Care, 19*, 292-295. doi:10.14475/kjhpc.2016.19.4.292

Cheung, E. (2016). Free Hong Kong doctors to help dying patients end their days at home. Retrieved from http://www.scmp.com/news/hong-kong/health-environment/article/1988078/free-hong-kong-doctors-help-dying-patients-end

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2002). Dignity in the terminally ill: a cross-sectional, cohort study. *The Lancet, 360*(9350), 2026-2030.

Choi, K. S., Chae, Y. M., Lee, C. G., Kim, S.-y., Lee, S.-w., Heo, D. S., . . . Yun, Y. H. (2005). Factors influencing preferences for place of terminal care and of death among cancer patients and their families in Korea. *Supportive Care in Cancer, 13*(8), 565-572. doi:10.1007/s00520-005-0809-4

Chung, I. (2013). *Aging Issues: Advance Care Planning*. Paper presented at the Singapore Public Health & Occupational Medicine Conference, Singapore.

Chung, I. (2017). Advance Care Planning in an Asian Country In K. Thomas, B. Lobo, & K. Detering (Eds.), *Advance care planning in end of life care*. U.K. : Oxford University Press.

Chung, R. Y., Wong, E. L., Kiang, N., Chau, P. Y., Lau, J. Y., Wong, S. Y., . . . Woo, J. W. (2017). Knowledge, Attitudes, and Preferences of Advance Decisions, End-of-Life Care, and Place of Care and Death in Hong Kong. A Population-Based Telephone Survey of 1067 Adults. *J Am Med Dir Assoc, 18*(4), 367.e319-367.e327. doi:10.1016/j.jamda.2016.12.066

Clark, D. (2002). Between hope and acceptance: the medicalisation of dying. *BMJ : British Medical Journal, 324*(7342), 905-907. doi:10.1136/bmj.324.7342.905

Cohen, J., Bilsen, J., Addington-Hall, J., Lofmark, R., Miccinesi, G., Kaasa, S., . . . Deliens, L. (2008). Population-based study of dying in hospital in six European countries. *Palliat Med, 22*(6), 702-710. doi:10.1177/0269216308092285

Connolly, J. G., & Gagne, J. J. (2016). Comparison of Calipers for Matching on the Disease Risk Score. *Am J Epidemiol, 183*(10), 937-948. doi:10.1093/aje/kwv302

Connors, A. F., Jr, Dawson, N. V., Desbiens, N. A., & et al. (1995). A controlled trial to improve care for seriously iii hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (support). *Jama, 274*(20), 1591-1598. doi:10.1001/jama.1995.03530200027032

Costa, V., Earle, C. C., Esplen, M. J., Fowler, R., Goldman, R., Grossman, D., . . . You, J. J. (2016). The determinants of home and nursing home death: a systematic review and meta-analysis. *BMC Palliat Care, 15*, 8. doi:10.1186/s12904-016-0077-8

Costantini, M. (2008). Editorial: place of death. It is time for a change of gear. *Palliat Med, 22*(7), 785-786. doi:10.1177/0269216308096424

Covinsky, K. E., Fuller, J. D., Yaffe, K., Johnston, C. B., Hamel, M. B., Lynn, J., . . . Phillips, R. S. (2000). Communication and decision-making in seriously ill patients: findings of the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *J Am Geriatr Soc, 48*(5 Suppl), S187-193. doi:10.1111/j.1532-5415.2000.tb03131.x

Creswell, J. W. (2007). Research Design: Choosing among five approaches. In: Sage, London.

Creswell, J. W., & Clark, V. L. P. (2011). *Designing and conducting mixed methods research*: Sage.

Currow, D. C., Agar, M., & Abernethy, A. P. (2013). Hospital can be the actively chosen place for death. *J Clin Oncol, 31*(5), 651-652. doi:10.1200/jco.2012.46.2556

Daryanani, D. (2017). *The Singapore Hospice and Palliative Care Story - The Movement that Refused To Die*. Singapore: Singapore Hospice Council.

Davies, E., Higginson, I. J., & Organization, W. H. (2004). The solid facts: palliative care.

Davis, F. A. (1988). Medicare hospice benefit: Early program experiences. *Health Care Financing Review, 9*(4), 99-111.

De Vleminck, A., Houttekier, D., Pardon, K., Deschepper, R., Van Audenhove, C., Vander Stichele, R., & Deliens, L. (2013). Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review. *Scandinavian Journal of Primary Health Care, 31*(4), 215-226. doi:10.3109/02813432.2013.854590

Denzin, N. K., & Lincoln, Y. S. (2011). *The Sage handbook of qualitative research*: Sage.

Department of Health. (2008). *End of life care strategy-promoting high quality care for all adults at the end of life*. Retrieved from www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf.

Department of Statistics. (2010). *Census of Population 2010 Statistical Release 1: Demographic Characteristics, Education, Language and Religion*. Republic of Singapore Retrieved from http://www.singstat.gov.sg/docs/default-source/default-document-library/publications/publications_and_papers/cop2010/census_2010_release1/cop2010sr1.pdf.

Department of Statistics. (2016). Population Trends 2016. Retrieved from www.singstat.gov.sg/-/media/files/publications/population/population2016.pdf

Department of Statistics Singapore. (2018). Latest data. Retrieved from http://www.singstat.gov.sg/statistics/latest-data#16

Detering, K., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end-of-life care in elderly patients: a randomised controlled trial. *Bmj, 340*. doi:10.1136/bmj.c1345

Detering, K., & Silveira, M. (2017). Advance care planning and advance directives. Retrieved from www.uptodate.com/contents/advance-care-planning-and-advance-directives

Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *Bmj, 340*, c1345.

Ditto, P. H., Jacobson, J. A., Smucker, W. D., Danks, J. H., & Fagerlin, A. (2006). Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Med Decis Making, 26*(4), 313-322. doi:10.1177/0272989x06290494

Dixon, J., King, D., & Knapp, M. (2016). Advance care planning in England: Is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People. *BMJ Supportive & Palliative Care*. doi:10.1136/bmjspcare-2015-000971

Dixon, J., Matosevic, T., & Knapp, M. (2015). The economic evidence for advance care planning: Systematic review of evidence. *Palliat Med, 29*(10), 869-884. doi:10.1177/0269216315586659

du Prel, J.-B., Hommel, G., Röhrig, B., & Blettner, M. (2009). Confidence Interval or P-Value?: Part 4 of a Series on Evaluation of Scientific Publications. *Deutsches Ärzteblatt International, 106*(19), 335-339. doi:10.3238/arztebl.2009.0335

Economist Intelligence Unit. (2010). The quality of death: ranking end-of-life care across the world. *London: The Economist*.

Ehlenbach, W. J., Hough, C. L., Crane, P. K., Haneuse, S. J., Carson, S. S., Curtis, J. R., & Larson, E. B. (2010). Association between acute care and critical illness hospitalization and cognitive function in older adults. *Jama, 303*(8), 763-770. doi:10.1001/jama.2010.167

Emanuel, L. L., Danis, M., Pearlman, R. A., & Singer, P. A. (1995). Advance care planning as a process: structuring the discussions in practice. *J Am Geriatr Soc, 43*(4), 440-446. doi:10.1111/j.1532-5415.1995.tb05821.x

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science, 196*(4286), 129-136.

Feilzer, Y. M. (2009). Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm. *Journal of Mixed Methods Research, 4*(1), 6-16. doi:10.1177/1558689809349691

Feinglass, J., & Holloway, J. J. (1991). The initial impact of the Medicare prospective payment system on U.S. health care: a review of the literature. *Med Care Rev, 48*(1), 91-115. doi:10.1177/002570879104800104

Finkelstein, E. A., Bilger, M., Flynn, T. N., & Malhotra, C. (2015). Preferences for end-of-life care among community-dwelling older adults and patients with advanced cancer: A discrete choice experiment. *Health Policy, 119*(11), 1482-1489. doi:10.1016/j.healthpol.2015.09.001.

Finlay, I. (2006). The continuing challenge of palliative care. *The British Journal of General Practice, 56*(522), 3-4.

Fischer, S., Min, S.-J., Cervantes, L., & Kutner, J. (2013). Where Do You Want to Spend Your Last Days of Life? Low Concordance Between Preferred and Actual Site of Death Among Hospitalized Adults. *Journal of hospital medicine, 8*(4), 178-183. doi:10.1002/jhm.2018

Fisher, E. S., Wennberg, D. E., Stukel, T. A., Gottlieb, D. J., Lucas, F. L., & Pinder, E. L. (2003). The implications of regional variations in Medicare spending. Part 2: health outcomes and satisfaction with care. *Ann Intern Med, 138*(4), 288-298. doi:10.7326/0003-4819-138-4-200302180-00007

Flo, E., Husebo, B. S., Bruusgaard, P., Gjerberg, E., Thoresen, L., Lillemoen, L., & Pedersen, R. (2016). A review of the implementation and research strategies of advance care planning in nursing homes. *BMC Geriatrics, 16*, 24. doi:10.1186/s12877-016-0179-4

Flory, J., Yinong, Y. X., Gurol, I., Levinsky, N., Ash, A., & Emanuel, E. (2004). Place of death: U.S. trends since 1980. *Health Aff (Millwood), 23*(3), 194-200. doi:10.1377/hlthaff.23.3.194

Foo, J. Y. (2017, April 3). Planning for death: Still not easy to talk about 'taboo' issue. *The New Paper*. Retrieved from http://www.tnp.sg/news/singapore/planning-death-still-not-easy-talk-about-taboo-issue

Ford, I., & Norrie, J. (2016). Pragmatic Trials. *New England Journal of Medicine, 375*(5), 454-463. doi:10.1056/NEJMra1510059

Foreman, L. M., Hunt, R. W., Luke, C. G., & Roder, D. M. (2006). Factors predictive of preferred place of death in the general population of South Australia. *Palliat Med, 20*(4), 447-453. doi:10.1191/0269216306pm1149oa

Fosse, A., Schaufel, M. A., Ruths, S., & Malterud, K. (2014). End-of-life expectations and experiences among nursing home patients and their relatives--a synthesis of qualitative studies. *Patient Educ Couns, 97*(1), 3-9. doi:10.1016/j.pec.2014.05.025

Fox, E. (1997). Predominance of the curative model of medical care. A residual problem. *Jama, 278*(9), 761-763. doi:10.1001/jama.1997.03550090085038

Fox, J. (2015). *Applied regression analysis and generalized linear models*: Sage Publications.

Fromme, E. K., Zive, D., Schmidt, T. A., Cook, J. N., & Tolle, S. W. (2014). Association between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and in-hospital death in Oregon. *J Am Geriatr Soc, 62*(7), 1246-1251. doi:10.1111/jgs.12889

Fuenmayor, R. (1991). Truth and openness: An epistemology for interpretive systemology. *Systems Practice, 4*(5), 473-490. doi:10.1007/BF01104462

Fuenmayor, R. (1993). A Theoretical Framework for an Interpretive-Systemic Study of Public Health Services in Venezuela. In F. A. Stowell, D. West, & J. G. Howell (Eds.), *Systems Science: Addressing Global Issues* (pp. 53-63). Boston, MA: Springer US.

Fujimori, M., & Uchitomi, Y. (2009). Preferences of cancer patients regarding communication of bad news: a systematic literature review. *Jpn J Clin Oncol, 39*(4), 201-216. doi:10.1093/jjco/hyn159

Fukui, S., Fujita, J., Tsujimura, M., Sumikawa, Y., Hayashi, Y., & Fukui, N. (2011). Late referrals to home palliative care service affecting death at home in advanced cancer patients in Japan: a nationwide survey. *Ann Oncol, 22*(9), 2113-2120. doi:10.1093/annonc/mdq719

Fukui, S., Kawagoe, H., Masako, S., Noriko, N., Hiroko, N., & Toshie, M. (2003). Determinants of the place of death among terminally ill cancer patients under home hospice care in Japan. *Palliat Med, 17*(5), 445-453. doi:10.1191/0269216303pm782oa

Fukui, S., Yoshiuchi, K., Fujita, J., Sawai, M., & Watanabe, M. (2011). Japanese people's preference for place of end-of-life care and death: a population-based nationwide survey. *J Pain Symptom Manage, 42*(6), 882-892. doi:10.1016/j.jpainsymman.2011.02.024

Gade, G., Venohr, I., Conner, D., McGrady, K., Beane, J., Richardson, R. H., . . . Della Penna, R. (2008). Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med, 11*(2), 180-190. doi:10.1089/jpm.2007.0055

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology, 13*(1), 117. doi:10.1186/1471-2288-13-117

Gan, K. (2011). Speech by Mr Gan Kim Yong, Minister for Health, at Assisi Hospice’s Charity Dinner 2011, Pan Pacific Singapore, 7 November 2011 [Press release]. Retrieved from https://www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2011/speech_by_mr_gankimyongministerforhealthatassisihospicescharityd.html

Gan, K. (2014). Speech by Mr Gan Kim Yong, Minister for Health, at Singapore Palliative Care Conference at Singapore Polytechnic Convention Centre, 28 June 2014 [Press release]. Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2014/speech-by-mr-gan-kim-yong--minister-for-health--at-singapore-pal.html

Gan, K. (2015). Speech by Mr Gan Kim Yong, Minister for Health, at the SG50 Scientific Conference on Ageing, on 19 March 2015 - Ageing in Singapore in the

Next 50 Years [Press release]. Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2015/speech-by-mr-gan-kim-yong--minister-for-health--at-the-sg50-scie.html

Gan, K. (2017). Speech by Mr Gan Kim Yong, Minister for Health, at the opening of the Asia Pacific Hospice Conference, 27 July 2017 [Press release]. Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2017/speech-by-mr-gan-kim-yong--minister-for-health--at-the-opening-o.html

Gao, W., Ho, Y. K., Verne, J., Glickman, M., & Higginson, I. J. (2013). Changing patterns in place of cancer death in England: a population-based study. *PLoS Med, 10*(3), e1001410. doi:10.1371/journal.pmed.1001410

Gatrad, A. R. (1994). Muslim customs surrounding death, bereavement, postmortem examinations, and organ transplants. *BMJ : British Medical Journal, 309*(6953), 521-523. doi:10.1136/bmj.309.6953.521

Gilissen, J., Pivodic, L., Smets, T., Gastmans, C., Vander Stichele, R., Deliens, L., & Van den Block, L. (2017). Preconditions for successful advance care planning in nursing homes: A systematic review. *Int J Nurs Stud, 66*, 47-59. doi:10.1016/j.ijnurstu.2016.12.003

Gill, T. M., Allore, H. G., Holford, T. R., & Guo, Z. (2004). Hospitalization, restricted activity, and the development of disability among older persons. *Jama, 292*(17), 2115-2124. doi:10.1001/jama.292.17.2115

Gilley, J. (1988). Intimacy and terminal care. *JR Coll Gen Pract, 38*(314), 424-425.

Given, L. M. (2008). *The Sage encyclopedia of qualitative research methods*: Sage Publications.

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. *J Cross Cult Gerontol, 25*(1), 1-19. doi:10.1007/s10823-009-9108-8

Gomes, B., Calanzani, N., Curiale, V., McCrone, P., & Higginson, I. J. (2013). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev*(6), Cd007760. doi:10.1002/14651858.CD007760.pub2

Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care, 12*(1), 7. doi:10.1186/1472-684x-12-7

Gomes, B., Calanzani, N., & Higginson, I. J. (2012). Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliat Med, 26*(2), 102-107. doi:10.1177/0269216311432329

Gomes, B., Calanzani, N., Koffman, J., & Higginson, I. J. (2015). Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC Medicine, 13*(1), 235. doi:10.1186/s12916-015-0466-5

Gomes, B., & Higginson, I. J. (2006). Factors influencing death at home in terminally ill patients with cancer: systematic review. *Bmj, 332*(7540), 515-521. doi:10.1136/bmj.38740.614954.55

Gomes, B., & Higginson, I. J. (2008). Where people die (1974--2030): past trends, future projections and implications for care. *Palliat Med, 22*(1), 33-41. doi:10.1177/0269216307084606

Gomes, B., Higginson, I. J., Calanzani, N., Cohen, J., Deliens, L., Daveson, B., . . . Toscani, F. (2012). Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of oncology, 23*(8), 2006-2015. doi:10.1093/annonc/mdr602

Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. H. (2004). Older peoples views about home as a place of care at the end of life. *Palliat Med, 18*. doi:10.1191/0269216304pm889oa

Gotze, H., Brahler, E., Gansera, L., Polze, N., & Kohler, N. (2014). Psychological distress and quality of life of palliative cancer patients and their caring relatives during home care. *Support Care Cancer, 22*(10), 2775-2782. doi:10.1007/s00520-014-2257-5

Gotze, H., Brahler, E., Gansera, L., Schnabel, A., Gottschalk-Fleischer, A., & Kohler, N. (2016). Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient's death. *Eur J Cancer Care (Engl)*. doi:10.1111/ecc.12606

Grande, G. E., Addington-Hall, J. M., & Todd, C. J. (1998). Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med, 47*(5), 565-579. doi:10.1016/S0277-9536(98)00115-4

Greco, P. J., Schulman, K. A., Lavizzo-Mourey, R., & Hansen-Flaschen, J. (1991). The Patient Self-Determination Act and the future of advance directives. *Ann Intern Med, 115*(8), 639-643. doi:10.7326/0003-4819-115-8-639

Greene, J. C. (2008). Is Mixed Methods Social Inquiry a Distinctive Methodology? *Journal of Mixed Methods Research, 2*(1), 7-22. doi:10.1177/1558689807309969

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: systematic review and recommendations. *Milbank Q, 82*(4), 581-629. doi:10.1111/j.0887-378X.2004.00325.x

Gruneir, A., Mor, V., Weitzen, S., Truchil, R., Teno, J., & Roy, J. (2007). Where people die: a multilevel approach to understanding influences on site of death in America. *Med Care Res Rev, 64*(4), 351-378. doi:10.1177/1077558707301810

Grunfeld, E., Lethbridge, L., Dewar, R., Lawson, B., Paszat, L. F., Johnston, G., . . . Earle, C. C. (2006). Towards using administrative databases to measure population-based indicators of quality of end-of-life care: testing the methodology. *Palliat Med, 20*(8), 769-777. doi:10.1177/0269216306072553

Gu, D., Liu, G., Vlosky, D. A., & Yi, Z. (2007). Factors Associated With Place of Death Among the Chinese Oldest Old. *Journal of Applied Gerontology, 26*(1), 34-57. doi:10.1177/0733464806296057

Guba, E. G., & Lincoln, Y. S. (1994). *Competing paradigms in qualitative research*. London: Sage.

Hack, K. (2000). Chinatown as a Microcosm of Singapore. Retrieved from http://www.hsse.nie.edu.sg/staff/blackburn/ChinatownHistory.pdf

Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: a multidisciplinary review. *Bmj, 327*(7425), 1219-1221. doi:10.1136/bmj.327.7425.1219

Hakanson, C., Ohlen, J., Morin, L., & Cohen, J. (2015). A population-level study of place of death and associated factors in Sweden. *Scand J Public Health, 43*(7), 744-751. doi:10.1177/1403494815595774

Hamel, M. B., Lynn, J., Teno, J. M., Covinsky, K. E., Wu, A. W., Galanos, A., . . . Phillips, R. S. (2000). Age-related differences in care preferences, treatment decisions, and clinical outcomes of seriously ill hospitalized adults: lessons from SUPPORT. *J Am Geriatr Soc, 48*(5 Suppl), S176-182. doi:10.1111/j.1532-5415.2000.tb03129.x

Hamel, M. B., Teno, J. M., Goldman, L., Lynn, J., Davis, R. B., Galanos, A. N., . . . Phillips, R. S. (1999). Patient age and decisions to withhold life-sustaining treatments from seriously ill, hospitalized adults. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Ann Intern Med, 130*(2), 116-125. doi:10.7326/0003-4819-130-2-199901190-00005

Hammes, B. J., & Rooney, B. L. (1998). Death and end-of-life planning in one midwestern community. *Archives of Internal Medicine, 158*(4), 383-390. doi:10.1001/archinte.158.4.383

Hammes, B. J., Rooney, B. L., & Gundrum, J. D. (2010). A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *J Am Geriatr Soc, 58*(7), 1249-1255. doi:10.1111/j.1532-5415.2010.02956.x

Hanson, L. C., & Rodgman, E. (1996). The use of living wills at the end of life. A national study. *Arch Intern Med, 156*(9), 1018-1022. doi:10.1001/archinte.1996.00440090128013

Harris, M. (1968). Emics, etics, and the new ethnography. *The rise of anthropological theory: A history of theories of culture*, 568-604.

Haseltine, W. A. (2013). *Affordable excellence: the Singapore healthcare story*. In. Retrieved from www.brookings.edu/wp-content/uploads/2016/07/AffordableExcellencePDF.pdf

Hattori, A., Masuda, Y., Fetters, M. D., Uemura, K., Mogi, N., Kuzuya, M., & Iguchi, A. (2005). A qualitative exploration of elderly patients' preferences for end-of-life care. *Japan Medical Association Journal, 48*(8), 388.

Hattori, K., & Ishida, D. N. (2012). Ethnographic study of a good death among elderly Japanese Americans. *Nurs Health Sci, 14*(4), 488-494. doi:10.1111/j.1442-2018.2012.00725.x

Hatziandreu, E., Archontakis, F., & Daly, A. (2008). The potential cost savings of greater use of home-and hospice-based end of life care in England. doi:10.7249/TR642

Hayhoe, B., & Howe, A. (2011). Advance care planning under the Mental Capacity Act 2005 in primary care. *The British Journal of General Practice, 61*(589), e537-e541. doi:10.3399/bjgp11X588592

Henriksson, A., Carlander, I., & Arestedt, K. (2015). Feelings of rewards among family caregivers during ongoing palliative care. *Palliat Support Care, 13*(6), 1509-1517. doi:10.1017/s1478951513000540

Henry, C., & Hayes, A. (2009). Promoting high quality care for all at the end of life: review of NHS National End of Life Care Programme 2004-2007 and implications for primary care. *London J Prim Care (Abingdon), 2*(2), 96-101.

Henry, C., Seymour, J., & Ryder, S. (2007). Advance care planning: a guide for health and social care staff. *London: Department of Health*.

Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., . . . Lam, M. (2006). What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *Cmaj, 174*(5), 627-633. doi:10.1503/cmaj.050626

Hickman, S. E., Hammes, B. J., Moss, A. H., & Tolle, S. W. (2005). Hope for the future: achieving the original intent of advance directives. *Hastings Cent Rep, Spec No*, S26-30.

Higginson, I. J., Evans, C. J., Grande, G., Preston, N., Morgan, M., McCrone, P., . . . Hotopf, M. (2013). Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC Medicine, 11*(1), 111. doi:10.1186/1741-7015-11-111

Higginson, I. J., & Sen-Gupta, G. J. (2000). Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med, 3*(3), 287-300. doi:10.1089/jpm.2000.3.287

Hirakawa, Y., Chiang, C., Hilawe, E. H., & Aoyama, A. (2017). Content of advance care planning among Japanese elderly people living at home: A qualitative study. *Archives of Gerontology and Geriatrics, 70*, 162-168. doi:http://dx.doi.org/10.1016/j.archger.2017.01.007

Ho, A. (2014). Better to die a good death at home. *The Straits Times*. Retrieved from https://www.straitstimes.com/opinion/better-to-die-a-good-death-at-home

Ho, A. H. Y., Luk, J. K. H., Chan, F. H. W., Ng, W. C., Kowk, C. K. K., Yuen, J. H. L., . . . Chan, C. L. W. (2015). Dignified palliative care in long-term care settings: an interpretive-systemic framework for end-of-life integrated care pathway (EoL-ICP) for terminally ill Chinese older adults. *American Journal of Hospice and Palliative Medicine*. doi:10.1177/1049909114565789

Ho, A. H. Y., & Tan, G. X. L. (2016). Protecting dignity at the end of life. *Handbook of social justice in loss and grief: Exploring diversity, equity, and inclusion. New York: Routledge*, 100-108.

Hoare, S., Morris, Z. S., Kelly, M. P., Kuhn, I., & Barclay, S. (2015). Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death. *PLOS ONE, 10*(11), e0142723. doi:10.1371/journal.pone.0142723

Hong, C. Y., Chow, K. Y., Poulose, J., Jin, A. Z., Devi, A., Chee, E. M., & Goh, C. (2011). Place of death and its determinants for patients with cancer in Singapore: an analysis of data from the Singapore Cancer Registry, 2000-2009. *J Palliat Med, 14*(10), 1128-1134. doi:10.1089/jpm.2011.0092

Horsfall, D., Leonard, R., Noonan, K., & Rosenberg, J. (2013). Working together–apart: Exploring the relationships between formal and informal care networks for people dying at home. *Progress in Palliative Care, 21*(6), 331-336. doi:10.1179/1743291X12Y.0000000047

Hosmer Jr, D. W., Lemeshow, S., & Sturdivant, R. X. (2013). *Applied logistic regression* (Vol. 398): John Wiley & Sons.

Houben, C. H. M., Spruit, M. A., Groenen, M. T. J., Wouters, E. F. M., & Janssen, D. J. A. (2014). Efficacy of Advance Care Planning: A Systematic Review and Meta-Analysis. *J Am Med Dir Assoc, 15*(7), 477-489. doi:10.1016/j.jamda.2014.01.008

Houben, C. H. M., Spruit, M. A., Wouters, E. F. M., & Janssen, D. J. A. (2014). A randomised controlled trial on the efficacy of advance care planning on the quality of end-of-life care and communication in patients with COPD: the research protocol. *BMJ Open, 4*(1), e004465. doi:10.1136/bmjopen-2013-004465

Houttekier, D., Cohen, J., Van den Block, L., Bossuyt, N., & Deliens, L. (2010). Involvement of palliative care services strongly predicts place of death in Belgium. *J Palliat Med, 13*(12), 1461-1468. doi:10.1089/jpm.2010.0279

How, C. H., & Koh, L. H. (2015). Not that way: Advance Care Planning. *Singapore Medical Journal, 56*(1), 19-22. doi:10.11622/smedj.2015005

Htut, Y., Shahrul, K., & Poi, P. J. (2007). The views of older Malaysians on advanced directive and advanced care planning: a qualitative study. *Asia Pac J Public Health, 19*(3), 58-67. doi:10.1177/101053950701900310

Huang, C. (2017). *Public healthcare system to be regrouped into three clusters*. Retrieved from: http://www.businesstimes.com.sg/government-economy/public-healthcare-system-to-be-regrouped-into-three-clusters

Huang, Y. C., Huang, S. J., & Ko, W. J. (2009). Going home to die from surgical intensive care units. *Intensive Care Med, 35*(5), 810-815. doi:10.1007/s00134-009-1452-1

Hunsaker, A. E., & Mann, A. (2013). An Analysis of the Patient Self-Determination Act of 1990. *Journal of Human Behavior in the Social Environment, 23*(7), 841-848. doi:10.1080/10911359.2013.809287

Hurley, S. L., Colling, C., Bender, L., Harris, P. S., Harrold, J. K., Teno, J. M., . . . Casarett, D. (2017). Increasing inpatient hospice use versus patient preferences in the USA: are patients able to die in the setting of their choice? *BMJ Support Palliat Care, 7*(1), 46-52. doi:10.1136/bmjspcare-2013-000599

Huynh, T. N., Kleerup, E. C., Wiley, J. F., Savitsky, T. D., Guse, D., Garber, B. J., & Wenger, N. S. (2013). The frequency and cost of treatment perceived to be futile in critical care. *JAMA Intern Med, 173*(20), 1887-1894. doi:10.1001/jamainternmed.2013.10261

Ikezaki, S., & Ikegami, N. (2011). Predictors of dying at home for patients receiving nursing services in Japan: A retrospective study comparing cancer and non-cancer deaths. *BMC Palliat Care, 10*, 3. doi:10.1186/1472-684x-10-3

Immigration and Checkpoints Authority Singapore. (2005-2015). *Report on registration of births and deaths*. Singapore.

Immigration and Checkpoints Authority Singapore. (2015). *Report on Registration of Births and Deaths 2014*. Singapore Retrieved from www.ica.gov.sg/cms/files/2014%20Annual%20RBD%20Report.pdf.

Institute of Medicine. (1997). *Approaching Death: Improving Care at the End of Life*. Washington, DC: The National Academies Press.

Institute of Medicine. (2015). *Dying in America: improving quality and honoring individual preferences near the end of life*. In. Retrieved from http://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near

Inter-Ministerial Committee. (1999). *Report of the Inter-Ministerial Committee on the Ageing Population*. Retrieved from http://app.msf.gov.sg/portals/0/summary/research/Materials_IMCReport.pdf.

Ishikawa, Y., Fukui, S., Saito, T., Fujita, J., Watanabe, M., & Yoshiuchi, K. (2013). Family Preference for Place of Death Mediates the Relationship between Patient Preference and Actual Place of Death: A Nationwide Retrospective Cross-Sectional Study. *PLOS ONE, 8*(3), e56848. doi:10.1371/journal.pone.0056848

Jeurkar, N., Farrington, S., Craig, T. R., Slattery, J., Harrold, J. K., Oldanie, B., . . . Casarett, D. J. (2012). Which hospice patients with cancer are able to die in the setting of their choice? Results of a retrospective cohort study. *J Clin Oncol, 30*(22), 2783-2787. doi:10.1200/jco.2011.41.5711

Jimenez, G., Tan, W. S., Virk, A. K., Low, C. K., Car, J., & Ho, A. H. Y. (2018a). Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons. *J Pain Symptom Manage, 56*(3), 436-459.e425. doi:10.1016/j.jpainsymman.2018.05.016

Jimenez, G., Tan, W. S., Virk, A. K., Low, C. K., Car, J., & Ho, A. H. Y. (2018b). State of advance care planning research: A descriptive overview of systematic reviews. *Palliat Support Care*, 1-11. doi:10.1017/s1478951518000500

Jimenez, G., Tan, W. S., Virk, A. K., Low, C. K., Car, J., & Yan Ho, A. H. (in press). Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons. *J Pain Symptom Manage*. doi:10.1016/j.jpainsymman.2018.05.016

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational researcher, 33*(7), 14-26. doi:10.3102/0013189X033007014

Johnson, S., Butow, P., Kerridge, I., & Tattersall, M. (2015). Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. *Psychooncology*. doi:10.1002/pon.3926

Johnson, S., Clayton, J., Butow, P. N., Silvester, W., Detering, K., Hall, J., . . . Tattersall, M. H. N. (2016). Advance care planning in patients with incurable cancer:

study protocol for a randomised controlled trial. *BMJ Open, 6*(12), e012387. doi:10.1136/bmjopen-2016-012387

Kahneman, D. (2005, Mar-Apr). *Determinants of health economic decisions in actual practice: the role of behavioral economics.* Paper presented at the ISPOR 10th Annual International Meeting, May 16, 2005, Washington, DC, USA

Karlsen, S., & Addington-Hall, J. (1998). How do cancer patients who die at home differ from those who die elsewhere? *Palliat Med, 12*(4), 279-286. doi:10.1191/026921698673427657

Kavalieratos, D., Corbelli, J., Zhang, D., Dionne-Odom, J. N., Ernecoff, N. C., Hanmer, J., . . . Schenker, Y. (2016). Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. *Jama, 316*(20), 2104-2114. doi:10.1001/jama.2016.16840

Kelley, A. S., Ettner, S. L., Morrison, R. S., Du, Q., Wenger, N. S., & Sarkisian, C. A. (2011). Determinants of medical expenditures in the last 6 months of life. *Ann Intern Med, 154*(4), 235-242. doi:10.7326/0003-4819-154-4-201102150-00004

Kendra, A., Rubin, E. B., & Halpern, S. D. (2016). The Problems With Physician Orders for Life-Sustaining Treatment. *Jama, 315*(3), 259-260. doi:10.1001/jama.2015.17362

Khaw, B. W. (2007). Speech at Official Opening of the Children Hospice International's 18th Congress - Live Long, Live Well, With Peace of Mind [Press release]. Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2007/official_opening_of_the_children_hospice_international_s_18th_congress.html

Khor, A. (2012). Speech by Minister-of-State for Health Dr Amy Khor at the Tsao Foundation Experts Series 2012 “Palliative care in the community: Nurses leading the way” [Press release]. Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2012/Speech-by-Minister-of-State-for-Health-Dr-Amy-Khor-at-the-Tsao-Foundation-Experts-Series-2012-Palliative-care-in-the-community-Nurses-leading-the-way.html

Khor, A. (2015). Speech by Dr Amy Khor, Senior Minister of State for Health, at the ILTC Manpower Development Awards Ceremony, 27 August 2015. Retrieved from https://www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2015/speech-by-dr-amy-khor--senior-minister-of-state-for-health--at-t6.html

Khor, A. (2016). Speech by Senior Minister of State for Health, Dr Amy Khor at the MOH Committee of Supply Debate 2016 - Better Health and Aged Care Support for Successful Ageing [Press release]. Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2016/speech-by-senior-minister-of-state-for-health--dr-amy-khor-at-th.html

Kim, K. H. (2010). Comparative study on three algorithms of the ICD-10 Charlson comorbidity index with myocardial infarction patients. *J Prev Med Public Health, 43*(1), 42-49. doi:10.3961/jpmph.2010.43.1.42

Kiong, T. C. (2004). *Chinese death rituals in Singapore*: Routledge.

Kirchhoff, K. T., Hammes, B. J., Kehl, K. A., Briggs, L. A., & Brown, R. L. (2010). Effect of a disease-specific planning intervention on surrogate understanding of patient goals for future medical treatment. *J Am Geriatr Soc, 58*(7), 1233-1240. doi:10.1111/j.1532-5415.2010.02760.x

Klingler, C., in der Schmitten, J., & Marckmann, G. (2016). Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. *Palliat Med, 30*(5), 423-433. doi:10.1177/0269216315601346

Kolarik, R. C., Arnold, R. M., Fischer, G. S., & Tulsky, J. A. (2002). Objectives for advance care planning. *J Palliat Med, 5*(5), 697-704. doi:10.1089/109662102320880516

Krishna, L. K., Alsuwaigh, R., Miti, P. T., Wei, S. S., Ling, K. H., & Manoharan, D. (2014). The influence of the family in conceptions of personhood in the palliative care setting in Singapore and its influence upon decision making. *Am J Hosp Palliat Care, 31*(6), 645-654. doi:10.1177/1049909113500136

Krishna, L. K., Watkinson, D. S., & Beng, N. L. (2015). Limits to relational autonomy--the Singaporean experience. *Nurs Ethics, 22*(3), 331-340. doi:10.1177/0969733014533239

Krishna, L. R. K. (2012). Best interests determination within the Singapore context. *Nursing Ethics, 19*(6), 787-799. doi:10.1177/0969733011433316

Kristjanson, L. J., & Aoun, S. (2004). Palliative Care for Families: Remembering the Hidden Patients. *The Canadian Journal of Psychiatry, 49*(6), 359-365. doi:10.1177/070674370404900604

Kwak, J., & Haley, W. E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist, 45*(5), 634-641. doi:10.1093/geront/45.5.634

Lackan, N. A., Eschbach, K., Stimpson, J. P., Freeman, J. L., & Goodwin, J. S. (2009). Ethnic Differences in In-Hospital Place of Death Among Older Adults in California: Effects of Individual and Contextual Characteristics and Medical Resource Supply. *Medical care, 47*(2), 138-145. doi:10.1097/MLR.0b013e3181844dba

Lai, L. (2015). MediShield Life: Answers to 101 frequently asked questions. *The Straits Times*. Retrieved from http://graphics.straitstimes.com/STI/STIMEDIA/2015/medishield-faq/faq-index.html

Lam, P. M. (2017). Speech by Dr Lam Pin Min, Senior Minister of State for Health, at Dover Park Hospice 25th Anniversary Roadshow, 23 September 2017 [Press release]. Retrieved from https://www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2017/speech-by-dr-lam-pin-min--senior-minister-of-state-for-health--a2.html

Langton, J. M., Blanch, B., Drew, A. K., Haas, M., Ingham, J. M., & Pearson, S. A. (2014). Retrospective studies of end-of-life resource utilization and costs in cancer care using health administrative data: a systematic review. *Palliat Med, 28*(10), 1167-1196. doi:10.1177/0269216314533813

Larson, D. G., & Tobin, D. R. (2000). End-of-life conversations: Evolving practice and theory. *Jama, 284*(12), 1573-1578. doi:10.1001/jama.284.12.1573

Law, F. (2015). Singapore makes strides in palliative care *TODAY*. Retrieved from www.todayonline.com/singapore/singapore-moves-quality-death-index

Lee, A., & Pang, W. S. (1998). Preferred place of death--a local study of cancer patients and their relatives. *Singapore Med J, 39*(10), 447-450.

Lee, K. C., Chang, W. C., Chou, W. C., Su, P. J., Hsieh, C. H., Chen, J. S., & Tang, S. T. (2013). Longitudinal changes and predictors of caregiving burden while providing end-of-life care for terminally ill cancer patients. *J Palliat Med, 16*(6), 632-637. doi:10.1089/jpm.2012.0499

Lee, S. K. (2009). East Asian Attitudes toward Death— A Search for the Ways to Help East Asian Elderly Dying in Contemporary America. *The Permanente Journal, 13*(3), 55-60.

Lee, T. H., & Cosgrove, D. (2014). Engaging physicians in the health care revolution. *Harvard Business Review*. Retrieved from www.hbr.org/2014/06/engaging-doctors-in-the-health-care-revolution

Leff, B., Kaffenbarger, K. P., & Remsburg, R. (2000). Prevalence, effectiveness, and predictors of planning the place of death among older persons followed in community-based long term care. *J Am Geriatr Soc, 48*(8), 943-948. doi:10.1111/j.1532-5415.2000.tb06892.x

Leng, T. K., & Sy, S. L. (1997). Advance medical directives in Singapore. *Med Law Rev, 5*(1), 63-101. doi:10.1093/medlaw/5.1.63

Leuven, E., & Sianesi, B. (2003). Stata module to perform full Mahalanobis and propensity score matching, common support graphing, and covariate imbalance testing. *Statistical Software Components S, 432001*.

Levy, C., Morris, M., & Kramer, A. (2008). Improving end-of-life outcomes in nursing homes by targeting residents at high-risk of mortality for palliative care: program description and evaluation. *J Palliat Med, 11*(2), 217-225. doi:10.1089/jpm.2007.0147

Leyland, A. H., & Goldstein, H. (2001). *Multilevel modelling of health statistics*: Wiley.

Li, J., Ngin, P. M., & Teo, A. C. (2008). Culture and leadership in Singapore: Combination of the East and the West.

Lim, E. S. (2009). Predictors of Nursing Home Admission: A Social Work Perspective. *Australian Social Work, 62*(1), 90-98. doi:10.1080/03124070802626901

Lim, W. S., Wong, S. F., Leong, I., Choo, P., & Pang, W. S. (2017). Forging a Frailty-Ready Healthcare System to Meet Population Ageing. *Int J Environ Res Public Health, 14*(12). doi:10.3390/ijerph14121448

Lin Goh, S. (2018). Singapore takes six steps forward in the Quality of Death Index rankings. *Asia-Pacific Journal of Oncology Nursing, 5*(1), 21-25. doi:10.4103/apjon.apjon_66_17

Lin, H.-C., Lin, Y.-J., Liu, T.-C., Chen, C.-S., & Lin, C.-C. (2007). Urbanization and place of death for the elderly: a 10-year population-based study. *Palliat Med, 21*(8), 705-711. doi:10.1177/0269216307083033

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (Vol. 75): Sage.

Low, J. A., Ng, W. C., Yap, K. B., & Chan, K. M. (2000). End-of-life issues--preferences and choices of a group of elderly Chinese subjects attending a day care centre in Singapore. *Ann Acad Med Singapore, 29*(1), 50-56.

Lund, S., Richardson, A., & May, C. (2015). Barriers to advance care planning at the end of life: an explanatory systematic review of implementation studies. *PLOS ONE, 10*(2), e0116629. doi:10.1371/journal.pone.0116629

Lunney, J. R., Lynn, J., Foley, D. J., Lipson, S., & Guralnik, J. M. (2003). Patterns of functional decline at the end of life. *Jama, 289*(18), 2387-2392. doi:10.1001/jama.289.18.2387

Luta, X., Maessen, M., Egger, M., Stuck, A. E., Goodman, D., & Clough-Gorr, K. M. (2015). Measuring Intensity of End of Life Care: A Systematic Review. *PLOS ONE, 10*(4), e0123764. doi:10.1371/journal.pone.0123764

Maas, C. J. M., & Hox, J. J. (2005). Sufficient Sample Sizes for Multilevel Modeling. *Methodology, 1*(3), 86-92. doi:10.1027/1614-2241.1.3.86

Mai, T. T. X., Lee, E., Cho, H., & Chang, Y. J. (2018). Increasing Trend in Hospital Deaths Consistent among Older Decedents in Korea: A Population-based Study Using Death Registration Database, 2001-2014. *17*(1), 16. doi:10.1186/s12904-017-0269-x

Malhotra, C., Chan, A., Do, Y. K., Malhotra, R., & Goh, C. (2012). Good End-of-Life Care: Perspectives of Middle-Aged and Older Singaporeans. *J Pain Symptom Manage, 44*(2), 252-263. doi:10.1016/j.jpainsymman.2011.09.007

Malhotra, C., Farooqui, M. A., Kanesvaran, R., Bilger, M., & Finkelstein, E. (2015). Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: A discrete choice experiment. *Palliat Med, 29*(9), 842-850. doi:10.1177/0269216315578803

Malhotra, C., Sim, D. K., Jaufeerally, F., Vikas, N. N., Sim, G. W., Tan, B. C., . . . Finkelstein, E. A. (2016). Impact of advance care planning on the care of patients with heart failure: study protocol for a randomized controlled trial. *Trials, 17*(1), 285. doi:10.1186/s13063-016-1414-1

Manalo, M. F. C. (2013). End-of-Life Decisions about Withholding or Withdrawing Therapy: Medical, Ethical, and Religio-Cultural Considerations. *Palliative Care, 7*, 1-5. doi:10.4137/PCRT.S10796

Martin, R. S., Hayes, B., Gregorevic, K., & Lim, W. K. (2016). The Effects of Advance Care Planning Interventions on Nursing Home Residents: A Systematic Review. *J Am Med Dir Assoc, 17*(4), 284-293. doi:10.1016/j.jamda.2015.12.017

Matsumura, S., Bito, S., Liu, H., Kahn, K., Fukuhara, S., Kagawa-Singer, M., & Wenger, N. (2002). Acculturation of attitudes toward end-of-life care: a cross-cultural survey of Japanese Americans and Japanese. *J Gen Intern Med, 17*(7), 531-539. doi:10.1046/j.1525-1497.2002.10734.x

May, C., & Finch, T. (2009). Implementing, Embedding, and Integrating Practices: An Outline of Normalization Process Theory. *Sociology, 43*(3), 535-554. doi:10.1177/0038038509103208

May, C., Finch, T., Mair, F., Ballini, L., Dowrick, C., Eccles, M., . . . Heaven, B. (2007). Understanding the implementation of complex interventions in health care: the normalization process model. *BMC Health Serv Res, 7*, 148-148. doi:10.1186/1472-6963-7-148

Mays, N., & Pope, C. (1996). *Qualitative research in health care*: Wiley Online Library.

McCullagh, P., & Nelder, J. A. (1989). Generalized Linear Models, no. 37 in Monograph on Statistics and Applied Probability. In: Chapman & Hall.

McEvoy, R., Ballini, L., Maltoni, S., O'Donnell, C. A., Mair, F. S., & MacFarlane, A. (2014). A qualitative systematic review of studies using the normalization process theory to research implementation processes. *Implementation Science, 9*(1), 2. doi:10.1186/1748-5908-9-2

McGann, S. (2011). Spatial practices and the home as hospice. *The Australasian Medical Journal, 4*(9), 495-499. doi:10.4066/AMJ.2011.931

McMillan, A., Mentnech, R. M., Lubitz, J., McBean, A. M., & Russell, D. (1990). Trends and patterns in place of death for Medicare enrollees. *Health Care Financing Review, 12*(1), 1-7.

Meeker, M. A., & Jezewski, M. A. (2005). Family decision making at end of life. *Palliat Support Care, 3*(2), 131-142. doi:https://doi.org/10.1017/S1478951505050212

Mehta, K. K. (2006). A Critical Review of Singapore's Policies Aimed at Supporting Families Caring for Older Members. *Journal of Aging & Social Policy, 18*(3-4), 43-57. doi:10.1300/J031v18n03_04

Meier, E. A., Gallegos, J. V., Montross-Thomas, L. P., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue. *The American journal of geriatric* *psychiatry : official journal of the American Association for Geriatric Psychiatry, 24*(4), 261-271. doi:10.1016/j.jagp.2016.01.135

Menard, S. (2002). *Applied logistic regression analysis* (Vol. 106): Sage.

Menon, S. (2013). The mental capacity act: implications for patients and doctors faced with difficult choices. *Ann Acad Med Singapore, 42*(4), 200-202.

Milligan, C., Turner, M., Blake, S., Brearley, S., Seamark, D., Thomas, C., . . . Payne, S. (2016). Unpacking the impact of older adults' home death on family care-givers' experiences of home. *Health Place, 38*, 103-111. doi:10.1016/j.healthplace.2016.01.005

Ming, K., & Rosenbaum, P. R. (2000). Substantial gains in bias reduction from matching with a variable number of controls. *Biometrics, 56*(1), 118-124. doi:10.1111/j.0006-341X.2000.00118.x

Ministerial Committee on Ageing. (2015). *$3 billion action plan to enable Singaporeans to age successfully*.

Ministry of Health. (1993). *Affordable Health Care: A White Paper*. Retrieved from https://www.moh.gov.sg/content/dam/moh_web/Publications/Reports/1993/Affordable_Health_Care.pdf.

Ministry of Health. (1997). *National Medical Ethics Committee*. Retrieved from www.moh.gov.sg/content/dam/moh_web/Publications/Reports/1998/National%20Medical%20Ethics.pdf.

Ministry of Health. (2008). *Advance Medical Directive: What you should know*. Retrieved from www.moh.gov.sg/content/dam/moh_web/Publications/Educational%20Resources/2008/AMD%20Booklet-final.pdf.

Ministry of Health. (2009). Further Medisave Liberalisation. In. Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/pressRoomItemRelease/2009/further_medisave_liberalisation.html.

Ministry of Health. (2015). Subsidies for Government-funded Intermediate Long-Term Care Services Retrieved from www.moh.gov.sg/content/moh_web/home/costs_and_financing/schemes_subsidies/subsidies_for_government_funded_ILTC_services.html

Ministry of Health. (2016a). *I feel young in my Singapore! Action Plan for Successful Ageing*. Singapore: Ministry of Health Retrieved from www.moh.gov.sg/content/dam/moh_web/SuccessfulAgeing/action-plan.pdf.

Ministry of Health. (2016b, Jul 11, 2016). Parliamentary Question and Answer - Advance Medical Directive (AMD). Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/Parliamentary_QA/2016/advanced-medical-directive--amd-.html

Ministry of Health. (2017a). Health Facilities. Retrieved from www.moh.gov.sg/content/moh_web/home/statistics/Health_Facts_Singapore/Health_Facilities.html

Ministry of Health. (2017b). *Medisave for Terminal Illness*. Retrieved from https://www.moh.gov.sg/content/moh_web/home/pressRoom/Parliamentary_QA/2016/medisave-for-terminal-illness.html.

Ministry of Health. (2017c). Pioneer Generation Package Retrieved from www.moh.gov.sg/content/moh_web/home/costs_and_financing/schemes_subsidies/pioneer-generation-package.html

Ministry of Health. (2017d). Reorganisation of healthcare system into three integrated clusters to better meet future healthcare needs [Press release]. Retrieved from www.moh.gov.sg/content/moh_web/home/pressRoom/pressRoomItemRelease/2017/reorganisation-of-healthcare-system-into-three-integrated-cluste.html

Ministry of Health. (2018). Summary of Medisave Withdrawal Limits Retrieved from https://www.moh.gov.sg/content/moh_web/home/costs_and_financing/schemes_subsidies/medisave/Withdrawal_Limits/Summary_of_Medisave_Withdrawal_Limits.html

Ministry of Health Labour and Welfare. (2015). Handbook of Health and Welfare Statistics 2015. Retrieved from http://www.mhlw.go.jp/english/database/db-hh/1-2.html

Ministry of Manpower. (2015). Frequently Asked Questions (FAQs) on Enhanced Foreign Domestic Worker (FDW) Levy Concessions 2015. Retrieved from http://www.mom.gov.sg/~/media/mom/documents/budget2015/faqs-on-enhanced-fdw-levy-concession.pdf

Ministry of Social and Family Development. (2015). *Families and Households in Singapore 2000-2014*. Retrieved from https://www.msf.gov.sg/research-and-data/Research-and-Statistics/Pages/Families-and-Households-in-Singapore-2000-2014.aspx.

MOH Holdings Pte Ltd. (2015). Caring for Our People: 50 Years of Healthcare in Singapore. In. Singapore. Retrieved from http://www.mohh.com.sg/Documents/book/caring-for-our-people-50-years-of-healthcare-in-singapore.pdf.

Mok, E., Chan, F., Chan, V., & Yeung, E. (2003). Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nurs, 26*(4), 267-275.

Molloy, D., Guyatt, G. H., Russo, R., Goeree, R., O'Brien, B. J., & Bédard, M. (2000). Systematic implementation of an advance directive program: a randomized trial in six nursing homes. *Jama, 283*. doi:10.1001/jama.283.11.1437

Moorman, S. M., Carr, D., Kirchhoff, K. T., & Hammes, B. J. (2012). An assessment of social diffusion in the Respecting Choices advance care planning program. *Death Stud, 36*(4), 301-322.

Moos, R. H. (1977). Coping with physical illness.

Mori, M., & Morita, T. (2016). Advances in Hospice and Palliative Care in Japan: A Review Paper. *Korean Journal of Hospice and Palliative Care, 19*(4), 283-291. doi:10.14475/kjhpc.2016.19.4.283

Morrison, R. S., Chichin, E., Carter, J., Burack, O., Lantz, M., & Meier, D. E. (2005). The Effect of a Social Work Intervention to Enhance Advance Care Planning

Documentation in the Nursing Home. *J Am Geriatr Soc, 53*(2), 290-294. doi:10.1111/j.1532-5415.2005.53116.x

Morse, J. M. (1991). Strategies for sampling. *Qualitative nursing research: A contemporary dialogue*, 127-145.

Moustakas, C. (1994). *Phenomenological research methods*: Sage.

Munday, D., Dale, J., & Murray, S. (2007). Choice and place of death: individual preferences, uncertainty, and the availability of care. *Journal of the Royal Society of Medicine, 100*(5), 211-215. doi:10.1258/jrsm.100.5.211

Munday, D., Johnson, S., & Griffiths, F. (2003). Complexity theory and palliative care. *Palliat Med, 17*(4), 308.

Munday, D., Petrova, M., & Dale, J. (2009). Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England. *Bmj, 339*. doi:10.1136/bmj.b2391

Murray, E., Treweek, S., Pope, C., MacFarlane, A., Ballini, L., Dowrick, C., . . . May, C. (2010). Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. *BMC Medicine, 8*(1), 63. doi:10.1186/1741-7015-8-63

Murray, L., & Butow, P. N. (2016). Advance care planning in motor neuron disease: A systematic review. *Palliat Support Care, 14*(4), 411-432. doi:10.1017/s1478951515001066

Murtagh, F., Bausewein, C., Petkova, H., Sleeman, K., Dodd, R., Gysels, M., . . . Shipman, C. (2012). *Understanding place of death for patients with non malignant conditions: a systematic literature review*. NIHR Service Delivery and Organisation Programme Retrieved from http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1813-257_V01.pdf.

National Audit Office. (2005). *Tackling cancer: improving the patient journey*. London: The Stationery Office,: Report by the Comptroller and Auditor General, HC 288 Session 2004–2005.

National Cancer Centre. (2006). NCCS launches specialist programme in Palliative Medicine [Press release]. Retrieved from https://www.nccs.com.sg/Newsroom/MediaReleases/2006MediaReleases/Pages/27Feb2006_NCCSLaunchesSpecialistProgrammeInPalliativeMedicine.aspx

National End of Life Care Intelligence Network. (2015). Place of death - Number and proportion of deaths by place of occurrence. Retrieved from http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

National Health Services Choices. (2015, July 9, 2015). What end of life care involves. Retrieved from https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/

National Medical Ethics Committee. (2010). *Guide for healthcare professionals on the ethical handling of communication in advance care planning*. Ministry of Health Retrieved from www.moh.gov.sg/content/moh_web/home/Publications/guidelines/national_medical_ethics_committee_guidelines/2010/guide_to_ethical_handling_of_communication_in_ACP.html.

National Population and Talent Division. (2013). *A Sustainable Population for a Dynamic Singapore: Population White Paper*. Singapore Retrieved from www.mti.gov.sg/MTIInsights/Documents/NPTDWP_LR.pdf.

National Strategy for Palliative Care Workgroup. (2011). *Report on the National Stategy for Palliative Care*
Retrieved from www.duke-nus.edu.sg/sites/default/files/Report_on_National_Strategy_for_Palliative_Care%205Jan2012.pdf.

Naylor, M. D. (2002). Transitional care of older adults. *Annu Rev Nurs Res, 20*, 127-147.

Ng, C. W. L., Cheong, S. K., Govinda Raj, A., Teo, W. S. K., & Leong, I. Y. O. (2016). End-of-life care preferences of nursing home residents: Results of a cross-sectional study. *Palliat Med, 30*(9), 843-853. doi:10.1177/0269216316634242

Ng, R. L. H. (2016). Advance Care Planning in the Healthcare Continuum: A Narrative Synthesis. *The Singapore Family Physician, 42*(3), 7-12.

Ng, W. C. (2011). My last wishes: More health-care institutions are trying to make sure patients have control over their final days by getting them to express their wishes and put them down in writing. *The Straits Times*. Retrieved from www.ttsh.com.sg/about-us/newsroom/news/article.aspx?id=2734

Niti, M., & Ng, T. P. (2003). Avoidable hospitalisation rates in Singapore, 1991-1998: assessing trends and inequities of quality in primary care. *J Epidemiol Community Health, 57*(1), 17-22.

Oechsle, K., Goerth, K., Bokemeyer, C., & Mehnert, A. (2013). Anxiety and depression in caregivers of terminally ill cancer patients: impact on their perspective of the patients' symptom burden. *J Palliat Med, 16*(9), 1095-1101. doi:10.1089/jpm.2013.0038

Oliver, D. P. (2005). End-of-Life Care in U.S. Nursing Homes: A Review of the Evidence. *J Am Med Dir Assoc, 6*(3), S20. doi:10.1016/j.jamda.2005.03.032

Omery, A. (1983). Phenomenology: a method for nursing research. *ANS Adv Nurs Sci, 5*(2), 49-63.

Ong, Y. J. (2017). End-of-life discussions must go beyond medical preferences. *The Straits Times*. Retrieved from www.straitstimes.com/forum/letters-in-print/end-of-life-discussions-must-go-beyond-medical-preferences

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health services research, 34*(5 Pt 2), 1189-1208.

Paul, P., Pennell, M. L., & Lemeshow, S. (2013). Standardizing the power of the Hosmer–Lemeshow goodness of fit test in large data sets. *Statistics in Medicine, 32*(1), 67-80. doi:10.1002/sim.5525

Payne, S., Brearley, S., Milligan, C., Seamark, D., Thomas, C., Wang, X., . . . Turner, M. (2012). The perspectives of bereaved family carers on dying at home: the study protocol of ‘unpacking the home: family carers’ reflections on dying at home. *BMC Palliative Care, 11*, 23-23. doi:10.1186/1472-684X-11-23

Penrod, J., Hupcey, J. E., Baney, B. L., & Loeb, S. J. (2011). End-of-Life Caregiving Trajectories. *Clinical nursing research, 20*(1), 7-24. doi:10.1177/1054773810384852

Peters, D. H., Adam, T., Alonge, O., Agyepong, I. A., & Tran, N. (2013). Implementation research: what it is and how to do it. *BMJ : British Medical Journal, 347*. doi:10.1136/bmj.f6753

Pham, B., & Krahn, M. (2014). End-of-Life Care Interventions: An Economic Analysis. *Ontario Health Technology Assessment Series, 14*(18), 1-70.

Phua, J., Joynt, G. M., Nishimura, M., Deng, Y., Myatra, S. N., Chan, Y. H., . . . Koh, Y. (2015). Withholding and withdrawal of life-sustaining treatments in intensive care units in Asia. *JAMA Intern Med, 175*(3), 363-371. doi:10.1001/jamainternmed.2014.7386

Phua, J., Kee, A. C., Tan, A., Mukhopadhyay, A., See, K. C., Aung, N. W., . . . Lim, T. K. (2011). End-of-life care in the general wards of a Singaporean hospital: an Asian perspective. *J Palliat Med, 14*(12), 1296-1301. doi:10.1089/jpm.2011.0215

Pollock, K. (2015). Is home always the best and preferred place of death? *BMJ : British Medical Journal, 351*. doi:10.1136/bmj.h4855

Pollock, K., & Wilson, E. (2015). Care and communication between health professionals and patients affected by severe or chronic illness in community care settings: a qualitative study of care at the end of life*., 31*(3). doi:10.3310/hsdr03310

Poulose, J. V., Do, Y. K., & Neo, P. S. (2013). Association between referral-to-death interval and location of death of patients referred to a hospital-based specialist palliative care service. *J Pain Symptom Manage, 46*(2), 173-181. doi:10.1016/j.jpainsymman.2012.08.009

Proctor, E., Silmere, H., Raghavan, R., Hovmand, P., Aarons, G., Bunger, A., . . . Hensley, M. (2011). Outcomes for Implementation Research: Conceptual Distinctions, Measurement Challenges, and Research Agenda. *Administration and Policy in Mental Health, 38*(2), 65-76. doi:10.1007/s10488-010-0319-7

Qian, X., Russell, L. B., Valiyeva, E., & Miller, J. E. (2011). "Quicker and sicker" under Medicare's prospective payment system for hospitals: new evidence on an old issue from a national longitudinal survey. *Bull Econ Res, 63*(1), 1-27.

QSR International Pty Ltd. (2016). NVivo qualitative data analysis Software (Version 11). Retrieved from http://www.qsrinternational.com/products_nvivo.aspx

Quah, E. (2015). *Singapore 2065: Leading Insights on Economy and Environment from 50 Singapore Icons and Beyond*: World Scientific.

Quan, H., Sundararajan, V., Halfon, P., Fong, A., Burnand, B., Luthi, J.-C., . . . Ghali, W. A. (2005). Coding algorithms for defining comorbidities in ICD-9-CM and ICD-10 administrative data. *Medical care*, 1130-1139. doi:10.1097/01.mlr.0000182534.19832.83 ,

Raijmakers, N. J. H., on behalf of, O., van Zuylen, L., on behalf of, O., Costantini, M., on behalf of, O., . . . on behalf of, O. (2011). Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects. *Annals of oncology, 22*(7), 1478-1486. doi:10.1093/annonc/mdq620

Rao, J. K., Anderson, L. A., Lin, F.-C., & Laux, J. P. (2014). Completion of Advance Directives Among U.S. Consumers. *American journal of preventive medicine, 46*(1), 65-70. doi:10.1016/j.amepre.2013.09.008

Ratner, E., Norlander, L., & McSteen, K. (2001). Death at home following a targeted advance-care planning process at home: the kitchen table discussion. *J Am Geriatr Soc, 49*(6), 778-781. doi:10.1046/j.1532-5415.2001.49155.x

Registrar-General of Births and Deaths. (1985-2000). *Report on registration of births and deaths* Singapore: Singapore : Registry of Births and Deaths.

Registry of Births and Deaths. (1965). *Report on the registration of births and deaths, marriages, and persons*. Singapore: Singapore : Registry of Births and Deaths.

Registry of Births and Deaths. (1970-1980). *Report on the registration of births and deaths and marriages*. Singapore: Singapore : Registry of Births and Deaths.

Reich, O., Signorell, A., & Busato, A. (2013). Place of death and health care utilization for people in the last 6 months of life in Switzerland: a retrospective analysis using administrative data. *BMC health services research, 13*(1), 1. doi:10.1186/1472-6963-13-116

Reidy, J., Halvorson, J., Makowski, S., Katz, D., Weinstein, B., McCluskey, C., . . . Tjia, J. (2017). Health System Advance Care Planning Culture Change for High-Risk Patients: The Promise and Challenges of Engaging Providers, Patients, and Families in Systematic Advance Care Planning. *J Palliat Med, 20*(4), 388-394. doi:10.1089/jpm.2016.0272

Reyniers, T., Deliens, L., Pasman, H. R., Vander Stichele, R., Sijnave, B., Cohen, J., & Houttekier, D. (2016). Reasons for End-of-Life Hospital Admissions: Results of a Survey Among Family Physicians. *J Pain Symptom Manage, 52*(4), 498-506. doi:10.1016/j.jpainsymman.2016.05.014

Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., . . . Korfage, I. J. (2017). Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *The Lancet Oncology, 18*(9), e543-e551. doi:10.1016/S1470-2045(17)30582-X

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). *Qualitative research practice: A guide for social science students and researchers*: sage.

Rolnick, J. A., Asch, D. A., & Halpern, S. D. (2017). Delegalizing Advance Directives - Facilitating Advance Care Planning. *N Engl J Med, 376*(22), 2105-2107. doi:10.1056/NEJMp1700502

Rosenbaum, P. R., & Rubin, D. B. (1983). The central role of the propensity score in observational studies for causal effects. *Biometrika, 70*(1), 41-55. doi:10.1093/biomet/70.1.41

Rothman , D. J. (2014). Where We Die. *New England Journal of Medicine, 370*(26), 2457-2460. doi:10.1056/NEJMp1404427

Rothman, K. J., Greenland, S., & Lash, T. L. (2008). Modern epidemiology.

Rubin, D. B. (2001). Using propensity scores to help design observational studies: application to the tobacco litigation. *Health Services and Outcomes Research Methodology, 2*(3), 169-188. doi:10.1023/A:1020363010465

Ruhnke, G. W., Wilson, S. R., Akamatsu, T., Kinoue, T., Takashima, Y., Goldstein, M. K., . . . Raffin, T. A. (2000). Ethical decision making and patient autonomy: a comparison of physicians and patients in Japan and the United States. *Chest, 118*(4), 1172-1182. doi:10.1378/chest.118.4.1172

Sabatino, C. P. (2010). The evolution of health care advance planning law and policy. *Milbank Q, 88*(2), 211-239. doi:10.1111/j.1468-0009.2010.00596.x

Sager, M. A., Easterling, D. V., Kindig, D. A., & Anderson, O. W. (1989). Changes in the Location of Death after Passage of Medicare's Prospective Payment System. *New England Journal of Medicine, 320*(7), 433-439. doi:10.1056/nejm198902163200705

Sanderson, C., Lobb, E. A., Mowll, J., Butow, P. N., McGowan, N., & Price, M. A. (2013). Signs of post-traumatic stress disorder in caregivers following an expected death: a qualitative study. *Palliat Med, 27*(7), 625-631. doi:10.1177/0269216313483663

Sankaran, S., Kenealy, T., Adair, A., Adair, V., Coster, H., Whitehead, N., . . . Bailey, L. (2010). A complex intervention to support 'rest home' care: a pilot study. *The New Zealand Medical Journal (Online), 123*(1308).

Sarhill, N., LeGrand, S., Islambouli, R., Davis, M. P., & Walsh, D. (2001). The terminally ill Muslim: death and dying from the Muslim perspective. *Am J Hosp Palliat Care, 18*(4), 251-255. doi:10.1177/104990910101800409

Sarmento, V. P., Gysels, M., Higginson, I. J., & Gomes, B. (2017). Home palliative care works: but how? A meta-ethnography of the experiences of patients and family caregivers. *BMJ Support Palliat Care, 7*(4), 0. doi:10.1136/bmjspcare-2016-001141

Schamp, R., & Tenkku, L. (2006). Managed death in a PACE: pathways in present and advance directives. *J Am Med Dir Assoc, 7*(6), 339-344. doi:10.1016/j.jamda.2006.01.022

Schubart, J. R., Kinzie, M. B., & Farace, E. (2008). Caring for the brain tumor patient: Family caregiver burden and unmet needs. *Neuro-Oncology, 10*(1), 61-72. doi:10.1215/15228517-2007-040

Schwartz, D., & Lellouch, J. (2009). Explanatory and pragmatic attitudes in therapeutical trials. *J Clin Epidemiol, 62*(5), 499-505. doi:10.1016/j.jclinepi.2009.01.012

Searight, H. R., & Gafford, J. (2005). Cultural diversity at the end of life: issues and guidelines for family physicians. *Am Fam Physician, 71*(3), 515-522.

Sessanna, L., & Jezewski, M. A. (2008). Advance Directive Decision Making Among Independent Community-Dwelling Older Adults:A Systematic Review of Health Science Literature. *Journal of Applied Gerontology, 27*(4), 486-510. doi:10.1177/0733464808315286

Sharma, G., Freeman, J., Zhang, D., & Goodwin, J. S. (2009). Continuity of care and ICU utilization during end of life. *Archives of Internal Medicine, 169*(1), 81-86. doi:10.1001/archinternmed.2008.514

Sharp, T., Moran, E., Kuhn, I., & Barclay, S. (2013). Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. *Br J Gen Pract, 63*(615), e657-668. doi:10.3399/bjgp13X673667

Sheikh, A. (1998). Death and dying--a Muslim perspective. *J R Soc Med, 91*(3), 138-140.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information, 22*(2), 63-75. doi:10.3233/EFI-2004-22201

Shih, C.-Y., Hu, W.-Y., Cheng, S.-Y., Yao, C.-A., Chen, C.-Y., Lin, Y.-C., & Chiu, T.-Y. (2015). Patient Preferences versus Family Physicians' Perceptions Regarding the Place of End-of-Life Care and Death: A Nationwide Study in Taiwan. *J Palliat Med, 18*(7), 625-630. doi:10.1089/jpm.2014.0386

Shin, D. W., Lee, J. E., Cho, B., Yoo, S. H., Kim, S., & Yoo, J. H. (2016). End-of-life communication in Korean older adults: With focus on advance care planning and advance directives. *Geriatr Gerontol Int, 16*(4), 407-415. doi:10.1111/ggi.12603

Siminoff, L. A. (2013). Incorporating patient and family preferences into evidence-based medicine. *BMC Medical Informatics and Decision Making, 13*(3), S6. doi:10.1186/1472-6947-13-s3-s6

Singapore, Parliament of Singapore. (1996). *Debates: Advance Medical Directive Bill (As reported from Select Committee)*. Singapore Government.

Singapore, Parliament of Singapore. (2006). *Oral Answers to Questions: Advance Medical Directive (Adoption Rates)*.

Singapore, Parliament of Singapore. (2010). *Answer to Question: Palliative care for ageing population*.

Singapore, Parliament of Singapore. (2016a). *Debate: Mental Capacity (Amendment) Bill*.

Singapore, Parliament of Singapore. (2016b). Oral Answer to Question: Number of Singaporeans who have signed Advance Medical Directives. In.

Singapore Hospice Council. (2015). *National Guidelines for Palliative Care and Interpretation Guide*. Singapore: Singapore Hospice Council Retrieved from singaporehospice.org.sg/shc/wp-content/uploads/2016/09/NGPCInterpret2015Dec.pdf.

Singer, P. A., & Bowman, K. W. (2002). Quality end-of-life care: A global perspective. *BMC Palliative Care, 1*, 4-4. doi:10.1186/1472-684X-1-4

Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: patients' perspectives. *Jama, 281*(2), 163-168. doi:10.1001/jama.281.2.163

Singer, Y., Bachner, Y. G., Shvartzman, P., & Carmel, S. (2005). Home death--the caregivers' experiences. *J Pain Symptom Manage, 30*(1), 70-74. doi:10.1016/j.jpainsymman.2005.01.016

Skinner, J., Staiger, D., & Fisher, E. S. (2010). Looking back, moving forward. *N Engl J Med, 362*(7), 569-574; discussion 574. doi:10.1056/NEJMp1000448

Song, M. K., Kirchhoff, K. T., Douglas, J., Ward, S., & Hammes, B. (2005). A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery. *Med Care, 43*(10), 1049-1053.

Stagg, V. (2015). CHARLSON: Stata module to calculate Charlson index of comorbidity. *Statistical Software Components*.

Stajduhar, K. I., Martin, W. L., Barwich, D., & Fyles, G. (2008). Factors Influencing Family Caregivers' Ability to Cope With Providing End-of-Life Cancer Care at Home. *Cancer Nurs, 31*(1), 77-85. doi:10.1097/01.NCC.0000305686.36637.b5

Stamuli, E. (2011). Health outcomes in economic evaluation: who should value health? *Br Med Bull, 97*, 197-210. doi:10.1093/bmb/ldr001

StataCorp. (2011). Stata Statistical Software: Release 12. College Station, TX: StataCorp LP.

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Jama, 284*(19), 2476-2482. doi:10.1001/jama.284.19.2476

Strauss, A. L., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedure and techniques*. Newbury Park: Sage Publications.

Sturmer, T., Joshi, M., Glynn, R. J., Avorn, J., Rothman, K. J., & Schneeweiss, S. (2006). A review of the application of propensity score methods yielded increasing use, advantages in specific settings, but not substantially different estimates compared with conventional multivariable methods. *J Clin Epidemiol, 59*(5), 437-447. doi:10.1016/j.jclinepi.2005.07.004

Sudore, R. L., & Fried, T. R. (2010). Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making. *Ann Intern Med, 153*(4), 256-261. doi:10.1059/0003-4819-153-4-201008170-00008

Sudore, R. L., Heyland, D. K., Lum, H. D., Rietjens, J. A. C., Korfage, I. J., Ritchie, C. S., . . . You, J. J. (2017). Outcomes that Define Successful Advance Care Planning: A Delphi Panel Consensus. *J Pain Symptom Manage*. doi:10.1016/j.jpainsymman.2017.08.025

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., . . . Heyland, D. K. (2017). Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage, 53*(5), 821-832.e821. doi:10.1016/j.jpainsymman.2016.12.331

Tai, J. (2017). Dying at home is what many want, but few do. *The Straits Times*. Retrieved from www.straitstimes.com/singapore/health/dying-at-home-is-what-many-want-but-few-do

Tan, C. H. (1989). Confucianism and nation building in Singapore. *International Journal of Social Economics, 16*(8), 5-16. doi:10.1108/03068298910133106

Tan, J., & Chin, J. J. (2011). *What doctors say about care of the dying*: Lien Foundation.

Tan, K. B., Tan, W. S., Bilger, M., & Ho, C. W. (2014). Monitoring and evaluating progress towards universal health coverage in Singapore. *PLoS Med, 11*(9), e1001695. doi:10.1371/journal.pmed.1001695

Tan, S. (2018). Speedoc app lets you call the nearest doctor to your home. *The New Paper*. Retrieved from https://www.tnp.sg/news/singapore/speedoc-app-lets-you-call-nearest-doctor-your-home

Tan, W. (2012). Dying at home is expensive. *TODAY*. Retrieved from http://doctors.com.sg/medical/healthcare-news/dying-at-home-is-expensive/

Tan, W. S., Lee, A., Yang, S. Y., Chan, S., Wu, H. Y., Ng, C. W., & Heng, B. H. (2016). Integrating palliative care across settings: A retrospective cohort study of a hospice home care programme for cancer patients. *Palliat Med, 30*(7), 634-641. doi:10.1177/0269216315622126

Tang, S. T. (2000). Meanings of dying at home for Chinese patients in Taiwan with terminal cancer: a literature review. *Cancer Nurs, 23*(5), 367-370.

Tang, S. T., Huang, E. W., Liu, T. W., Rau, K. M., Hung, Y. N., & Wu, S. C. (2010). Propensity for home death among Taiwanese cancer decedents in 2001-2006, determined by services received at end of life. *J Pain Symptom Manage, 40*(4), 566-574. doi:10.1016/j.jpainsymman.2010.01.020

Tang, S. T., & McCorkle, R. (2003). Determinants of congruence between the preferred and actual place of death for terminally ill cancer patients. *J Palliat Care, 19*(4), 230-237.

Tang, S. T., McCorkle, R., & Bradley, E. H. (2004). Determinants of death in an inpatient hospice for terminally ill cancer patients. *Palliat Support Care, 2*(4), 361-370.

Tangka, F. K., Subramanian, S., Sabatino, S. A., Howard, D. H., Haber, S., Hoover, S., & Richardson, L. C. (2015). End-of-Life Medical Costs of Medicaid Cancer Patients. *Health Serv Res, 50*(3), 690-709. doi:10.1111/1475-6773.12259

Tay, K., Yu Lee, R. J., Sim, S. W., Menon, S., Kanesvaran, R., & Radha Krishna, L. K. (2017). Cultural influences upon advance care planning in a family-centric society. *Palliat Support Care*, 1-10. doi:10.1017/s1478951516001139

Tay, M., Chia, S. E., & Sng, J. (2010). Knowledge, attitudes and practices of the Advance Medical Directive in a residential estate in Singapore. *Ann Acad Med Singapore, 39*(6), 424-428.

Teno, J. M., Gruneir, A., Schwartz, Z., Nanda, A., & Wetle, T. (2007). Association between advance directives and quality of end-of-life care: a national study. *J Am Geriatr Soc, 55*(2), 189-194. doi:10.1111/j.1532-5415.2007.01045.x

Teo, W. S., Raj, A. G., Tan, W. S., Ng, C. W., Heng, B. H., & Leong, I. Y. (2014). Economic impact analysis of an end-of-life programme for nursing home residents. *Palliat Med, 28*(5), 430-437. doi:10.1177/0269216314526270

The Economist Intelligence Unit. (2015). *The 2015 Quality of Death Index Ranking palliative care across the world.* Retrieved from http://www.economistinsights.com/healthcare/analysis/quality-death-index-2015

The Singapore Free Press. (1948). The Street of the Houses of the Dead, 4. Retrieved from http://eresources.nlb.gov.sg/newspapers/Digitised/Article/freepress19480925-1.2.44

The Straits Times. (1962). Death Houses Now Refuse the Living. *The Straits Times,* (4). Retrieved from http://eresources.nlb.gov.sg/newspapers/Digitised/Article/straitstimes19620911-1.2.28

Thomas, C., Morris, S. M., & Clark, D. (2004). Place of death: preferences among cancer patients and their carers. *Soc Sci Med, 58*(12), 2431-2444. doi:10.1016/j.socscimed.2003.09.005

Thomas, R. E., Wilson, D., & Sheps, S. (2006). A literature review of randomized controlled trials of the organization of care at the end of life. *Can J Aging, 25*(3), 271-293. doi:10.1353/cja.2007.0011

Thorley, J. (2015). Too many die without dignity. *Lancet Oncol, 16*(7), e315. doi:10.1016/s1470-2045(15)00008-x

Toh, Y. C. (2016). Who is looking after the elderly? 'I'd rather die than go to a home'. Retrieved from www.straitstimes.com/singapore/id-rather-die-than-go-to-a-home

Townsend, J., Frank, A. O., Fermont, D., Dyer, S., Karran, O., Walgrove, A., & Piper, M. (1990). Terminal cancer care and patients' preference for place of death: a prospective study. *Bmj, 301*(6749), 415-417.

Tse, D. M., Chan, K. S., Lam, W. M., Leu, K., & Lam, P. T. (2007). The impact of palliative care on cancer deaths in Hong Kong: a retrospective study of 494 cancer deaths. *Palliat Med, 21*(5), 425-433. doi:10.1177/0269216307079825

Tunis, S. R., Stryer, D. B., & Clancy, C. M. (2003). Practical clinical trials: increasing the value of clinical research for decision making in clinical and health policy. *Jama, 290*(12), 1624-1632. doi:10.1001/jama.290.12.1624

Turley, M., Wang, S., Meng, D., Kanter, M. H., & Garrido, T. (2016). An information model for automated assessment of concordance between advance care preferences and care delivered near the end of life. *J Am Med Inform Assoc, 23*(e1), e118-124. doi:10.1093/jamia/ocv149

van der Steen, J. T., van Soest-Poortvliet, M. C., Hallie-Heierman, M., Onwuteaka-Philipsen, B. D., Deliens, L., de Boer, M. E., . . . de Vet, H. C. (2014). Factors associated with initiation of advance care planning in dementia: a systematic review. *J Alzheimers Dis, 40*(3), 743-757. doi:10.3233/jad-131967

Vanderhaeghen, B., Bossuyt, I., Opdebeeck, S., Menten, J., & Rober, P. (2017). Toward Hospital Implementation of Advance Care Planning: Should Hospital Professionals Be Involved? *Qual Health Res, 28*(3), 456-465. doi:10.1177/1049732317735834

Waghorn, M., Young, H., & Davies, A. (2011). Opinions of patients with cancer on the relative importance of place of death in the context of a 'good death'. *BMJ Support Palliat Care, 1*. doi:10.1136/bmjspcare-2011-000041

Wagstaff, A. (2007). Health systems in East Asia: what can developing countries learn from Japan and the Asian Tigers? *Health Econ, 16*(5), 441-456. doi:10.1002/hec.1180

Wahid, A. S., Sayma, M., Jamshaid, S., Kerwat, D. a., Oyewole, F., Saleh, D., . . . Payne, S. (2017). Barriers and facilitators influencing death at home: A meta-ethnography. *Palliat Med*, 0269216317713427. doi:10.1177/0269216317713427

Walczak, A., Butow, P. N., Bu, S., & Clayton, J. M. (2016). A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work? *Patient Educ Couns, 99*(1), 3-16. doi:10.1016/j.pec.2015.08.017

Wang, L., Piet, L., Kenworthy, C. M., & Dy, S. M. (2015). Association between palliative case management and utilization of inpatient, intensive care unit, emergency department, and hospice in medicaid beneficiaries. *Am J Hosp Palliat Care, 32*(2), 216-220. doi:10.1177/1049909113520067

Wang, S. Y., Aldridge, M. D., Gross, C. P., Canavan, M., Cherlin, E., & Bradley, E. (2017). End-of-Life Care Transition Patterns of Medicare Beneficiaries. *J Am Geriatr Soc, 65*(7), 1406-1413. doi:10.1111/jgs.14891

Weathers, E., Cornally, N., Daly, E., Coffey, A., & Molloy, W. (2014). *Planning for end-of-life: a systematic review of randomised controlled trials conducted with older adults*. Cork: 14th Annual Nursing and Midwifery Research Conference.

Weathers, E., O'Caoimh, R., Cornally, N., Fitzgerald, C., Kearns, T., Coffey, A., . . . Molloy, D. W. (2016). Advance care planning: A systematic review of randomised controlled trials conducted with older adults. *Maturitas, 91*, 101-109. doi:10.1016/j.maturitas.2016.06.016

Wendler, D., & Rid, A. (2011). Systematic review: the effect on surrogates of making treatment decisions for others. *Ann Intern Med, 154*(5), 336-346. doi:10.7326/0003-4819-154-5-201103010-00008

Wicher, C. P., & Meeker, M. A. (2012). What influences African American end-of-life preferences? *J Health Care Poor Underserved, 23*(1), 28-58. doi:10.1353/hpu.2012.0027

Williams, A. M. (2004). Shaping the practice of home care: critical case studies of the significance of the meaning of home. *Int J Palliat Nurs, 10*(7), 333-342. doi:10.12968/ijpn.2004.10.7.14575

Wilson, D. M., Truman, C. D., Thomas, R., Fainsinger, R., Kovacs-Burns, K., Froggatt, K., & Justice, C. (2009). The rapidly changing location of death in Canada, 1994-2004. *Soc Sci Med, 68*(10), 1752-1758. doi:10.1016/j.socscimed.2009.03.006

Winzelberg, G. S., Hanson, L. C., & Tulsky, J. A. (2005). Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *J Am Geriatr Soc, 53*(6), 1046-1050. doi:10.1111/j.1532-5415.2005.53317.x

Woo, J. A., Maytal, G., & Stern, T. A. (2006). Clinical Challenges to the Delivery of End-of-Life Care. *Primary Care Companion to The Journal of Clinical Psychiatry, 8*(6), 367-372.

Wood, C., & Salter, J. (2013). A time and a place: What people want at the end of life. *Sue Ryder*.

World Health Organization. (2018). WHO Definition of Palliative Care. Retrieved from http://www.who.int/cancer/palliative/definition/en/

Wright, A. A., Keating, N. L., Balboni, T. A., Matulonis, U. A., Block, S. D., & Prigerson, H. G. (2010). Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol, 28*(29), 4457-4464. doi:10.1200/jco.2009.26.3863

Wright, A. A., Mack, J. W., Kritek, P. A., Balboni, T. A., Massaro, A. F., Matulonis, U. A., . . . Prigerson, H. G. (2010). Influence of Patients' Preferences and Treatment Site on Cancer Patients' End-of-Life Care. *Cancer, 116*(19), 4656-4663. doi:10.1002/cncr.25217

Yamagishi, A., Morita, T., Miyashita, M., Yoshida, S., Akizuki, N., Shirahige, Y., . . . Eguchi, K. (2012). Preferred place of care and place of death of the general public and cancer patients in Japan. *Support Care Cancer, 20*(10), 2575-2582. doi:10.1007/s00520-011-1373-8

Yang, L., Sakamoto, N., & Marui, E. (2006). A study of home deaths in Japan from 1951 to 2002. *BMC Palliative Care, 5*, 2-2. doi:10.1186/1472-684X-5-2

Yeo, G. (1994). Speech by BG (NS) George Yeo, Minister for Health and Minister for Information and the Arts at Dover Park Hospice Charity Golf Dinner at Shan Shui Palace Restaurant, Raffles Country Club on Friday, 21 October 1994 at 7:00 pm; [Press release]. Retrieved from http://www.nas.gov.sg/archivesonline/data/pdfdoc/yybg19941021s.pdf

Yu, M., Guerriere, D. N., & Coyte, P. C. (2015). Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada. *Health Soc Care Community, 23*(6), 605-618. doi:10.1111/hsc.12170

Yun, Y. H., Lim, M. K., Choi, K. S., & Rhee, Y. S. (2006). Predictors associated with the place of death in a country with increasing hospital deaths. *Palliat Med, 20*(4), 455-461. doi:10.1191/0269216306pm1129oa

Yun, Y. H., You, C. H., Lee, J. S., Park, S. M., Lee, K. S., Lee, C. G., & Kim, S. (2006). Understanding disparities in aggressive care preferences between patients with terminal illness and their family members. *J Pain Symptom Manage, 31*(6), 513-521. doi:10.1016/j.jpainsymman.2005.11.009

Zhang, B., Wright, A. A., Huskamp, H. A., Nilsson, M. E., Maciejewski, M. L., Earle, C. C., . . . Prigerson, H. G. (2009). Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med, 169*(5), 480-488. doi:10.1001/archinternmed.2008.587

Zimmer, J. G., Groth-Juncker, A., & McCusker, J. (1985). A randomized controlled study of a home health care team. *Am J Public Health, 75*(2), 134-141.

Chapter 12 Appendices

Appendix 1 Summary of factors influencing place of death

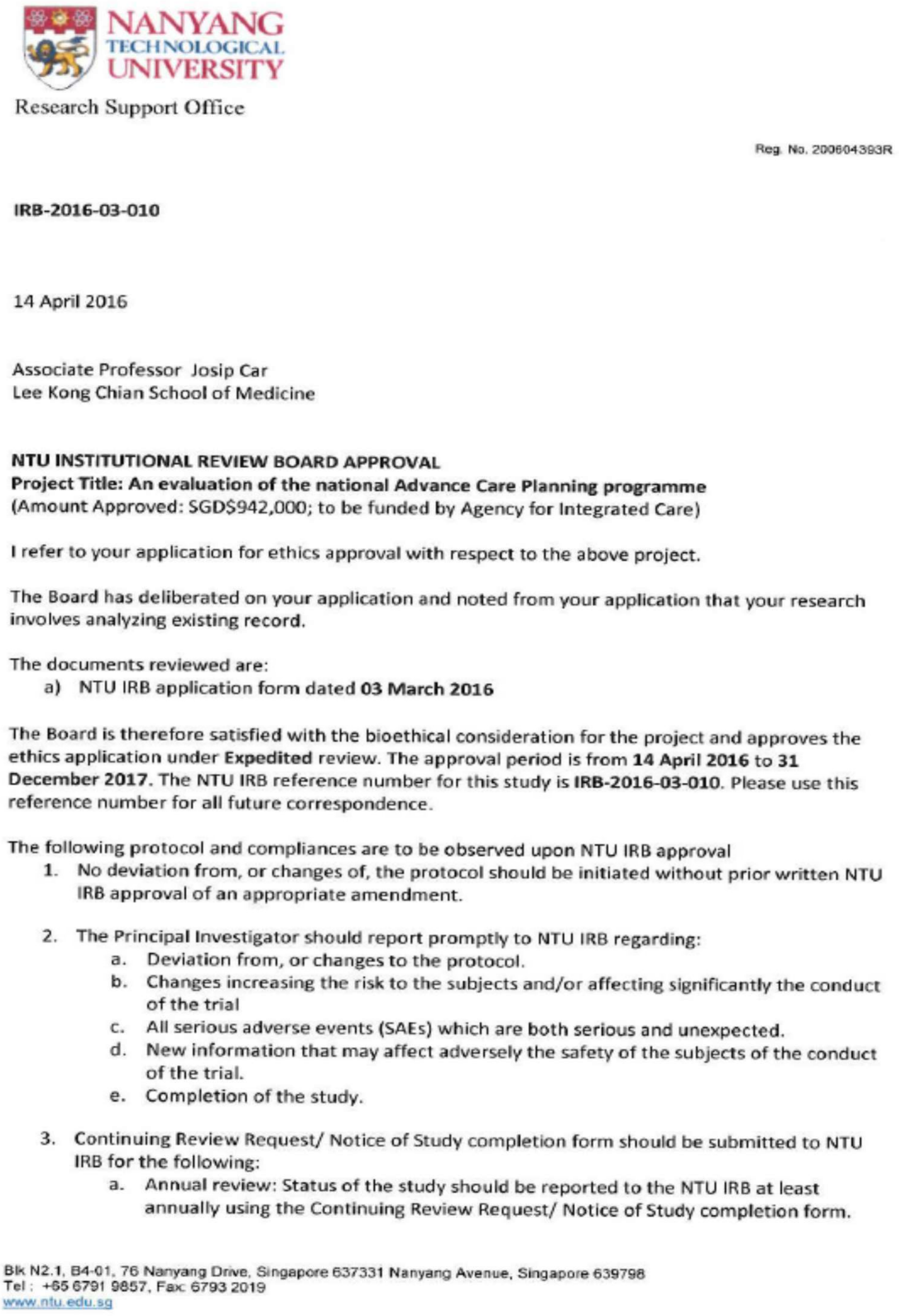
Authors et al.	Year	Specific Objective	No. of included studies	Countries of included studies	Method of synthesis	Systematic review analysis and result presentation
Gomes & Higginson	2006	To determine the relative influence of different factors on place of death in patients with cancer	58 different studies were included; 15 studies using multivariable analysis and have reported the OR of home death were included in quantitative comparison of OR	5 studies from Australia (9%); 3 studies from Asia (5%); 32 studies from Europe (55%); and 18 studies from North America (31%);	Narrative synthesis	Seventeen factors were associated with home death: • Factors related to illnesses: Non-solid tumours (OR range 0.34-0.61); Long length of disease (1.17- 2.4); low functional status (2.29-11.1); • Individual factors: good social conditions (1.06-3.47); ethnic minorities (0.78); patient's preferences (2.19-8.38); • Environmental factors: (i) Healthcare input: use of home care (1.37-5.1); intensity of home care (1.06-8.66); availability of inpatient beds (0.31-0.85); previous admission to hospital (0.04-0.16); rural environment (1.46-2.57); areas with greater hospital provision (0.5-0.74); (ii) Social support: living with relatives (1.78-7.95); extended family support (2.28-5.47); being married (1.29-1.75); caregiver's preferences (3.19-3.45); (iii) Historical trends (1.06-1.8)

Authors et al.	Year	Specific Objective	No. of included studies	Countries of included studies	Method of synthesis	Systematic review analysis and result presentation
Howell	2010	To examine all studies of place of death in haematology patients	21 studies were included; 17 studies using multivariable analysis and have reported the OR of home death were included in a meta-analysis	3 studies from Australia (14%); 13 studies from Europe (59%); and 6 studies from US (27%) *	Meta-analysis	Compared to other cancer deaths, haematology patients were more than twice as likely to die in hospital (OR 2.25 [95% C.I., 2.07-2.44]).
Murtagh	2012	To identify, critically appraise and synthesise the evidence on preferences, regarding place of care and place of death, factors influencing place of death, and key transitions towards end-of-life, for patients with advanced non-malignant conditions	Out of 290 studies that were included in the overall review, 34 studies used multivariable analysis on factors influencing place of death and were further examined	2 studies from Australia (6%); 8 studies from Asia (24%); 4 studies from Europe (11%); 20 studies from North America (59%)	Narrative synthesis	Factors found to strongly increase the likelihood of home deaths: diagnoses of heart disease (but not congestive heart failure), chronic obstructive pulmonary disease and dementia; lower comorbid burden; lower hospital bed availability. Other factors associated with home death with moderate to low level of evidence included: older age, minority ethnic group; living alone; increased household income; severe cognitive impairment; expected death; and gradual decline of illnesses.
Costa et al.	2016	To evaluate the determinants of home and nursing home death in adult patients diagnosed with an advanced, life-limiting illness	26 retrospective cohort studies using multivariable analyses were included	8 studies from Asia (31%); 6 studies from Europe (23%); 1 from New Zealand (4%); and 6 studies from North America (23%)	Narrative synthesis, meta-analysis	Factors associated with higher likelihood of home versus hospital deaths: multidisciplinary home palliative care; preference for home death; cancer versus other diagnoses; early referral to palliative care; not living alone; having a caregiver; and caregiver's coping skills. Meta-

Authors et al.	Year	Specific Objective	No. of included studies	Countries of included studies	Method of synthesis	Systematic review analysis and result presentation
						analytic results indicated: hematologic cancer (OR range 0.53-0.87); cardiovascular diseases (0.63-0.65); cancer diagnosis (1.21-2.52); and not living alone (1.68-2.59)
Wahid et al.	2017	To identify and understand the facilitators and barriers influencing death at home	38 studies were included	All studies were from the UK	Meta-ethnography	Seven overarching barriers acting against home death: lack of knowledge, skills and support among informal caregivers and healthcare professionals; informal caregiver and family burden; recognising death; unfavourable social circumstances; inadequate discharge process; condition specific discrepancies; and poor planning. Facilitators of home death include: support for patients and healthcare professionals; effective communication; coordinated care; and skilled staff.

OR: Odds Ratio
*1 study examined both UK and US

Appendix 2 NTU ethics approval for the quantitative study



NANYANG
TECHNOLOGICAL
UNIVERSITY
Research Support Office

Reg. No. 200604393R

IRB-2016-03-010

14 April 2016

Associate Professor Josip Car
Lee Kong Chian School of Medicine

NTU INSTITUTIONAL REVIEW BOARD APPROVAL
Project Title: An evaluation of the national Advance Care Planning programme
(Amount Approved: SGD$942,000; to be funded by Agency for Integrated Care)

I refer to your application for ethics approval with respect to the above project.

The Board has deliberated on your application and noted from your application that your research involves analyzing existing record.

The documents reviewed are:
a) NTU IRB application form dated **03 March 2016**

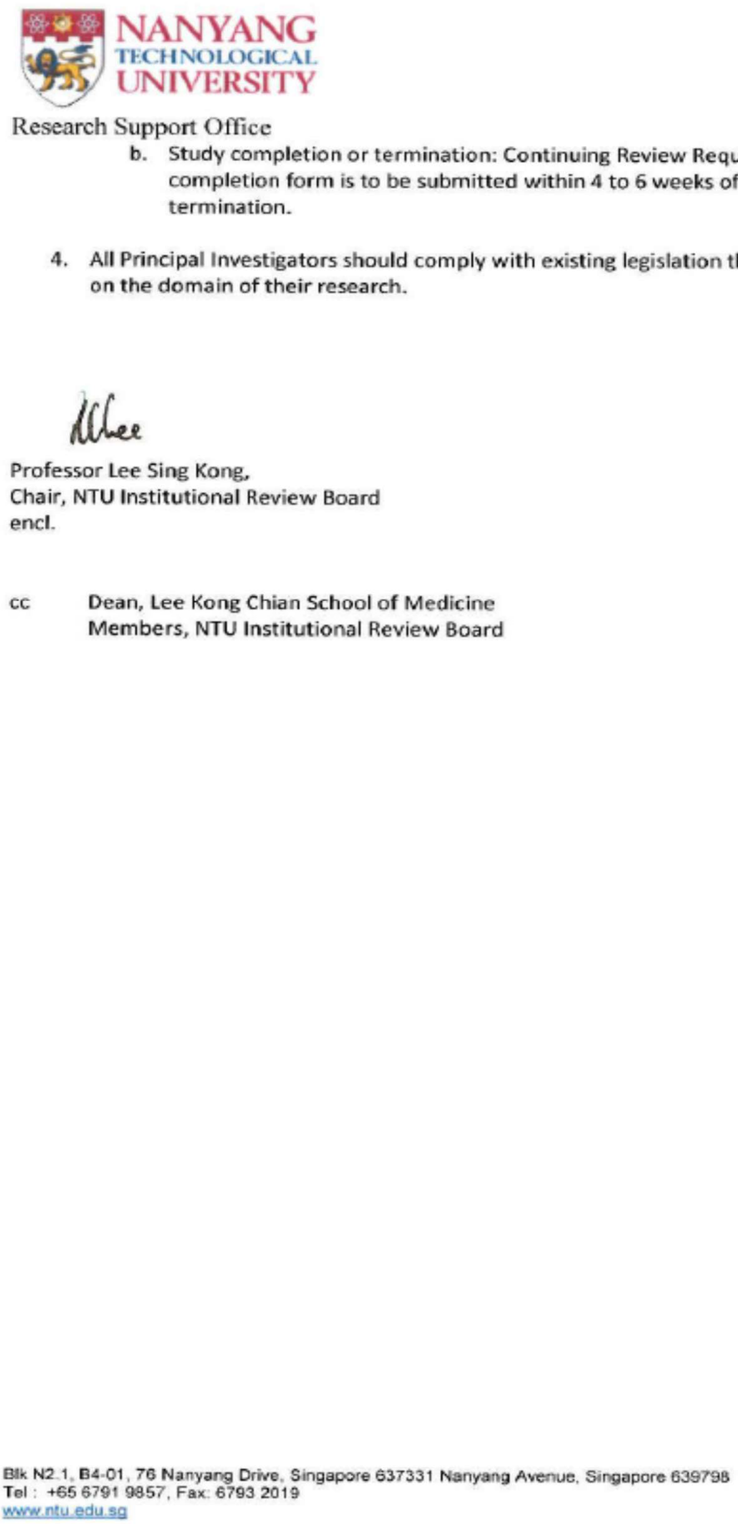
The Board is therefore satisfied with the bioethical consideration for the project and approves the ethics application under **Expedited** review. The approval period is from **14 April 2016** to **31 December 2017.** The NTU IRB reference number for this study is **IRB-2016-03-010**. Please use this reference number for all future correspondence.

The following protocol and compliances are to be observed upon NTU IRB approval

1. No deviation from, or changes of, the protocol should be initiated without prior written NTU IRB approval of an appropriate amendment.

2. The Principal Investigator should report promptly to NTU IRB regarding:
    a. Deviation from, or changes to the protocol.
    b. Changes increasing the risk to the subjects and/or affecting significantly the conduct of the trial
    c. All serious adverse events (SAEs) which are both serious and unexpected.
    d. New information that may affect adversely the safety of the subjects of the conduct of the trial.
    e. Completion of the study.

3. Continuing Review Request/ Notice of Study completion form should be submitted to NTU IRB for the following:
    a. Annual review: Status of the study should be reported to the NTU IRB at least annually using the Continuing Review Request/ Notice of Study completion form.



NANYANG
TECHNOLOGICAL
UNIVERSITY
Research Support Office

   b. Study completion or termination: Continuing Review Request/ Notice of Study completion form is to be submitted within 4 to 6 weeks of study completion or termination.

4. All Principal Investigators should comply with existing legislation that would have an impact on the domain of their research.

Professor Lee Sing Kong,
Chair, NTU Institutional Review Board
encl.

cc Dean, Lee Kong Chian School of Medicine
Members, NTU Institutional Review Board

Appendix 3 NHG ethics approval for the quantitative study

National Healthcare Group
Adding years of healthy life

3 Fusionopolis Link
#03-08 Nexus@one-north
Singapore 138543
Tel: 6496 6600 Fax:6486 6870
www.nhg.com.sg
RCB No. 200002150H

NHG DSRB Ref: **2016/00739**

14 October 2016

Dr Raymond Ng
Department of Palliative Medicine
Tan Tock Seng Hospital

Dear Dr Ng

NHG DOMAIN SPECIFIC REVIEW BOARD (DSRB) APPROVAL

STUDY TITLE: Evaluation of the National Advance Care Planning Programme - Quantitative Study

We are pleased to inform you that the NHG Domain Specific Review Board has approved the application as titled above to be conducted in **Tan Tock Seng Hospital** and **Agency for Integrated Care**.

The approval period is from **14 October 2016** to **13 October 2017**. The NHG DSRB reference number for this study is **2016/00739**. Please use this reference number for all future correspondence.

The documents reviewed are:

a) NHG DSRB Application Form: **Version No. 1**
b) Study Protocol: **Version 1 dated 03 October 2016**
c) Fields for data retrieval: **Version 1 dated 24 July 2016**
d) TTSH Fields of Audit-Deaths: **Version 1 dated 24 June 2016**

The NHG DSRB has approved your request for waiver of informed consent.

Continued approval is conditional upon your compliance with the following requirements:

1. No deviation from or changes to the study should be implemented without documented approval from the NHG DSRB, except where necessary to eliminate apparent immediate hazard(s) to the study subjects.

2. Any deviation from or changes to the study to eliminate an immediate hazard should be promptly reported to the NHG DSRB within seven calendar days.

3. Please note that for studies requiring Clinical Trial Certificate, apart from the approval from NHG DSRB, no deviation from, or changes of the Research Protocol and Informed Consent Form should be implemented without documented approval from the Health Sciences Authority unless otherwise advised by the Health Sciences Authority.

4. Please submit the following to the NHG DSRB:

a. All Unanticipated Problems Involving Risk To Subjects Or Others (UPIRTSOs) must be reported to the NHG DSRB. For more than minimal risk studies, all problems involving local deaths must be reported immediately within 24 hours after first knowledge by the Investigator, regardless of the causality and expectedness of the death. For no more than minimal risk studies, only problems involving local deaths that are related or possibly related to the study must be reported immediately within 24 hours after first knowledge by the Investigator. All other problems that fulfil the UPIRTSOs reporting criteria must be reported as soon as possible but not later than seven calendar days after first knowledge by the Investigator.

b. Report(s) on any new information that may adversely affect the safety of the subject or the conduct of the study.

c. NHG DSRB Study Status Report Form – this is to be submitted 4 to 6 weeks prior to expiry of the approval period. The study cannot continue beyond **13 October 2017** until approval is renewed by the NHG DSRB.

d. Study completion – this is to be submitted using the NHG DSRB Study Status Report Form within 4 to 6 weeks of study completion.

Established since May 2006, the NHG Research Quality Management (RQM) Program seeks to promote the responsible conduct of research in a research culture with high ethical standards, identify potential systemic weaknesses and make recommendations for continual improvement. Hence, this research study may be randomly selected for a review by the Research Quality Management (RQM) team. For more information, please visit www.research.nhg.com.sg.

The NHG DSRB operates in accordance to the ICH GCP, Singapore Guideline for Good Clinical Practice and all applicable laws and regulations.

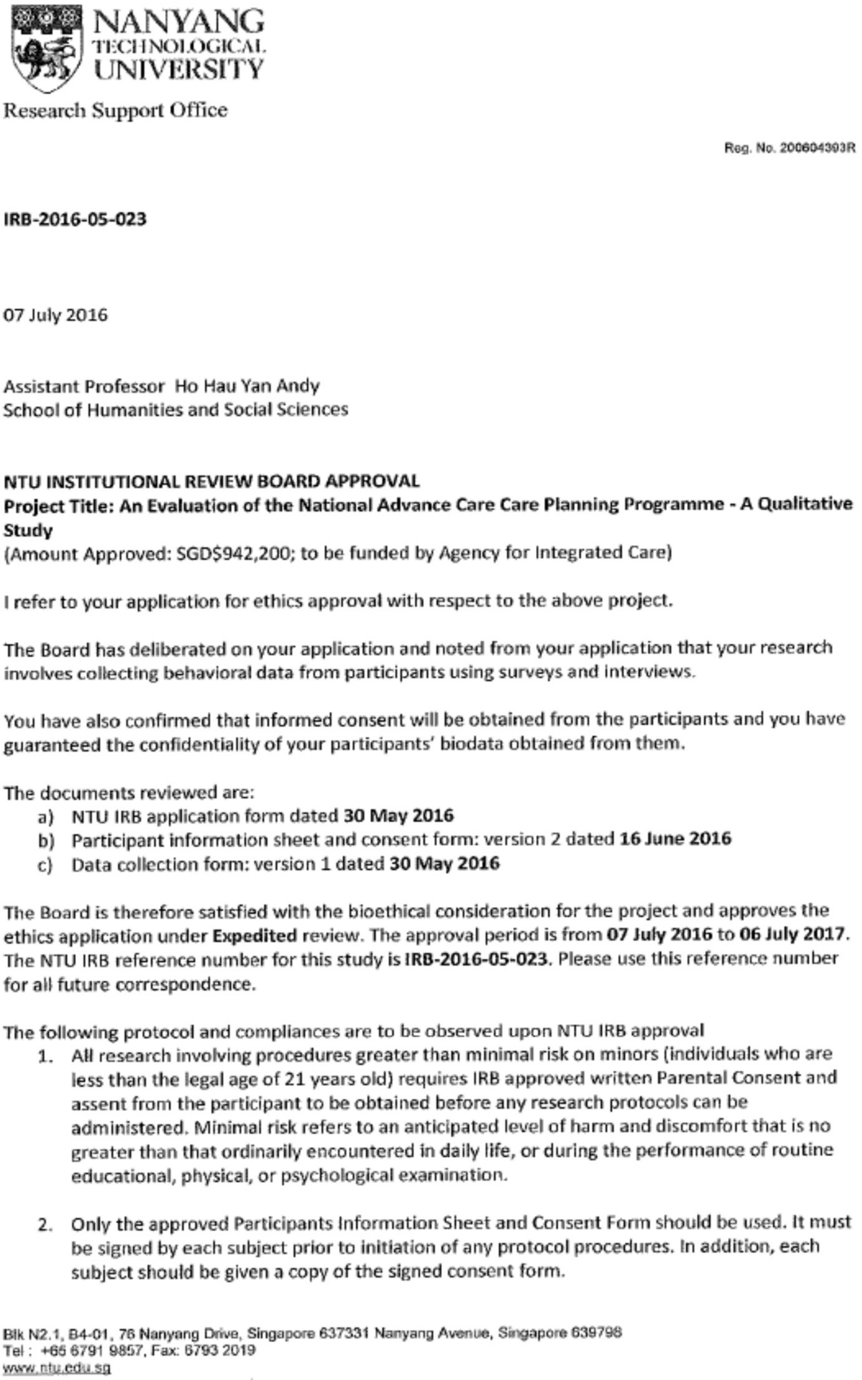
Yours Sincerely

A/Prof Jason Yap
Chairman
NHG Domain Specific Review Board F1

Cc: Institutional Representative, TTSH
c/o Clinical Research Unit, TTSH
Departmental Representative of Palliative Medicine, TTSH

Cc: Institutional Representative, AIC
Departmental Representative of Care Integration Division, AIC

Appendix 4 NTU ethics approval for the qualitative study



NANYANG
TECHNOLOGICAL
UNIVERSITY
Research Support Office

Reg. No. 200604393R

IRB-2016-05-023

07 July 2016

Assistant Professor Ho Hau Yan Andy
School of Humanities and Social Sciences

NTU INSTITUTIONAL REVIEW BOARD APPROVAL
Project Title: An Evaluation of the National Advance Care Care Planning Programme - A Qualitative Study
(Amount Approved: SGD$942,200; to be funded by Agency for Integrated Care)

I refer to your application for ethics approval with respect to the above project.

The Board has deliberated on your application and noted from your application that your research involves collecting behavioral data from participants using surveys and interviews.

You have also confirmed that informed consent will be obtained from the participants and you have guaranteed the confidentiality of your participants' biodata obtained from them.

The documents reviewed are:

a) NTU IRB application form dated **30 May 2016**
b) Participant information sheet and consent form: version 2 dated **16 June 2016**
c) Data collection form: version 1 dated **30 May 2016**

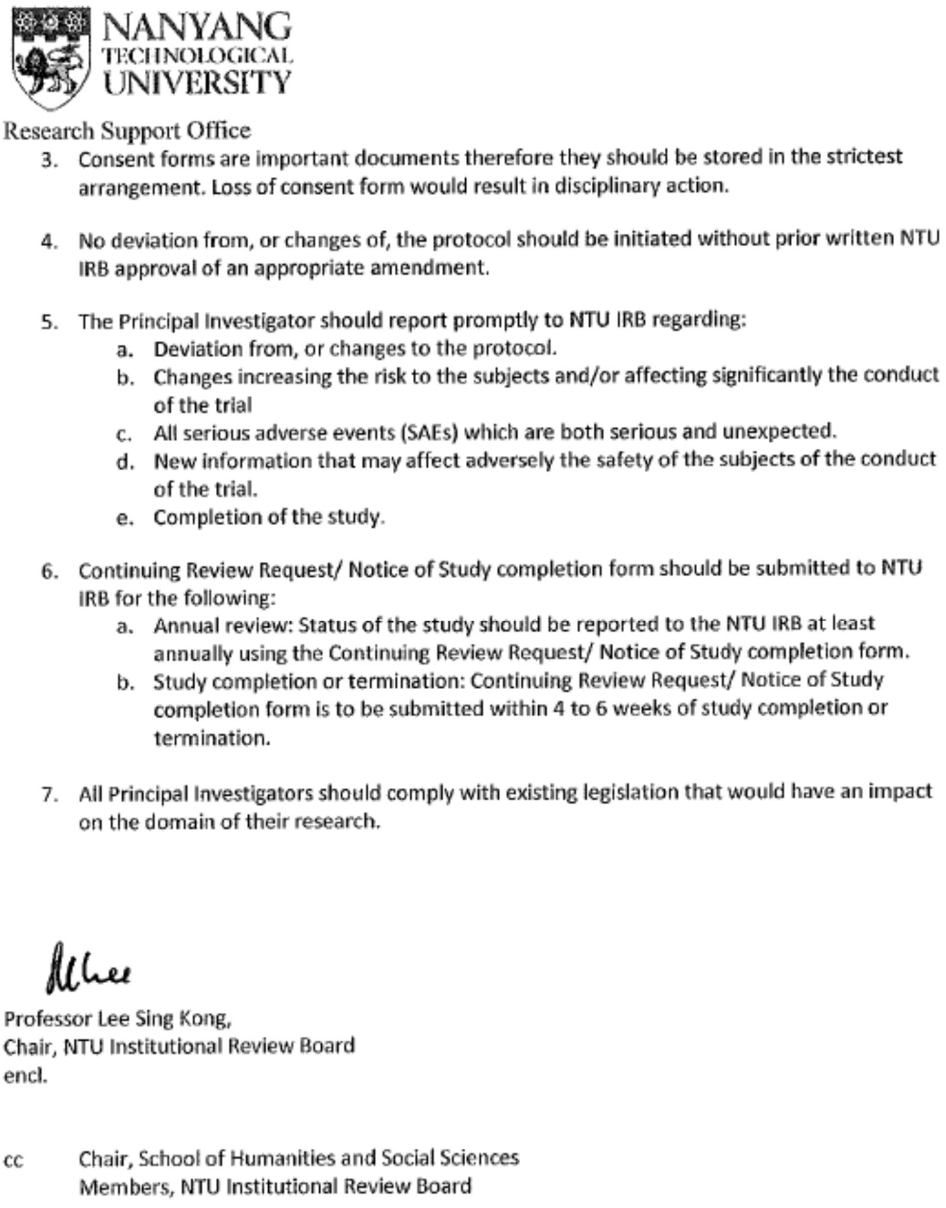
The Board is therefore satisfied with the bioethical consideration for the project and approves the ethics application under **Expedited** review. The approval period is from **07 July 2016** to **06 July 2017**. The NTU IRB reference number for this study is **IRB-2016-05-023**. Please use this reference number for all future correspondence.

The following protocol and compliances are to be observed upon NTU IRB approval

1. All research involving procedures greater than minimal risk on minors (individuals who are less than the legal age of 21 years old) requires IRB approved written Parental Consent and assent from the participant to be obtained before any research protocols can be administered. Minimal risk refers to an anticipated level of harm and discomfort that is no greater than that ordinarily encountered in daily life, or during the performance of routine educational, physical, or psychological examination.

2. Only the approved Participants Information Sheet and Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.

Blk N2.1, B4-01, 76 Nanyang Drive, Singapore 637331 Nanyang Avenue, Singapore 639798
Tel : +65 6791 9857, Fax: 6793 2019
www.ntu.edu.sg



NANYANG
TECHNOLOGICAL
UNIVERSITY

Research Support Office

3. Consent forms are important documents therefore they should be stored in the strictest arrangement. Loss of consent form would result in disciplinary action.

4. No deviation from, or changes of, the protocol should be initiated without prior written NTU IRB approval of an appropriate amendment.

5. The Principal Investigator should report promptly to NTU IRB regarding:
    a. Deviation from, or changes to the protocol.
    b. Changes increasing the risk to the subjects and/or affecting significantly the conduct of the trial
    c. All serious adverse events (SAEs) which are both serious and unexpected.
    d. New information that may affect adversely the safety of the subjects of the conduct of the trial.
    e. Completion of the study.

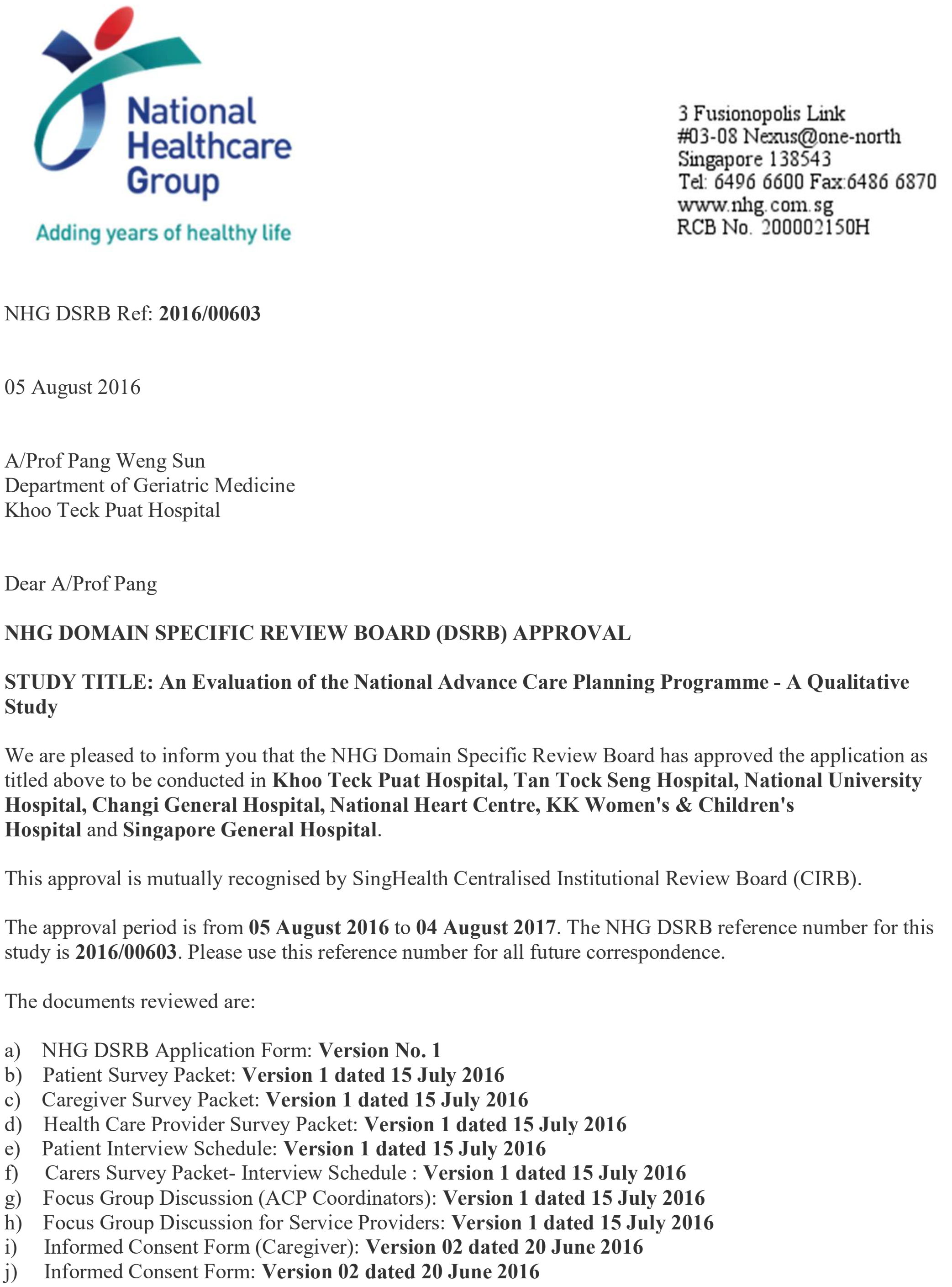
6. Continuing Review Request/ Notice of Study completion form should be submitted to NTU IRB for the following:
    a. Annual review: Status of the study should be reported to the NTU IRB at least annually using the Continuing Review Request/ Notice of Study completion form.
    b. Study completion or termination: Continuing Review Request/ Notice of Study completion form is to be submitted within 4 to 6 weeks of study completion or termination.

7. All Principal Investigators should comply with existing legislation that would have an impact on the domain of their research.

Professor Lee Sing Kong,
Chair, NTU Institutional Review Board
encl.

cc	Chair, School of Humanities and Social Sciences
	Members, NTU Institutional Review Board

Appendix 5 NHG ethics approval for the qualitative study



National Healthcare Group
Adding years of healthy life

3 Fusionopolis Link
#03-08 Nexus@one-north
Singapore 138543
Tel: 6496 6600 Fax:6486 6870
www.nhg.com.sg
RCB No. 200002150H

NHG DSRB Ref: **2016/00603**

05 August 2016

A/Prof Pang Weng Sun
Department of Geriatric Medicine
Khoo Teck Puat Hospital

Dear A/Prof Pang

NHG DOMAIN SPECIFIC REVIEW BOARD (DSRB) APPROVAL

STUDY TITLE: An Evaluation of the National Advance Care Planning Programme - A Qualitative Study

We are pleased to inform you that the NHG Domain Specific Review Board has approved the application as titled above to be conducted in **Khoo Teck Puat Hospital, Tan Tock Seng Hospital, National University Hospital, Changi General Hospital, National Heart Centre, KK Women's & Children's Hospital** and **Singapore General Hospital**.

This approval is mutually recognised by SingHealth Centralised Institutional Review Board (CIRB).

The approval period is from **05 August 2016** to **04 August 2017**. The NHG DSRB reference number for this study is **2016/00603**. Please use this reference number for all future correspondence.

The documents reviewed are:

a) NHG DSRB Application Form: **Version No. 1**
b) Patient Survey Packet: **Version 1 dated 15 July 2016**
c) Caregiver Survey Packet: **Version 1 dated 15 July 2016**
d) Health Care Provider Survey Packet: **Version 1 dated 15 July 2016**
e) Patient Interview Schedule: **Version 1 dated 15 July 2016**
f) Carers Survey Packet- Interview Schedule : **Version 1 dated 15 July 2016**
g) Focus Group Discussion (ACP Coordinators): **Version 1 dated 15 July 2016**
h) Focus Group Discussion for Service Providers: **Version 1 dated 15 July 2016**
i) Informed Consent Form (Caregiver): **Version 02 dated 20 June 2016**
j) Informed Consent Form: **Version 02 dated 20 June 2016**

k) Informed Consent Form (HCP): **Version 02 dated 20 June 2016**
l) Informed Consent Form (Participant Obs-Patient): **Version 02 dated 20 June 2016**
m) Informed Consent Form (Participant Obs-Care Team): **Version 02 dated 20 June 2016**
n) ACP Informant Telephone Scripts (Patient and Caregivers): **Version 1 dated 15 July 2016**

Continued approval is conditional upon your compliance with the following requirements:
1. Only the approved Informed Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.

2. No deviation from or changes to the study should be implemented without documented approval from the NHG DSRB, except where necessary to eliminate apparent immediate hazard(s) to the study subjects.

3. Any deviation from or changes to the study to eliminate an immediate hazard should be promptly reported to the NHG DSRB within seven calendar days.

4. Please note that for studies requiring Clinical Trial Certificate, apart from the approval from NHG DSRB, no deviation from, or changes of the Research Protocol and Informed Consent Form should be implemented without documented approval from the Health Sciences Authority unless otherwise advised by the Health Sciences Authority.

5. Please submit the following to the NHG DSRB:

a. All Unanticipated Problems Involving Risk To Subjects Or Others (UPIRTSOs) must be reported to the NHG DSRB. For more than minimal risk studies, all problems involving local deaths must be reported immediately within 24 hours after first knowledge by the Investigator, regardless of the causality and expectedness of the death. For no more than minimal risk studies, only problems involving local deaths that are related or possibly related to the study must be reported immediately within 24 hours after first knowledge by the Investigator. All other problems that fulfil the UPIRTSOs reporting criteria must be reported as soon as possible but not later than seven calendar days after first knowledge by the Investigator.

b. Report(s) on any new information that may adversely affect the safety of the subject or the conduct of the study.

c. NHG DSRB Study Status Report Form – this is to be submitted 4 to 6 weeks prior to expiry of the approval period. The study cannot continue beyond **04 August 2017** until approval is renewed by the NHG DSRB.

d. Study completion – this is to be submitted using the NHG DSRB Study Status Report Form within 4 to 6 weeks of study completion.

Established since May 2006, the NHG Research Quality Management (RQM) Program seeks to promote the responsible conduct of research in a research culture with high ethical standards, identify potential systemic weaknesses and make recommendations for continual improvement. Hence, this research study may be randomly selected for a review by the Research Quality Management (RQM) team. For more information, please visit www.research.nhg.com.sg.

The NHG DSRB operates in accordance to the ICH GCP, Singapore Guideline for Good Clinical Practice and all applicable laws and regulations.

Yours Sincerely

Dr Patricia Yap
Chairperson

NHG Domain Specific Review Board F2

Cc: Institutional Representative, NUH
c/o Research Office, NUH
Departmental Representative of Haematology-Oncology, NUH

Cc: Institutional Representative, KTPH
c/o Clinical Research Unit, KTPH
Departmental Representative of Geriatric Medicine, KTPH

Cc: Institutional Representative, TTSH
c/o Clinical Research Unit, TTSH
Departmental Representative of Palliative Medicine, TTSH

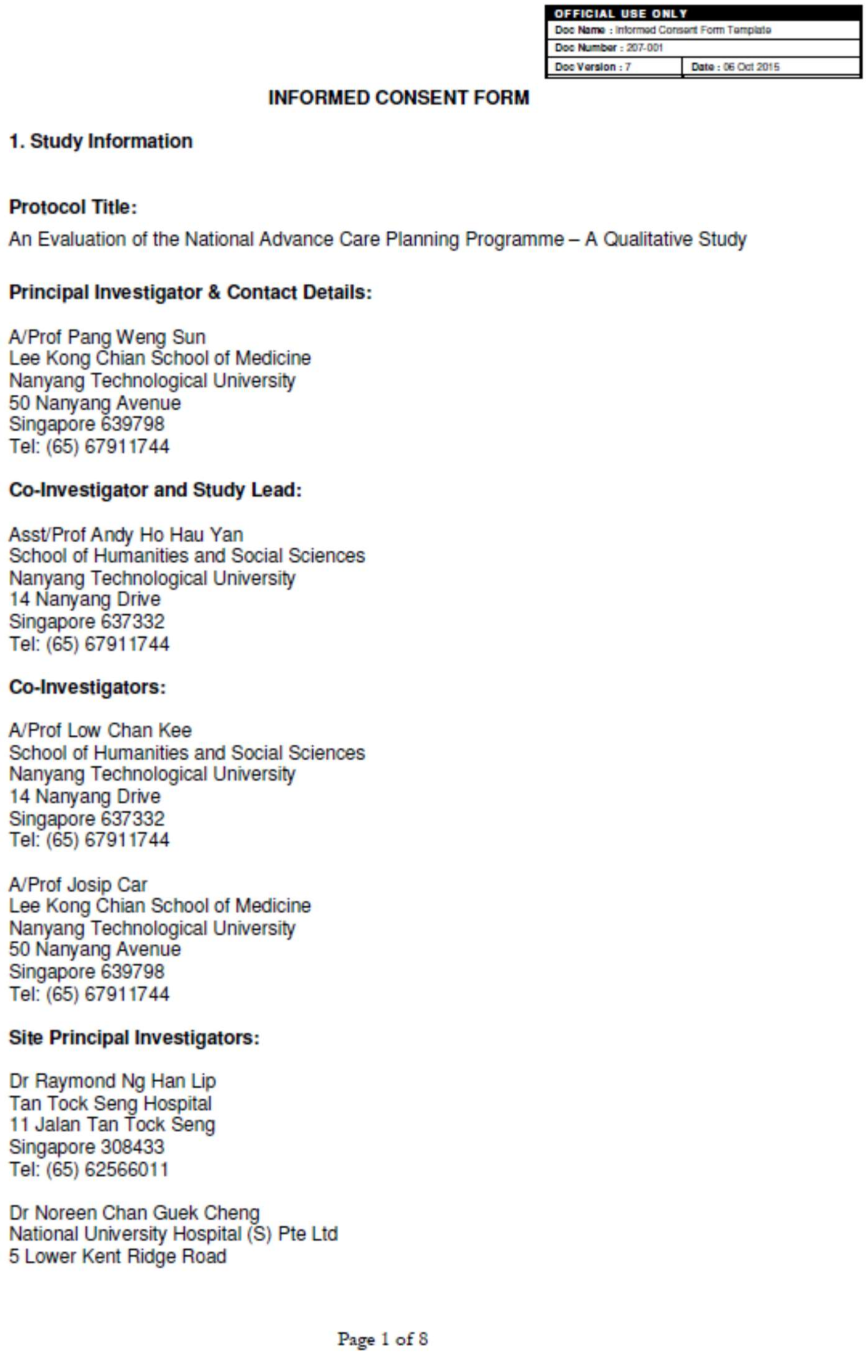
Cc: Institutional Representative, CGH
Departmental Representative of Geriatric Medicine, CGH

Cc: Institutional Representative, KKH
Departmental Representative of Haematology / Oncology Services, KKH

Cc: Institutional Representative, NHC
Departmental Representative of Cardiology, NHC

Cc: Institutional Representative, SGH
Departmental Representative of Geriatric Medicine, SGH

Appendix 6 Informed consent form



OFFICIAL USE ONLY	
Doc Name : Informed Consent Form Template	
Doc Number : 207-001	
Doc Version : 7	**Date** : 06 Oct 2015

INFORMED CONSENT FORM

1. Study Information

Protocol Title:

An Evaluation of the National Advance Care Planning Programme – A Qualitative Study

Principal Investigator & Contact Details:

A/Prof Pang Weng Sun
Lee Kong Chian School of Medicine
Nanyang Technological University
50 Nanyang Avenue
Singapore 639798
Tel: (65) 67911744

Co-Investigator and Study Lead:

Asst/Prof Andy Ho Hau Yan
School of Humanities and Social Sciences
Nanyang Technological University
14 Nanyang Drive
Singapore 637332
Tel: (65) 67911744

Co-Investigators:

A/Prof Low Chan Kee
School of Humanities and Social Sciences
Nanyang Technological University
14 Nanyang Drive
Singapore 637332
Tel: (65) 67911744

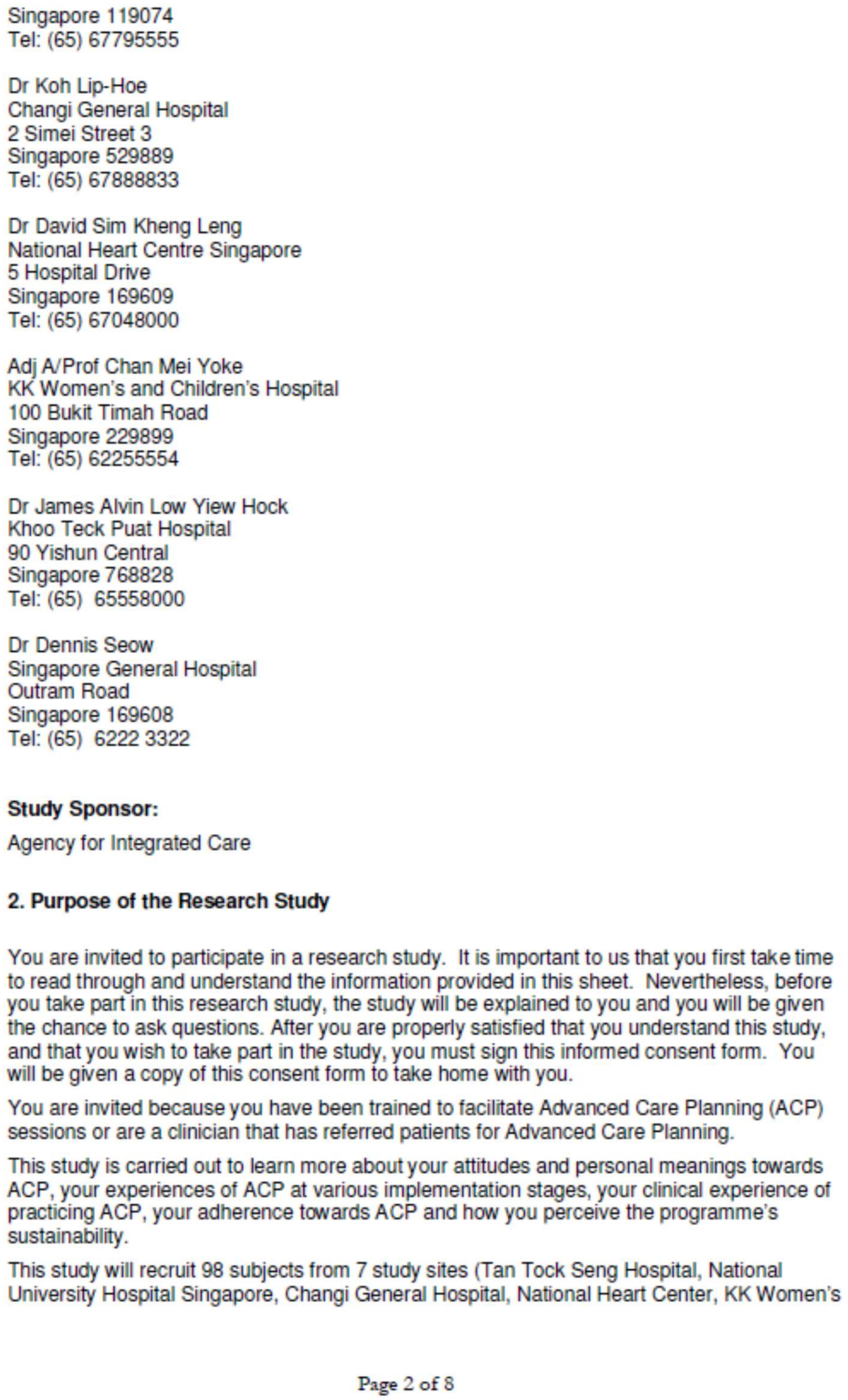
A/Prof Josip Car
Lee Kong Chian School of Medicine
Nanyang Technological University
50 Nanyang Avenue
Singapore 639798
Tel: (65) 67911744

Site Principal Investigators:

Dr Raymond Ng Han Lip
Tan Tock Seng Hospital
11 Jalan Tan Tock Seng
Singapore 308433
Tel: (65) 62566011

Dr Noreen Chan Guek Cheng
National University Hospital (S) Pte Ltd
5 Lower Kent Ridge Road

Page 1 of 8



Singapore 119074
Tel: (65) 67795555

Dr Koh Lip-Hoe
Changi General Hospital
2 Simei Street 3
Singapore 529889
Tel: (65) 67888833

Dr David Sim Kheng Leng
National Heart Centre Singapore
5 Hospital Drive
Singapore 169609
Tel: (65) 67048000

Adj A/Prof Chan Mei Yoke
KK Women's and Children's Hospital
100 Bukit Timah Road
Singapore 229899
Tel: (65) 62255554

Dr James Alvin Low Yiew Hock
Khoo Teck Puat Hospital
90 Yishun Central
Singapore 768828
Tel: (65) 65558000

Dr Dennis Seow
Singapore General Hospital
Outram Road
Singapore 169608
Tel: (65) 6222 3322

Study Sponsor:

Agency for Integrated Care

2. Purpose of the Research Study

You are invited to participate in a research study. It is important to us that you first take time to read through and understand the information provided in this sheet. Nevertheless, before you take part in this research study, the study will be explained to you and you will be given the chance to ask questions. After you are properly satisfied that you understand this study, and that you wish to take part in the study, you must sign this informed consent form. You will be given a copy of this consent form to take home with you.

You are invited because you have been trained to facilitate Advanced Care Planning (ACP) sessions or are a clinician that has referred patients for Advanced Care Planning.

This study is carried out to learn more about your attitudes and personal meanings towards ACP, your experiences of ACP at various implementation stages, your clinical experience of practicing ACP, your adherence towards ACP and how you perceive the programme's sustainability.

This study will recruit 98 subjects from 7 study sites (Tan Tock Seng Hospital, National University Hospital Singapore, Changi General Hospital, National Heart Center, KK Women's and Children's Hospital, Khoo Teck Puat Hospital, Singapore General Hospital) across Singapore over a period of 4 to 5 months.

3. What procedures will be followed in this study

If you take part in this study, you will be invited to participate in a focus group discussion conducted by a member of the study team about your experiences with ACP.

Your participation in the study will consist of a single focus group discussion exercise. The interview process is expected to last about 90-120 minutes.

If you agree to take part in this study, the following will happen to you:

1. Survey Packet: You will be asked to complete a survey packet consisting of the following items:

    - Demographic Questionnaire
    - Patient Health Questionnaire-2
    - Self-Rated Health Question
    - Death Attitude Profile- Revised
    - Traditional Death Beliefs
    - Maslach Burnout Inventory – General
    - Barriers to Care
    - Satisfaction with Life Scale

2. Focus Group Discussion: You will be asked to participate in a Focus Group Discussion session lasting about 90-120 minutes. The session will cover issues such as your attitudes and personal meanings towards ACP, your experiences of ACP at various implementation stages, your clinical experience of practicing ACP, your adherence towards ACP and how you perceive the programme's sustainability.

The focus group discussion will be audiotaped for transcription purposes and the data collected from the sessions as well as the survey packet will be stored securely in the research laboratory at Lee Kong Chian School of Medicine's Experimental Medicine Building made available only to the research team. Any identifying information will be removed and the data anonymized.

4. Your Responsibilities in This Study

If you agree to participate in this study, you should follow the advice given to you by the study team. You should be prepared to visit the hospital once and undergo all the procedures that are outlined above.

5. What Is Not Standard Care or is Experimental in This Study

The study is being conducted because the Advanced Care Planning programme is not yet proven to be a standard procedure in with patients in an acute hospital setting. We hope that your participation will help us to determine whether the Advanced Care Planning programme is equal or superior to existing informal 'options of care' conversations by primary healthcare providers. The procedures of this study are conducted solely for the purposes of research and are not part of standard routine training or assessment.

6. Possible Risks and Side Effects

The research team expects minimal risks towards participants. However, as we will be discussing issues of end of life care, some psychological stress may be expected. In the event that you feel unfit to continue with the study, you may inform the research team and cease participation immediately. The clinical team will also provide you with emotional support throughout the interview process, as well as referral service to the counseling and social work team of your hospital if required.

7. Possible Benefits from Participating in the Study

There is no known benefit from participation in this study. There is no known benefit from participation in this study. However, past research and our clinical experience show that individuals find the sharing of life experiences empowering and therapeutic. Moreover, you can stand to benefit from the study by gaining introspective insight of your role in the current ACP discourse, while also having the opportunity to contribute to the more efficacious delivery of the National ACP programme.

8. Costs & Payments if Participating in the Study

There will be no costs nor reimbursement for participation in the study.

9. Voluntary Participation

Your participation in this study is voluntary. You may stop participating in this study at any time. Your decision not to take part in this study or to stop your participation will not affect your medical care or any benefits to which you are entitled. If you decide to stop taking part in this study, you should tell the Principal Investigator.

There will not be any consequences for your withdrawal.

However, the data that have been collected until the time of your withdrawal will be kept and analysed. The reason is to enable a complete and comprehensive evaluation of the study.

Your doctor, the Investigator and/or the Sponsor of this study may stop your participation in the study at any time if they decide that it is in your best interests. They may also do this if you do not follow instructions required to complete the study adequately.

In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you *(or your legally acceptable representative, if relevant)* will be informed in a timely manner by the Principal Investigator or his/her representative.

10. Compensation for Injury

By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

11. Confidentiality of Study and Medical Records

Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available. In order to protect your identity and the confidentiality of your information, all information and audio files that concern you will be stored on a central computer. Access to this information will be strictly controlled with the aid of a security code system

However, the Sponsoring company, Regulatory Agencies and NHG Domain-Specific Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public. By signing the Informed Consent Form attached, you (*or your legally acceptable representative, if relevant*) are authorizing (i) collection, access to, use and storage of your "Personal Data", and (ii) disclosure to authorised service providers and relevant third parties.

"Personal Data" means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organisation has or likely to have access. This includes medical conditions, medications, investigations and treatment history.

Research arising in the future, based on this "Personal Data", will be subject to review by the relevant institutional review board.

Data collected and entered into the Case Report Forms are the property of Nanyang Technological University, the Agency for Integrated care and the current site of recruitment to study. In the event of any publication regarding this study, your identity will remain confidential.

By participating in this research study, you are confirming that you have read, understood and consent to the Personal Data Protection Notification available at:

Agency for Integrated Care:

http://aic.sg/Data_Protection_Policy/

Nanyang Technological University:

http://www.ntu.edu.sg/pdpa/Pages/index.aspx

Site of Recruitment (Please select where applicable):

☐ Khoo Teck Puat Hospital :

https://www.ktph.com.sg/pdpa

☐ Tan Tock Seng Hospital :

https://www.ttsh.com.sg/patient-guide/page.aspx?id=4468

☐ KK Women's and Children's Hospital :

http://www.kkh.com.sg/ABOUTUS/PDPA/Pages/Home.aspx

☐ Singapore General Hospital :

http://www.sgh.com.sg/others/contact-us/pages/pdpa.aspx

☐ National Heart Center :

https://www.nhcs.com.sg/aboutnhc/pdpa/Pages/Home.aspx

☐ Changi General Hospital :

https://www.cgh.com.sg/Contact%20Us/Pages/pdpa.aspx

☐ National University Hospital :

http://www.nuhs.edu.sg/personal-data-protection/nuhsnuh-data-protection-policy.html

12. Who To Contact if You Have Questions

If you have questions about this research study, you may contact the Principal Investigator,

Principal Investigator:
A/Prof Pang Weng Sun
Lee Kong Chian School of Medicine
Nanyang Technological University
50 Nanyang Avenue
Singapore 639798
Tel: (65) 67911744

Co-Investigator and Study Lead:
Asst/Prof Andy Ho Hau Yan
School of Humanities and Social Sciences
Nanyang Technological University
14 Nanyang Drive
Singapore 637332
Tel: (65) 67911744

In case of any injuries during the course of this study, you may contact the Principal Investigator,

Principal Investigator:
A/Prof Pang Weng Sun
Lee Kong Chian School of Medicine
Nanyang Technological University
50 Nanyang Avenue
Singapore 639798
Tel: (65) 67911744

The study has been reviewed by the NHG Domain Specific Review Board (the central ethics committee) for ethics approval.

If you want an independent opinion to discuss problems and questions, obtain information and offer inputs on your rights as a research subject, you may contact the NHG Domain Specific Review Board Secretariat at 6471-3266. You can also find more information about participating in clinical research and the NHG Domain Specific Review Board at www.research.nhg.com.sg.

If you have any complaints or feedback about this research study, you may contact the Principal Investigator or the NHG Domain Specific Review Board Secretariat.

CONSENT FORM

Protocol Title:

An Evaluation of the National Advanced Care Planning Programme – A Qualitative Study

Contact Details:

Principal Investigator
A/Prof Pang Weng Sun
Lee Kong Chian School of Medicine
Nanyang Technological University
50 Nanyang Avenue
Singapore 639798
Tel: (65) 67911744

Co-Investigator and Study Lead:
Asst/Prof Andy Ho Hau Yan
School of Humanities and Social Sciences
Nanyang Technological University
14 Nanyang Drive
Singapore 637332
Tel: (65) 67911744

I voluntarily consent to take part in this research study. I have fully discussed and understood the purpose and procedures of this study. This study has been explained to me in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all my questions have been answered to my satisfaction.

By participating in this research study, I confirm that I have read, understood and consent to the Personal Data Protection Notification available at:

Agency for Integrated Care:
http://aic.sg/Data_Protection_Policy/
Nanyang Technological University:
http://www.ntu.edu.sg/pdpa/Pages/index.aspx

and the Site of Recruitment (Please select where applicable):
☐ Khoo Teck Puat Hospital :
https://www.ktph.com.sg/pdpa
☐ Tan Tock Seng Hospital :
https://www.ttsh.com.sg/patient-guide/page.aspx?id=4468
☐ KK Women's and Children's Hospital :
http://www.kkh.com.sg/ABOUTUS/PDPA/Pages/Home.aspx
☐ Singapore General Hospital :
http://www.sgh.com.sg/others/contact-us/pages/pdpa.aspx
☐ National Heart Center :

https://www.nhcs.com.sg/aboutnhc/pdpa/Pages/Home.aspx

☐ Changi General Hospital :

https://www.cgh.com.sg/Contact%20Us/Pages/pdpa.aspx

☐ National University Hospital :

http://www.nuhs.edu.sg/personal-data-protection/nuhsnuh-data-protection-policy.html

I also consent to the use of my Personal Data for the purposes of engaging in related research arising the future.

________________________	______________________________	__________________
Name of Participant	Signature	Date

Investigator Statement

I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant signing this informed consent form clearly understands the nature, risks and benefits of his / her participation in the study.

________________________	______________________________	__________________
Name of Investigator / Person administering consent	Signature	Date

Appendix 7 Interview schedule for ACP coordinators

Acceptability

1. What are your own thoughts on the process of death and dying?
2. What attracted you to working in Advanced Care Planning?
3. What are your feelings towards ACP?
4. What type of training did you receive for ACP?
   [Discuss the process of ACP training]
5. Are you aware of the mentorship programme?
   [Facilitate a discussion on the mentorship programme]

Adherence

6. How would you describe your role as an ACP coordinator?
   [Probe: What are some key defining characteristics/responsibilities about being an ACP coordinator?]
7. How do you initiate an ACP conversation with patients?
   Probe: What role does the patients' family play in the ACP conversation?
8. How adequate was your training in ACP?
   Probe: Do you feel that they have prepared you for the ACP session?
9. How would you conduct an ACP session?
   [Facilitate a discussion on the process of conducting an ACP session
10. Do you follow guidelines given by AIC?
    [Facilitate a discussion on why they choose or choose not to follow guidelines set by AIC]
11. Have you ever had the opportunity to reflect on your facilitation work?
    a) What might constitute a successful ACP session?

Feasibility

12. How confident are you in employing the ACP programme's tools (e.g. IT system, worksheets)?
    Probe: How useful are they in your sessions?
13. How do patients respond to ACP?
14. How do patients' families' respond to ACP?
15. What types of preferences do patients' express?
    [Facilitate a discussion on medical care options and healthcare spokesperson]
    Probe: What is usually their preferred site of care?
    Probe: What about their site of death?
16. What are some of the challenges you face in meeting these preferences?
17. How does your team work together to ensure completion of these preferences?
18. What challenges have you faced in completion of these preferences?
    [Facilitate a discussion on barriers and facilitators to ACP]

Penetration

19. How do other members of your team feel towards ACP?
    [Facilitate a discussion on other healthcare provider's attitudes towards ACP]
20. Do you feel that other members of your team are willing to adopt ACP?
    Probe: How would you describe communication channels between team members?
    [Facilitate a discussion on the adoption of ACP across sectors]
21. What did the institution do to promote buy-in?
    [Facilitate a discussion on how the institution facilitated adoption of ACP across sectors]

Sustainability

22. How has ACP effected your interaction with patients?

Probe: how has ACP effected your interaction with families or care givers?

23. What are you hoping to achieve from ACP?
24. How could ACP be better implemented?
25. How sustainable is ACP?

Appendix 8 Interview schedule for healthcare providers

Acceptability

1. How would you describe your role as a healthcare provider?

   Probe: What are some key defining characteristics/responsibilities about being a healthcare provider?
2. What has been your experience of disclosing a diagnosis of a terminal illness to a patient?

   Probe: How is the patients' family involved in the process of disclosure?
3. What are your own thoughts on the process of death and dying?
4. What do you know about ACP?

   [Facilitate a discussion on the meaning of ACP]
5. What are your feelings towards ACP?
6. Do you feel that your role as a healthcare provider should encompass ACP?

   [Facilitate a discussion on how their perceive their role in relation to ACP]
7. What were End of Life conversations like before the National ACP Programme was implemented?

   Probe: What happened when ACP was first brought in?
8. Have you undertaken any training for ACP?

   Probe: why did you undertake the training?

   Probe: Did you volunteer to undertake training?
9. Are you aware of the mentorship programme?

   [Facilitate a discussion on the mentorship programme]

Adherence

10. Have you ever referred a patient for ACP?

    Probe: What is your criteria for referral of a patient to ACP?
11. Have you ever referred a patient with no caregivers to ACP?

Probe: Why or why not?

12. Have you ever dealt with patients who were not fully aware of their diagnosis?
    Probe: how do you deal with these cases?
13. Have you ever facilitated an ACP session?
    Probe: how would you describe an ACP session?
14. How do you initiate an ACP conversation with patients?
    Probe: What role does the patients' family play in the ACP conversation?
15. How adequate was your training in ACP?
    Probe: Do you feel that they have prepared you for the ACP session?
16. Do you follow guidelines given by AIC?
    [Facilitate a discussion on why they choose or choose not to follow guidelines set by AIC]
17. What might constitute a successful ACP session?

Feasibility

18. How confident are you in employing the ACP programme's tools (e.g IT system, worksheets)?
    Probe: How useful are they in your sessions?
19. How do patients respond to ACP?
20. How do patients' families' respond to ACP?
21. What types of preferences do patients' express?
    [Facilitate a discussion on medical care options and healthcare spokesperson]
    Probe: What is usually their preferred site of care?
    Probe: What about their site of death?
22. How does your team work together to ensure completion of these preferences?
23. What challenges have you faced in completion of these preferences?
    [Facilitate a discussion on barriers and facilitators to ACP]

Penetration

24. How do other members of your team feel towards ACP?

    [Facilitate a discussion on other healthcare provider's attitudes towards ACP]

25. Do you feel that other members of your team are willing to adopt ACP?

    Probe: How would you describe communication channels between team members?

    [Facilitate a discussion on the adoption of ACP across sectors]

26. What did the institution do to promote buy-in?

    [Facilitate a discussion on how the institution facilitated adoption of ACP across sectors]

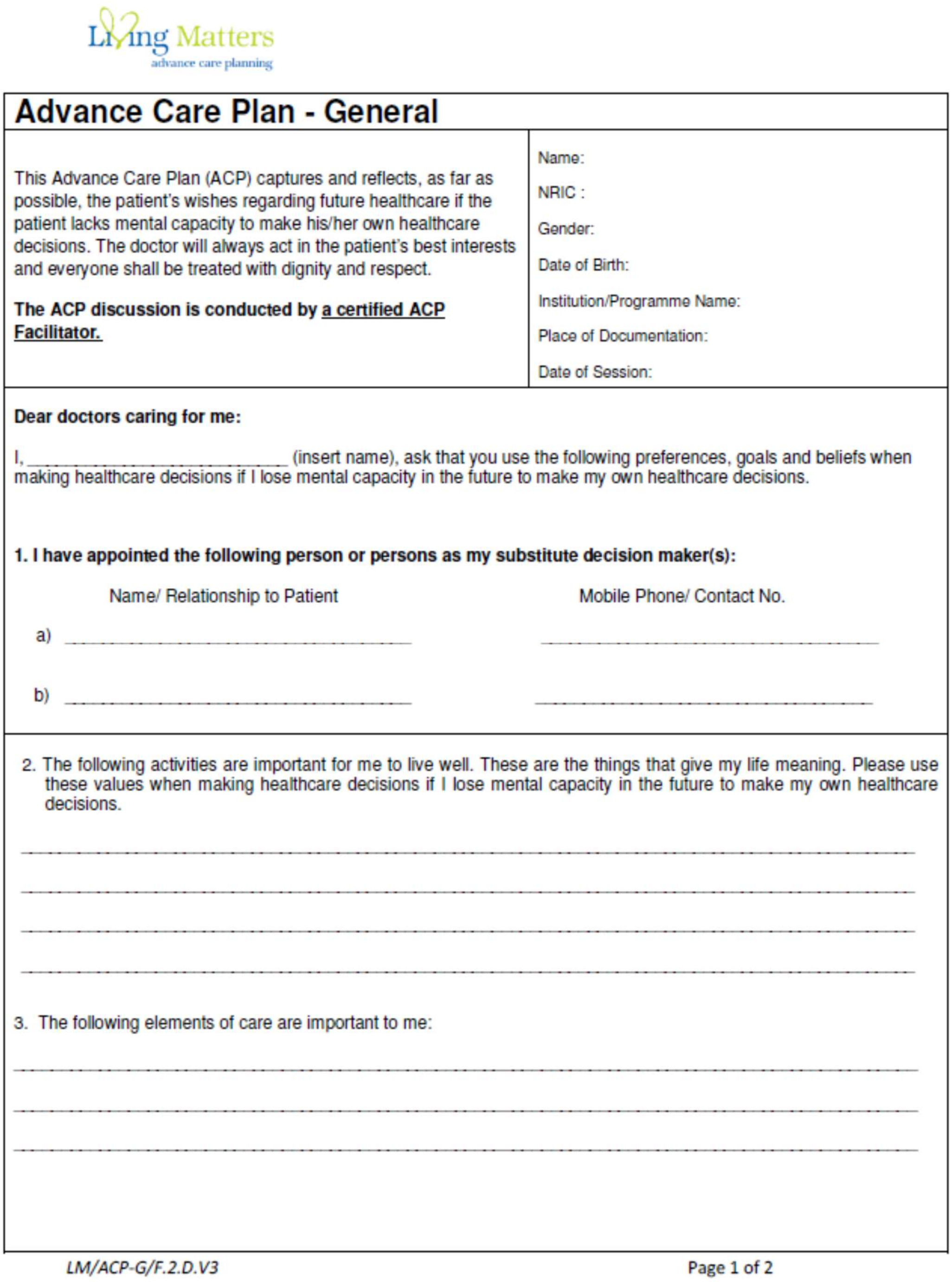
Sustainability

27. How has ACP effected your interaction with patients?

    Probe: how has ACP effected your interaction with families or care givers?

28. What are you hoping to achieve from ACP?
29. How could ACP be better implemented?
30. How sustainable is ACP?

Appendix 9 General ACP form for healthy individuals



Living Matters
advance care planning

Advance Care Plan - General

This Advance Care Plan (ACP) captures and reflects, as far as possible, the patient's wishes regarding future healthcare if the patient lacks mental capacity to make his/her own healthcare decisions. The doctor will always act in the patient's best interests and everyone shall be treated with dignity and respect.

The ACP discussion is conducted by <u>a certified ACP Facilitator.</u>

Name:
NRIC :
Gender:
Date of Birth:
Institution/Programme Name:
Place of Documentation:
Date of Session:

Dear doctors caring for me:

I, ___________________________ (insert name), ask that you use the following preferences, goals and beliefs when making healthcare decisions if I lose mental capacity in the future to make my own healthcare decisions.

1. I have appointed the following person or persons as my substitute decision maker(s):

	Name/ Relationship to Patient	Mobile Phone/ Contact No.
a)	____________________	____________________
b)	____________________	____________________

2. The following activities are important for me to live well. These are the things that give my life meaning. Please use these values when making healthcare decisions if I lose mental capacity in the future to make my own healthcare decisions.

____

____

____

____

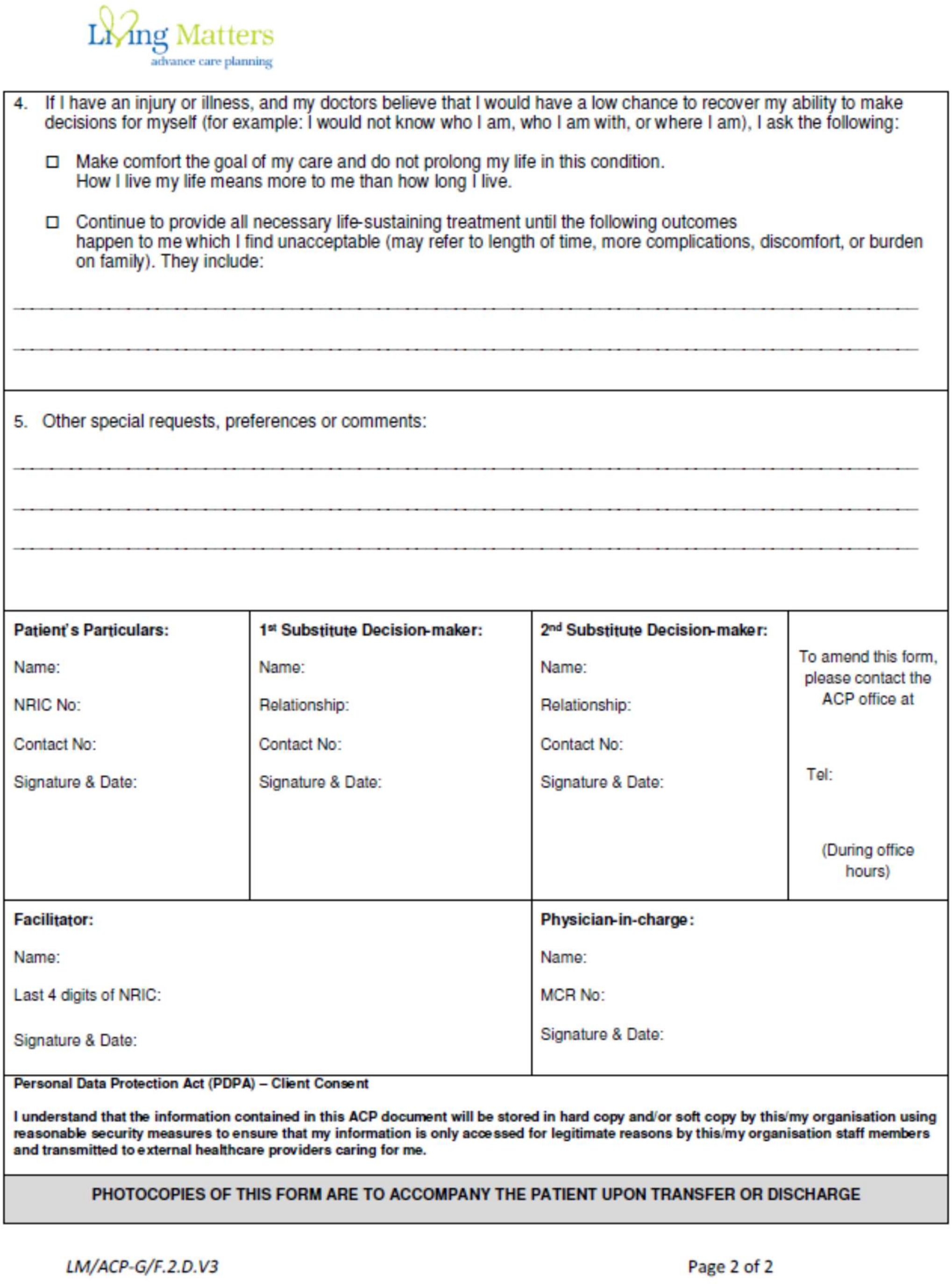
3. The following elements of care are important to me:

____

____

____

LM/ACP-G/F.2.D.V3 Page 1 of 2



Living Matters
advance care planning

4. If I have an injury or illness, and my doctors believe that I would have a low chance to recover my ability to make decisions for myself (for example: I would not know who I am, who I am with, or where I am), I ask the following:

☐ Make comfort the goal of my care and do not prolong my life in this condition.
How I live my life means more to me than how long I live.

☐ Continue to provide all necessary life-sustaining treatment until the following outcomes happen to me which I find unacceptable (may refer to length of time, more complications, discomfort, or burden on family). They include:

----

5. Other special requests, preferences or comments:

Patient's Particulars:	**1st Substitute Decision-maker:**	**2nd Substitute Decision-maker:**	To amend this form, please contact the ACP office at
Name:	Name:	Name:	
NRIC No:	Relationship:	Relationship:	
Contact No:	Contact No:	Contact No:	Tel:
Signature & Date:	Signature & Date:	Signature & Date:	(During office hours)

Facilitator:	**Physician-in-charge:**
Name:	Name:
Last 4 digits of NRIC:	MCR No:
Signature & Date:	Signature & Date:

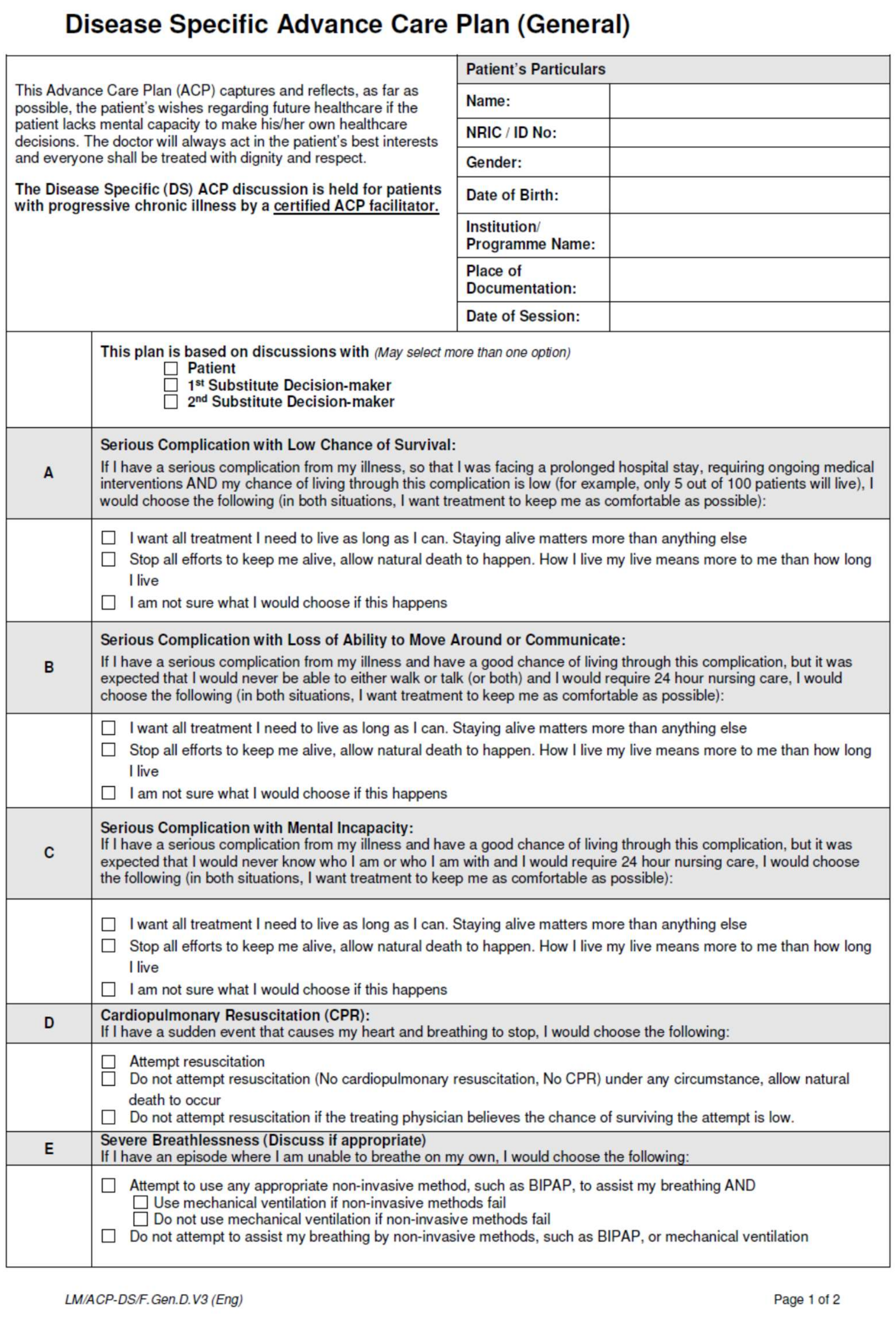
Personal Data Protection Act (PDPA) – Client Consent

I understand that the information contained in this ACP document will be stored in hard copy and/or soft copy by this/my organisation using reasonable security measures to ensure that my information is only accessed for legitimate reasons by this/my organisation staff members and transmitted to external healthcare providers caring for me.

PHOTOCOPIES OF THIS FORM ARE TO ACCOMPANY THE PATIENT UPON TRANSFER OR DISCHARGE

LM/ACP-G/F.2.D.V3 Page 2 of 2

Appendix 10 Disease Specific ACP form for individuals with chronic illnesses



Disease Specific Advance Care Plan (General)

This Advance Care Plan (ACP) captures and reflects, as far as possible, the patient's wishes regarding future healthcare if the patient lacks mental capacity to make his/her own healthcare decisions. The doctor will always act in the patient's best interests and everyone shall be treated with dignity and respect.

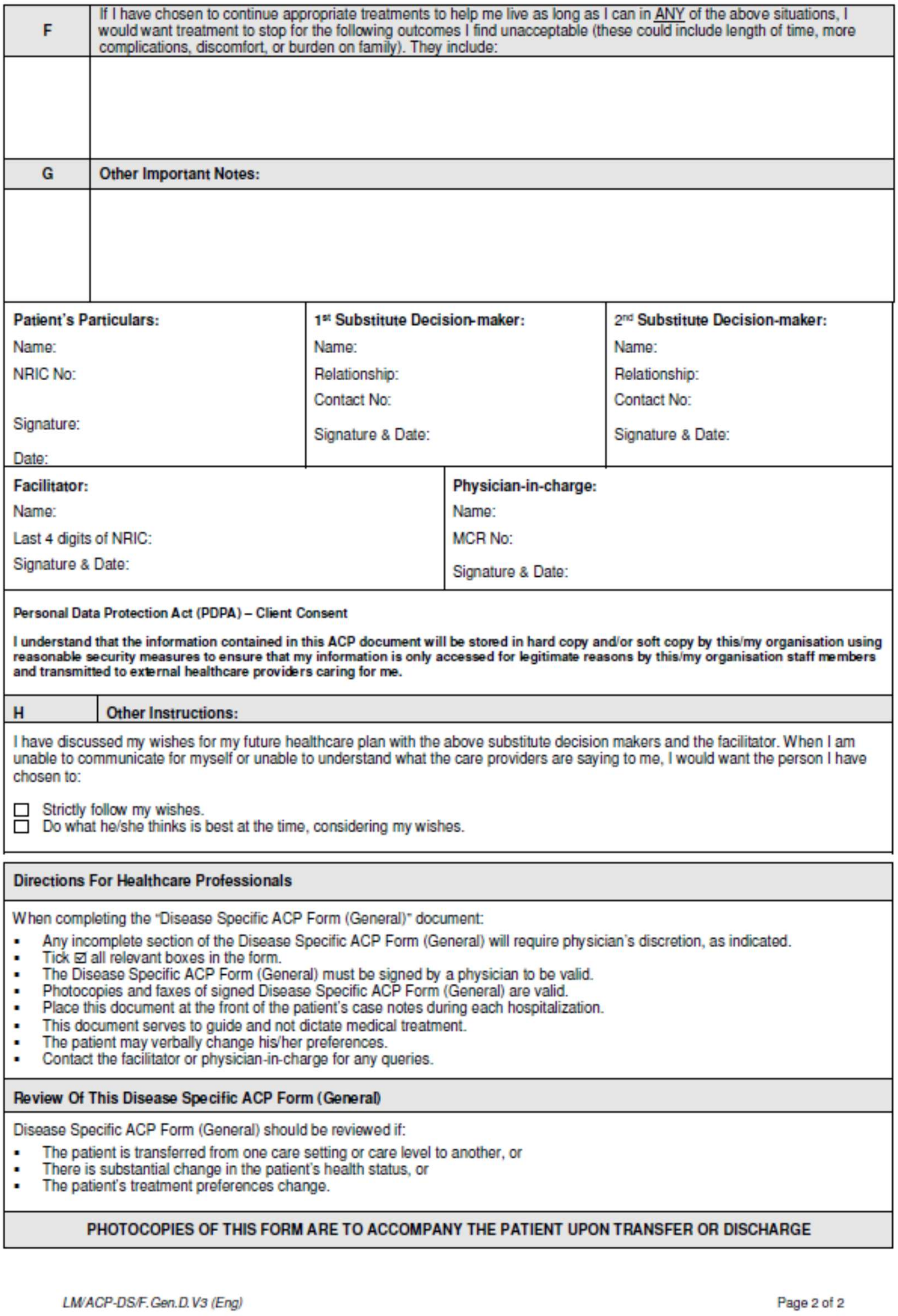
The Disease Specific (DS) ACP discussion is held for patients with progressive chronic illness by a certified ACP facilitator.

Patient's Particulars	
Name:	
NRIC / ID No:	
Gender:	
Date of Birth:	
Institution/ Programme Name:	
Place of Documentation:	
Date of Session:	

	This plan is based on discussions with *(May select more than one option)* ☐ **Patient** ☐ **1st Substitute Decision-maker** ☐ **2nd Substitute Decision-maker**
A	**Serious Complication with Low Chance of Survival:** If I have a serious complication from my illness, so that I was facing a prolonged hospital stay, requiring ongoing medical interventions AND my chance of living through this complication is low (for example, only 5 out of 100 patients will live), I would choose the following (in both situations, I want treatment to keep me as comfortable as possible):
	☐ I want all treatment I need to live as long as I can. Staying alive matters more than anything else ☐ Stop all efforts to keep me alive, allow natural death to happen. How I live my live means more to me than how long I live ☐ I am not sure what I would choose if this happens
B	**Serious Complication with Loss of Ability to Move Around or Communicate:** If I have a serious complication from my illness and have a good chance of living through this complication, but it was expected that I would never be able to either walk or talk (or both) and I would require 24 hour nursing care, I would choose the following (in both situations, I want treatment to keep me as comfortable as possible):
	☐ I want all treatment I need to live as long as I can. Staying alive matters more than anything else ☐ Stop all efforts to keep me alive, allow natural death to happen. How I live my live means more to me than how long I live ☐ I am not sure what I would choose if this happens
C	**Serious Complication with Mental Incapacity:** If I have a serious complication from my illness and have a good chance of living through this complication, but it was expected that I would never know who I am or who I am with and I would require 24 hour nursing care, I would choose the following (in both situations, I want treatment to keep me as comfortable as possible):
	☐ I want all treatment I need to live as long as I can. Staying alive matters more than anything else ☐ Stop all efforts to keep me alive, allow natural death to happen. How I live my live means more to me than how long I live ☐ I am not sure what I would choose if this happens
D	**Cardiopulmonary Resuscitation (CPR):** If I have a sudden event that causes my heart and breathing to stop, I would choose the following:
	☐ Attempt resuscitation ☐ Do not attempt resuscitation (No cardiopulmonary resuscitation, No CPR) under any circumstance, allow natural death to occur ☐ Do not attempt resuscitation if the treating physician believes the chance of surviving the attempt is low.
E	**Severe Breathlessness (Discuss if appropriate)** If I have an episode where I am unable to breathe on my own, I would choose the following:

	☐ Attempt to use any appropriate non-invasive method, such as BIPAP, to assist my breathing AND
	  ☐ Use mechanical ventilation if non-invasive methods fail
	  ☐ Do not use mechanical ventilation if non-invasive methods fail
	☐ Do not attempt to assist my breathing by non-invasive methods, such as BIPAP, or mechanical ventilation

LM/ACP-DS/F.Gen.D.V3 (Eng) Page 1 of 2



F	If I have chosen to continue appropriate treatments to help me live as long as I can in ANY of the above situations, I would want treatment to stop for the following outcomes I find unacceptable (these could include length of time, more complications, discomfort, or burden on family). They include:
G	**Other Important Notes:**

Patient's Particulars: Name: NRIC No: Signature: Date:	**1st Substitute Decision-maker:** Name: Relationship: Contact No: Signature & Date:	**2nd Substitute Decision-maker:** Name: Relationship: Contact No: Signature & Date:

Facilitator: Name: Last 4 digits of NRIC: Signature & Date:	**Physician-in-charge:** Name: MCR No: Signature & Date:

Personal Data Protection Act (PDPA) – Client Consent

I understand that the information contained in this ACP document will be stored in hard copy and/or soft copy by this/my organisation using reasonable security measures to ensure that my information is only accessed for legitimate reasons by this/my organisation staff members and transmitted to external healthcare providers caring for me.

H **Other Instructions:**

I have discussed my wishes for my future healthcare plan with the above substitute decision makers and the facilitator. When I am unable to communicate for myself or unable to understand what the care providers are saying to me, I would want the person I have chosen to:

☐ Strictly follow my wishes.
☐ Do what he/she thinks is best at the time, considering my wishes.

Directions For Healthcare Professionals

When completing the "Disease Specific ACP Form (General)" document:

- Any incomplete section of the Disease Specific ACP Form (General) will require physician's discretion, as indicated.
- Tick ☑ all relevant boxes in the form.
- The Disease Specific ACP Form (General) must be signed by a physician to be valid.
- Photocopies and faxes of signed Disease Specific ACP Form (General) are valid.
- Place this document at the front of the patient's case notes during each hospitalization.
- This document serves to guide and not dictate medical treatment.
- The patient may verbally change his/her preferences.
- Contact the facilitator or physician-in-charge for any queries.

Review Of This Disease Specific ACP Form (General)

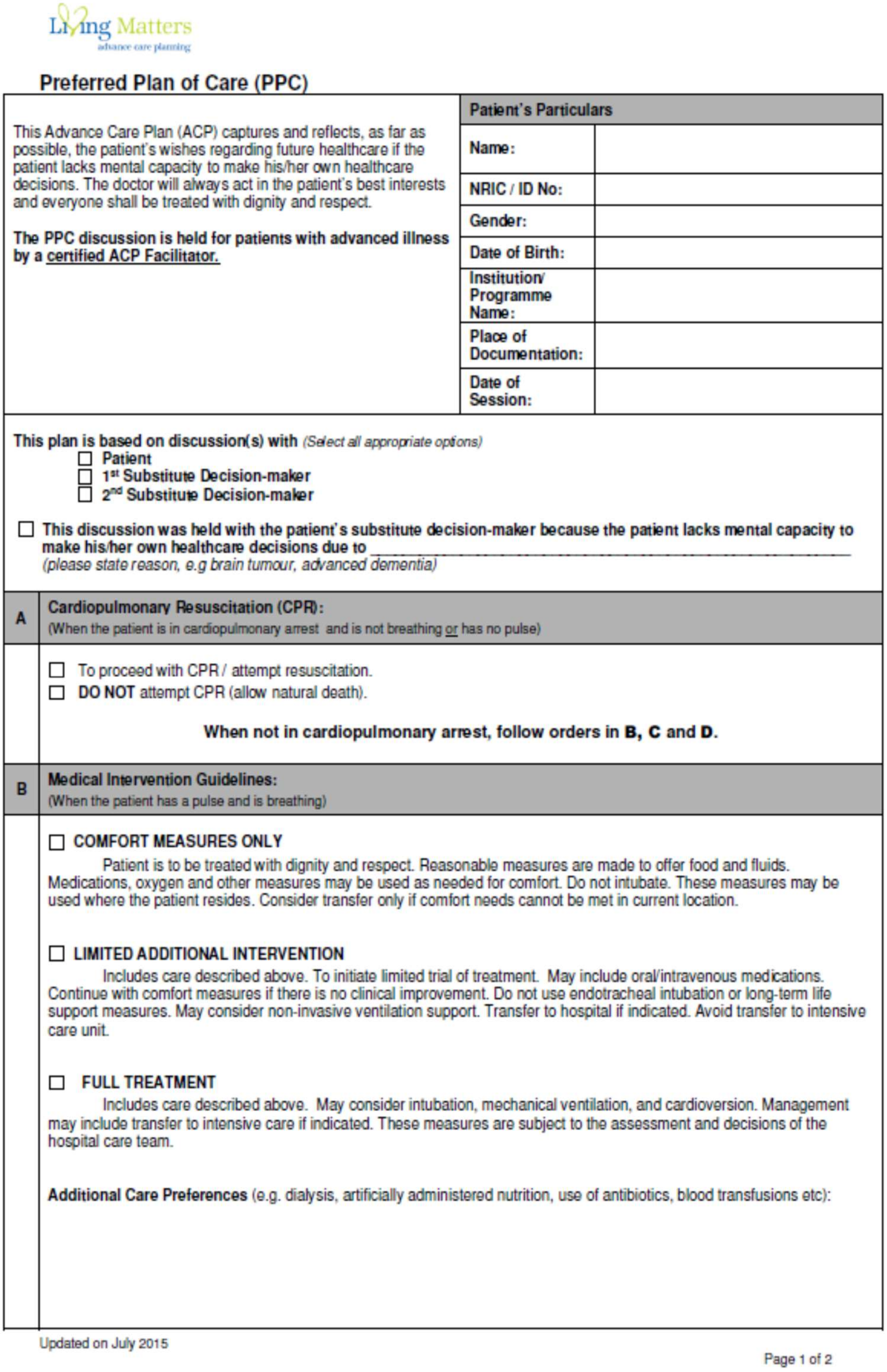
Disease Specific ACP Form (General) should be reviewed if:

- The patient is transferred from one care setting or care level to another, or
- There is substantial change in the patient's health status, or
- The patient's treatment preferences change.

PHOTOCOPIES OF THIS FORM ARE TO ACCOMPANY THE PATIENT UPON TRANSFER OR DISCHARGE

LM/ACP-DS/F.Gen.D.V3 (Eng) Page 2 of 2

Appendix 11 PPC form for individuals with advanced illnesses



Living Matters
advance care planning

Preferred Plan of Care (PPC)

This Advance Care Plan (ACP) captures and reflects, as far as possible, the patient's wishes regarding future healthcare if the patient lacks mental capacity to make his/her own healthcare decisions. The doctor will always act in the patient's best interests and everyone shall be treated with dignity and respect.

The PPC discussion is held for patients with advanced illness by a certified ACP Facilitator.

Patient's Particulars	
Name:	
NRIC / ID No:	
Gender:	
Date of Birth:	
Institution/ Programme Name:	
Place of Documentation:	
Date of Session:	

This plan is based on discussion(s) with *(Select all appropriate options)*
☐ **Patient**
☐ **1st Substitute Decision-maker**
☐ **2nd Substitute Decision-maker**

☐ **This discussion was held with the patient's substitute decision-maker because the patient lacks mental capacity to make his/her own healthcare decisions due to** ______________________________
(please state reason, e.g brain tumour, advanced dementia)

A **Cardiopulmonary Resuscitation (CPR):**
(When the patient is in cardiopulmonary arrest and is not breathing or has no pulse)

☐ To proceed with CPR / attempt resuscitation.
☐ **DO NOT** attempt CPR (allow natural death).

When not in cardiopulmonary arrest, follow orders in B, C and D.

B **Medical Intervention Guidelines:**
(When the patient has a pulse and is breathing)

☐ **COMFORT MEASURES ONLY**
Patient is to be treated with dignity and respect. Reasonable measures are made to offer food and fluids. Medications, oxygen and other measures may be used as needed for comfort. Do not intubate. These measures may be used where the patient resides. Consider transfer only if comfort needs cannot be met in current location.

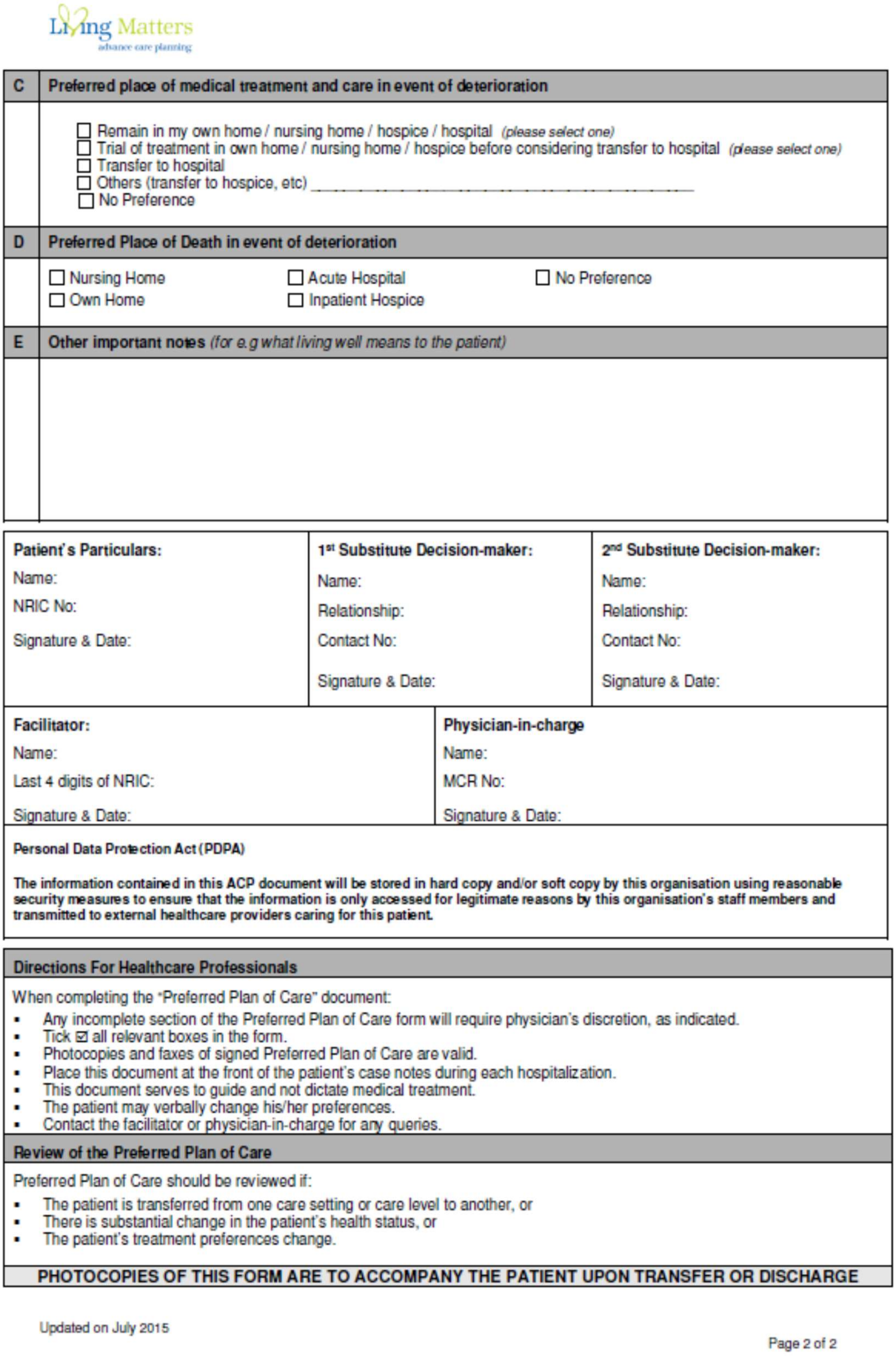
☐ **LIMITED ADDITIONAL INTERVENTION**
Includes care described above. To initiate limited trial of treatment. May include oral/intravenous medications. Continue with comfort measures if there is no clinical improvement. Do not use endotracheal intubation or long-term life support measures. May consider non-invasive ventilation support. Transfer to hospital if indicated. Avoid transfer to intensive care unit.

☐ **FULL TREATMENT**
Includes care described above. May consider intubation, mechanical ventilation, and cardioversion. Management may include transfer to intensive care if indicated. These measures are subject to the assessment and decisions of the hospital care team.

Additional Care Preferences (e.g. dialysis, artificially administered nutrition, use of antibiotics, blood transfusions etc):

Updated on July 2015

Page 1 of 2



Living Matters
advance care planning

C	**Preferred place of medical treatment and care in event of deterioration**
	☐ Remain in my own home / nursing home / hospice / hospital *(please select one)* ☐ Trial of treatment in own home / nursing home / hospice before considering transfer to hospital *(please select one)* ☐ Transfer to hospital ☐ Others (transfer to hospice, etc) ______________________________ ☐ No Preference
D	**Preferred Place of Death in event of deterioration**
	☐ Nursing Home ☐ Acute Hospital ☐ No Preference ☐ Own Home ☐ Inpatient Hospice
E	**Other important notes** *(for e.g what living well means to the patient)*

Patient's Particulars: Name: NRIC No: Signature & Date:	**1st Substitute Decision-maker:** Name: Relationship: Contact No: Signature & Date:	**2nd Substitute Decision-maker:** Name: Relationship: Contact No: Signature & Date:

Facilitator: Name: Last 4 digits of NRIC: Signature & Date:	**Physician-in-charge** Name: MCR No: Signature & Date:

Personal Data Protection Act (PDPA)

The information contained in this ACP document will be stored in hard copy and/or soft copy by this organisation using reasonable security measures to ensure that the information is only accessed for legitimate reasons by this organisation's staff members and transmitted to external healthcare providers caring for this patient.

Directions For Healthcare Professionals

When completing the "Preferred Plan of Care" document:

- Any incomplete section of the Preferred Plan of Care form will require physician's discretion, as indicated.
- Tick ☑ all relevant boxes in the form.
- Photocopies and faxes of signed Preferred Plan of Care are valid.
- Place this document at the front of the patient's case notes during each hospitalization.
- This document serves to guide and not dictate medical treatment.
- The patient may verbally change his/her preferences.
- Contact the facilitator or physician-in-charge for any queries.

Review of the Preferred Plan of Care

Preferred Plan of Care should be reviewed if:

- The patient is transferred from one care setting or care level to another, or
- There is substantial change in the patient's health status, or
- The patient's treatment preferences change.

PHOTOCOPIES OF THIS FORM ARE TO ACCOMPANY THE PATIENT UPON TRANSFER OR DISCHARGE

Updated on July 2015

Page 2 of 2

Appendix 12 Researcher notes on preliminary themes for factors influencing place of death

(1) Health system issues

Formal support care services

- Role of nurses and doctors:
    - Nurses may need to provide caregiver training, emotional support, and to guide the family on what to do when the patient passes on at home.
    - Healthcare professionals need to ensure that the family is emotionally ready to cope with necessary care during the final hours, have the necessary equipment, and also understand that prognostication can be uncertain, and the family should be prepared to care for the patient at home should the patient live beyond the expected length of time.

- Healthcare professionals such as nurses are not empowered to provide medical advice
    - The hospital system currently does not empower acute care healthcare professionals to provide off-site telephonic advice on care matters. For instance, a patient had expressed a preference for home death but when the family contacted the hospital during a crisis, they were informed by the nurses to admit the patient to the hospital.

- Community care readiness
    - Respondents expressed that patients on home care might have higher rates of preferences being honoured as home care teams are able to respond accordingly when they are activated.
    - Lack of community services to support patients' wishes as current home hospices and inpatient hospices services are in shortage. More short-terms services are needed to support care for the last-stage of life.
    - Hospice home care has specific inclusion criteria such as requiring the patient to have a caregiver at home. For example, an old patient with current acute events may not be accepted for home hospice.
    - Continuity of care from acute care supports the individual to be cared for, and to eventually die at home. This was expressed by individuals who work in hospitals, where palliative care services can be activated for post-discharge home visits.
    - The need to certify an individual's death at home necessitates the engagement of a private general practitioner. It was mentioned that when families are unable to engage one, they are left with no choice but to contact the ambulance service.

- The expression of preferences as documented in the ACP is not legally binding and as such, it can be overridden by doctors based on medical judgement or by the patients’ family.

(2) Carer related factors

Availability of paid informal caregiver and informal family caregivers

- Even with home care services, the likelihood of the patient dying at death is still dependent on the availability of family caregiver, or having a domestic helper in the home. This because a caregiver is required to care for the patient outside of the service hours of the home care providers.
- There is a perceived lacking in the readiness and ability of the family caregiver in carrying out care procedures that are essential for patient to live at home
- The anxiety level in caregivers becomes high when patients become breathless at home.
- Patient’s family members are also in the state of grief at the last stage of life, and may not be able to cope.

Financial impediments

- The cost of obtaining hospital bed and required equipment for home care is expensive.
- Families might be unable to afford hiring a full-time caregiver (foreign domestic helper).
- Families might be unable to take care of patient 24/7 as they need to work.

Family dynamics do not support treatment or death at home

- Complexity of previous family history and dynamics may exclude home as a choice for care and death.
- For nursing home patients, they are usually in the nursing homes because alternative caregiving arrangements are not possible. Therefore, even though they are free to choose other sites including their residential homes as the place of death, it is not in reality a feasible option.

(3) Culturally-driven behaviours and beliefs that led to discordance between preferred and actual home deaths

- Due to religion, Muslim patients may prefer to care for the patient at home partly due to the required ritual of burial before sun down. The FGD respondents perceived a greater sense of commitment from these families to support the care of the patient at home to facilitate dying at home. Financial issues are often circumvented by pooling resources within the extended family.

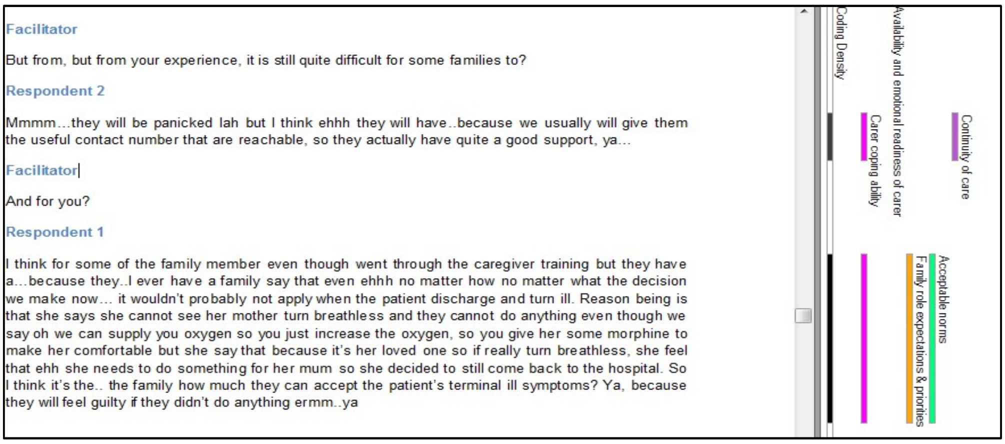
- Muslim patients often choose to pass away at home and while they might need support for symptom management – may not be what can be termed as a peaceful passing but being physically at home outweighs the rest.
- For the Chinese, there is fear that dying at home might scare the children or affect the property value.
- Caregivers perceived that by allowing the patient to die at home, they will be seen as "not doing anything to help the patient". They also perceive admitting the patient to the hospital as at least "doing something".
- A handful of individuals expressed that although they prefer to die at home, they will however choose to die in an institution so as not to be a burden to the family (typically young families).
- One's preferences for the location of care and death might be influenced by the individual's readiness to think about death and dying. Patients who have being sicker tend to have a clear idea of where they would want to be.
- Giving due consideration to the burden of care on their children, elderly patients may say they have no specific preferences even though they do.

(4) Medical factors

- Illness condition does not permit care or death at home. E.g. The individual's medical condition may necessitate full-time care (e.g. 2-hourly sanctioning).
- Patient's condition may not permit dying at home, but some patients weigh dying at home more importantly than comfort.
- Patients' choices in treatment and place of death might be at odds. For example, a patient may choose comfort, and to die at home but being at home may reduce the comfort level due to his/her medical condition. The respondents reflected that in such cases, most people often choose comfort over site of care/death.

Appendix 13 Example of coded transcript excerpt for factors influencing place of death

The screenshots from NVIVO® below show extracts from two different focus group discussion interview transcripts. For each extract, the panel on the left contains the transcript that was analysed, while the corresponding coding stripes were displayed in the right panel.



Facilitator

But from, but from your experience, it is still quite difficult for some families to?

Respondent 2

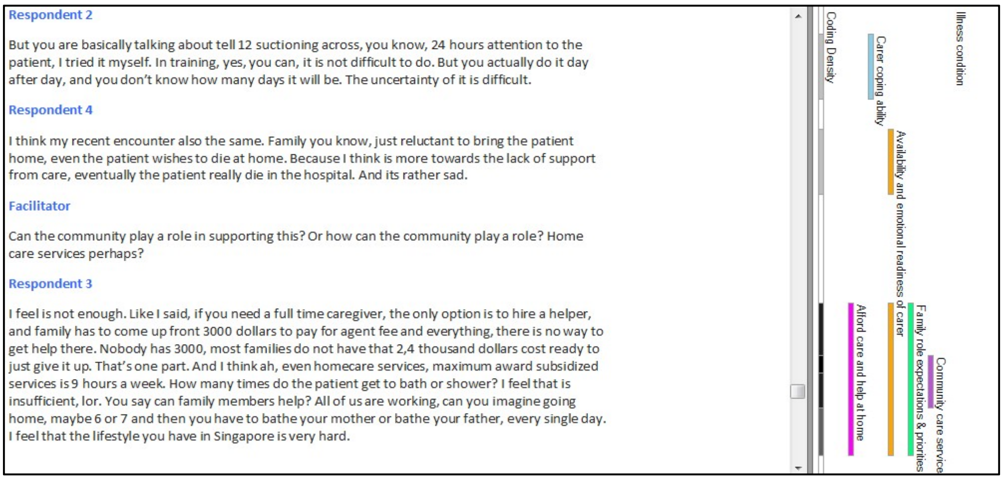
Mmmm...they will be panicked lah but I think ehhh they will have..because we usually will give them the useful contact number that are reachable, so they actually have quite a good support, ya...

Facilitator

And for you?

Respondent 1

I think for some of the family member even though went through the caregiver training but they have a...because they..I ever have a family say that even ehhh no matter how no matter what the decision we make now... it wouldn't probably not apply when the patient discharge and turn ill. Reason being is that she says she cannot see her mother turn breathless and they cannot do anything even though we say oh we can supply you oxygen so you just increase the oxygen, so you give her some morphine to make her comfortable but she say that because it's her loved one so if really turn breathless, she feel that ehh she needs to do something for her mum so she decided to still come back to the hospital. So I think it's the.. the family how much they can accept the patient's terminal ill symptoms? Ya, because they will feel guilty if they didn't do anything ermm..ya



Respondent 2

But you are basically talking about tell 12 suctioning across, you know, 24 hours attention to the patient, I tried it myself. In training, yes, you can, it is not difficult to do. But you actually do it day after day, and you don't know how many days it will be. The uncertainty of it is difficult.

Respondent 4

I think my recent encounter also the same. Family you know, just reluctant to bring the patient home, even the patient wishes to die at home. Because I think is more towards the lack of support from care, eventually the patient really die in the hospital. And its rather sad.

Facilitator

Can the community play a role in supporting this? Or how can the community play a role? Home care services perhaps?

Respondent 3

I feel is not enough. Like I said, if you need a full time caregiver, the only option is to hire a helper, and family has to come up front 3000 dollars to pay for agent fee and everything, there is no way to get help there. Nobody has 3000, most families do not have that 2,4 thousand dollars cost ready to just give it up. That's one part. And I think ah, even homecare services, maximum award subsidized services is 9 hours a week. How many times do the patient get to bath or shower? I feel that is insufficient, lor. You say can family members help? All of us are working, can you imagine going home, maybe 6 or 7 and then you have to bathe your mother or bathe your father, every single day. I feel that the lifestyle you have in Singapore is very hard.

Appendix 14 Example of analysis based on the NPT constructs

NPT constructs	Sub constructs	Overall Remarks
1. Coherence - Description of individual as well as collective work done to make sense of ACP, and to put it into action	1.1 Differentiation	There is a need to distinguish the goals and practices of DRG, EOC from ACP and/or to align all practices within each hospital, and to ensure all doctors understand the care implications of choices related to "comfort care", "limited intervention" and "full treatment". This lack of distinction was raised more frequently by participants from hospitals that have recently implemented ACP. At the societal level, ACP should be clearly distinguished from living will, LPA and AMD. One clear benefit of ACP that is different from previous practice of end-of-life care discussions is that systematic documentation allows more efficient and timely retrieval of the information.
	1.2 Communal Specification	There is a general lack of shared understanding of the aims, objectives and expected benefits of ACP. Communication from national level strategy to inform institutional level plans are also lacking. Surgeons, cardiologists, and senior doctors have been cited to not support the programme especially given the curative culture which is perceived to be at odds with ACP. HCPs understood the goals of ACP to: (a) Reduce healthcare cost, (b) Provide guidance on plan of care at end-of-life to the medical team, and (c) Facilitate planning of post-discharge care. Doctors may not agree with empowering patients to make medical decisions because they do not think patients understand the full implications.
	1.3 Individual Specification	Individually, HCPs have identified specific tasks and behaviours that will support the ACP process but ACP-trained nurses who work in the wards may not view or understand ACP to be part of their job role. The role of ACP trainer was also questioned as there is no explicit criteria to qualify one as a trainer.
	1.4 Internalisation	Nonetheless, across all participating hospitals, FGD participants strongly believe in the value and benefit of ACP at the patient-, family- and hospital level. However, doubts were raised by participants from late adopters about the value of general ACP, empty promise of honouring patients' preferences, and the role of the doctor as an ACP facilitator.

ACP: Advance Care Planning; AMD: Advanced Medical Directive; DNR: Do-Not-Resuscitate; EOC: Extent of Care; FGD: Focus Group Discussion; HCP: Healthcare Professional; LPA: Lasting Powers of Attorney

Appendix 15 A case example of the organisation of ACP and its processes

Organisation and staff roles	Nature and process of work	Facilitators of ACP
• Physician led model • ACP is physician led and headed by head of discipline (Cardiology, Gastroenterology, Respiratory, Neurology, Renal, Oncology, Infectious Diseases) • Each of the 5 full-time ACP facilitators are assigned two disciplines, and are responsible to monitoring hospital admissions of patients who completed ACP, admissions and follow-up appointments of patients with ACP in progress, and those who have been referred • ACP facilitators are accountable to head of discipline for numbers completed; assist HCP with the administrative matters related to ACP • For medically complex cases, trained doctors will conduct the ACP; simpler cases are referred to ACP facilitators and junior doctors might jointly conduct the session with ACP facilitators to address medical questions	**Settings** • Inpatient and outpatient referrals are made to ACP facilitators for their assigned disciplines **Referral criteria and process** • Screening every new admission for ACP suitability, which has been described as the health journey of the patient in the last 6- to 12-months with frequent readmission can be an indicator of health decline; non-crisis state; cognitively sound • Rely on the surprise question to identify patient for PPC • Doctors put in a formal referral request to the ACP facilitators, who then arrange for a suitable time with the patient and their family members • Doctors will introduce the concept of ACP to the patients • In the palliative care team, a list of patients who have undergone/or not undergone ACP will be reviewed jointly with ACP facilitators **Documentation** • Individual facilitators will fill in the ACP forms in hardcopy, and key the information into the AIC IT system. The completed hardcopy form is scanned into the hospital-based IT system	**Advocacy & Capacity building** • Mandatory for all the residents to be trained in conducting ACP and every resident must at least go through one formal ACP facilitation • Sending nurses and doctors to ACP workshops but not mandatory for nurses • Brochures are available in the wards for patients and family members **Communication of ACP decisions** • ACP form can be accessed under "scanned note" in the electronic medical records but for the AIC IT system, you need to log in separately • There will be an icon that flashes that says that ACP has been done • Doctors are asked to mention that ACP has been completed in the discharge summary **Review of ACP decisions** • Brochure with a contact number is provided to the patient if they want to change their documented choices **Mentorship** • For the first few ACP sessions, ACP facilitators buddy up with senior colleagues

ACP: Advance Care Planning; AIC: Agency for Integrated Care; IT: Information Technology; PPC: Preferred Plan of Care

Appendix 16 Procedure and diagnosis-related codes to identify life-sustaining treatments

ICD-9-CM	Description	ACHI	Description	DRG	Description
Cardiopulmonary Resuscitation					
99.60	Cardiopulmonary resuscitation	9205200	Cardiopulmonary resuscitation		
99.63	Closed chest cardiac massage	9205300	Closed chest cardiac massage		
		9204200	Nonmechanical methods of resuscitation		
Mechanical Ventilation & Intubation					
96.04	Insertion of endotracheal tube	1388200	Management of continuous ventilatory support, <= 24 hours	A06C	Ventilation >95 hours W/O Catastrophic CC
96.05	Other intubation of respiratory tract	1388201	Management of continuous ventilatory support, more than 24 hours and less than 96 hours	B42A	Nervous System Diagnosis W Ventilator Support W Catastrophic CC
96.7	Other continuous invasive mechanical ventilation	1388202	Management of continuous ventilatory support, 96 hours or more	B42B	Nervous System Diagnosis W Ventilator Support W/O Catastrophic CC
96.70	Continuous invasive mechanical ventilation of unspecified duration			E40A	Respiratory System Diagnosis W Ventilator Support W Catastrophic CC
96.71	Continuous invasive mechanical ventilation for less than 96 consecutive hours			E40B	Respiratory System Diagnosis W Ventilator Support W/O Catastrophic CC
96.72	Continuous invasive mechanical ventilation for 96 consecutive hours or more			F40A	Circulatory System Diagnosis W Ventilator Support W Catastrophic CC
				F40B	Circulatory System Diagnosis W Ventilator Support W/O Catastrophic CC
				T40Z	Infectious and Parasitic Diseases W Ventilator Support*
				W01Z	Ventilation or Cranial Procedures for Multiple Significant Trauma*

ICD-9-CM	Description	ACHI	Description	DRG	Description
				X40Z	Injuries, Poisoning and Toxic Effects of Drugs W Ventilator Support*
				Y01Z	Ventilation for Burns and Severe Full Thickness Burns*
Tracheostomy					
31.1	Temporary tracheostomy			A06A	Tracheostomy W Ventilation >95 hours W Catastrophic CC
31.21	Mediastinal tracheostomy			A06B	Trach W Vent >95 hours W/O Cat CC or Trach/Vent >95 hours W Cat CC
31.29	Other permanent tracheostomy			A06D	Tracheostomy W/O Catastrophic CC
Non-invasive ventilation					
93.90	Non-invasive mechanical ventilation			E41Z	Respiratory System Diagnosis W Non-Invasive Ventilation
				F43Z	Circulatory System Diagnosis W Non-Invasive Ventilation

ACHI: Australian Classification of Health Interventions codes; CC: complications; DRG: Diagnosis-Related Group; ICD-9-CM: International Classification of Diseases, Ninth Revision, Clinical Modification; W: with; W/O: without

Appendix 17 Place of medical treatment or care concordance mapping

1. Coding preferences for place of medical treatment or care

The preferences for a single place of care were first assigned codes ranging from A to E whereas conditional preferences were indicated by the same letters of the alphabets in accordance to the sequence.

Preferences for place of care	**Code**
Home	A
Hospice	B
Nursing Home	C
Hospital	D
Trial of treatment in own home before considering transfer to hospital	AD
Trial of treatment in own home before considering transfer to hospital or hospice	AD, AB
Trial of treatment in hospice before considering transfer to hospital	BD
Trial of treatment in nursing home before considering transfer to hospital	CD
Unsure	E
No preference	E
Others	E

2. Coding transitions in places of medical treatment/care

Transitions in places of care were established by looking through the service records obtained from the MOH case mix and subvention database, and intermediate and long-term care information system. For each of the services used, the date of admission or discharge was compared with the date of death of the individual to ascertain whether the patient had utilised the service in the 14-, 30- and 90-days prior to death. A sequence of services utilised within each of these timeframes was constructed. The table below illustrates the sequence generated for an individual with a unique identifying number "1234".

PUIN	Service Description	Code	Date of admission	Date of discharge	Date of death	14-days transition
1234	Home medical	A	01/06/2016	31/01/2017	31/01/2017	A
1234	Home palliative care	A	01/09/2016	31/01/2017	31/01/2017	AA
1234	Hospital	D	15/01/2017	31/01/2017	31/01/2017	AAD

3. Coding of the match between preferences and transitions in care

In the example above, if the individual "1234" had opted for a "trial of care at home before transfer to hospital" (coded as "AD") as his/her preferred place of care, the level of concordance would have been coded as 1 since the individual indeed transited between care at home and the hospital in the last 14-days prior to death (coded as “AAD”). However, if the individual “1234” had opted for hospital (coded as “B”) as the preferred place of care, the level of concordance would have been coded as 0 for non-concordance.

4. Deriving aggregate level of concordance

To obtain the final level of concordance number of individuals for preferred place of medical treatment/care, the number of individuals who received care at their preferred locations was divided by the number of individuals for each category of place of medical treatment/care.

Appendix 18 Cancer diagnosis codes

Type of cancer	ICD-9-CM	ICD-10-CM
Any malignancy including lymphoma and leukaemia	140.x-172.x, 174.x-195.8, 200.x-208.x	C00.x-c26.x, C30.x-C34.x, C37.x-c41.x, C43.x, C45.x-C58.x, C60.x-C76.x, C81.x-C85.x, C88.x, C90.x-C97.x
Metastatic solid tumours	196.x-199.1	C77.x-C80.x

ICD-9-CM: International Classification of Diseases, 9th version with clinical modification; ICD-10-CM: International Classification of Diseases, 10th version with clinical modification

Appendix 19 Steps to establish analytical samples to evaluate the impact of ACP

The table below lists the steps undertaken to derive the analytical dataset for the intervention group:

Steps	Definition	Data From
1	Obtain the list of NRIC numbers of individuals who have completed the ACP discussion from January 2011 to 31 December 2015.	AIC, TTSH
2	Generate a list of PUINs to match each NRIC number from the above list.	3rd party vendor
3	Identify the eligible sample based on date of death (deceased as at 31 Dec 2015).	MOH
4	Identify sociodemographic and health services utilisation data for the above individuals from the casemix and subvention dataset using PUINs to link across datasets	MOH
5	Distinguish between cancer and non-cancer samples based on ICD-9-CM and ICD-10-CM codes	MOH

The table below describes the steps involved for obtaining the comparator sample.

Steps	Definition	Data source
1	Obtain the list of PUINs of individuals who died in Singapore between January 2011 and December 2015 and sift out individuals who had completed their ACP	3rd party vendor
2	Merge the PUINs with inpatient data obtained from the casemix and subvention database to obtain the sociodemographic and clinic profile and health services utilisation data for each deceased individual	MOH
3	Identify individuals diagnosed with cancer and non-cancer based on ICD-9-CM and ICD-10-CM codes	MOH
4	For the cancer and non-cancer groups, separately compute the propensity scores for the intervention group and dataset obtained above. Using nearest neighbour matching (2:1) to obtain the final analytical sample	MOH

AIC: Agency for Integrated Care; ICD-9-CM: International Classification of Diseases, 9th version with clinical modification; ICD-10-CM: International Classification of Diseases, 10th version with clinical modification; MOH: Ministry of Health; NRIC: National Registry Identification Card; PUIN: Personal Unique Identifying Number; TTSH: Tan Tock Seng Hospital

Appendix 20 Contributions to Science (2015 – 2018)

1. Selected papers

Publication and manuscripts included in the thesis

- **Tan, W. S.,** Bajpai, R., Low, C. K., Ho, A. H. Y., & Car, J. (2018). Using routinely collected data to ascertain concordance with advance care planning preferences. *J Pain Symptom Manage*, 56(5), 659-666.e652. doi:10.1016/j.jpainsymman.2018.07.017. (Chapter 8)

- **Tan, W.S.**, Bajpai, R., Ho, A.H.Y., Low, C.H., Wu, H.Y., Car, J. Real-life decisions about end-of-life care preferences in a Southeast Asian country. *BMJ Open* (under review). (Chapter 4)

- **Tan, W.S.**, Lall, P., Wu, H.Y., Ho, A.H.Y. A qualitative study of healthcare professionals' perceptions of end-of-life care preference elicitation and influences of home deaths. *J Gen Intern Med* (under review). (Chapter 5)

- **Tan, W.S.**, Bajpai, R., Low, C.H., Ho, A.H.Y., Wu, H.Y., Car, J. Individual, clinical and system factors associated with home deaths: A linked national database study. *PLoS One* (under review). (Chapter 6)

- **Tan, W.S.,** Car, J., Lall, P., Low, C.K., Ho, A.H.Y. Implementing Advance Care Planning in acute hospitals: Leading the transformation of norms. *J Am Geriatr Soc.* (under review). (Chapter 7)

Publication related to and not included in the thesis

- Jimenez, G., **Tan, W.S.**, Virk, A.K., Low, C.K., Car, J., & Ho, A.H.Y. (2018). State of Advance Care Planning research: A descriptive overview of systematic reviews. *Palliat Support Care*, 1-11. doi:10.1017/s1478951518000500

- Jimenez, G., **Tan, W.S.,** Virk, A.K., Low, C.K., Car, J., & Ho, A.H.Y. (2018). Overview of systematic reviews of Advance Care Planning: Summary of evidence and global lessons. *J Pain Symptom Manage*, 56(3), 436-459.e425. doi:10.1016/j.jpainsymman.2018.05.016

- Ho, A.Y.H., Lall, P., **Tan W.S.**, Patinadan, P.V., Wong, L.H., Dutta, O., Pang, W.S., Low, C.K., Car, J. Advance Care Planning in Asia: an interpretive-systemic framework. *Soc Sci Med.* (under review)

- Dutta, O., Lall, P., Victor, P., Car, J., Low, C.K., **Tan, W.S.**, Ho, A.H.Y. Practitioners' perspectives on patient autonomy and participation in end-of-life care: a Singaporean experience. *Palliat Med.* (under review)

Publication during candidature unrelated and not included in thesis

- Wu, C.X., **Tan, W.S.**, See, R.C., Yu, W., Kwek, L.S., Toh, M.P., Chee, T.G., Chua, G.S. (2015). A matched-group study protocol to evaluate the implementation of an integrated care pathway programme for Chronic Obstructive Pulmonary Disease in Singapore. *BMJ Open*, *5*(1): e005655. doi: 10.1136/bmjopen-2014-005655

- **Tan, W.S.**, Lee, A., Yang, S.Y., Chan, S., Wu, H.Y., Ng, C.W. Heng, B.H. (2016). Integrating palliative care across settings: A retrospective cohort study of a hospice home care programme for cancer patients. *Palliat Med, 30*(7), 634-41. doi: 10.1177/0269216315622126

- Car, J., **Tan, W.S.**, Huang, Z., Sloot, P., Franklin, B.D. (2017). eHealth in the future of medications management: Personalisation, monitoring and adherence. *BMC Med, 15*(1), 73. doi: 10.1186/s12916-017-0838-0

- Saxena, N., George, P.P., Teo, K.W., **Tan, W.S.**, Ng, C., Heng, B.H., Yeo, C.Y.Y., Anthony, P., Tan, C., Low, K.Y., Wu, V., Ali, N.B., Chong, M.S. (2017) Evaluation of an integrated primary care-led dementia shared care program in Singapore – an effectiveness and cost-effectiveness study. *Geriatr Gerontol Int*, *18*(3), 479-486. doi: 10.1111/ggi.13196

- Chong, P.H., Molina, J.A.D., Teo, K.W., **Tan, W.S.** (2018) Paediatric palliative care improves patient outcomes and reduces healthcare cost: Evaluation of a home-based program. *BMC Palliat Care*, *17*(1), 11. doi: 10.1186/s12904-017-0267-z.

- Wu, C.X., Hwang, C.H., **Tan, W.S.**, Tai, K.P., Kwek, L.S.L., Chee, T.G., Choo, Y.M., Phng, F.W.L., Chua, G.S. (2018). The effectiveness of a chronic obstructive pulmonary disease integrated care pathway programme in Singapore:

A matched-group study. *BMJ Open, 8*(3), e019425. doi: 10.1136/bmjopen-2017-019425.

2. Conference posters and symposia presentations

- **Tan, W.S.** *Demystifying economic evaluation in palliative care studies.* (2017, July). In L. Tan & C.M. Yee (Chair), Pre-conference research methods workshop. Symposium at the Asia Pacific Hospice Care Conference, Singapore.

- **Tan, W.S.** (2017, July). *Integrated palliative care: Working as a community.* Asia Pacific Hospice Care Conference, Singapore.

- **Tan, W.S**. (2017, October). *Economics of integrating palliative care.* Singapore Health & Biomedical Congress, Singapore.

- **Tan, W.S**. (2018, April). *Before and beyond effectiveness.* In: H. Legido-Quigley (Chair), How do we know if our programme or interventions are effective? Evaluation framework and taxonomy. Symposium at the Singapore Population Health Conversation and Workshop, Singapore.

- **Tan, W.S.**, Bajpai, R., Ho, A.H.Y., Low, C.K., Cheah, J., Wong, C., Car, J. (2018, June). *End-of-life care preferences in a national sample in Singapore*. Poster presented at the Annual Research Meeting, Seattle, US

- **Tan, W.S.**, Bajpai, R., Low, C.K., Ho, A.H.Y., Cheah, J., Wong, C., Car, J. (2018, June). *Individual, clinical and system factors associated with home deaths: A national population-based study*. Poster presented at the Annual Research Meeting, Seattle, US

- **Tan, W.S.**, Car, J., Lall, P., Low, C.K., Cheah, J., Wong, C., Ho, A.H.Y. (2018, June). *Initiating, implementing and integrating Advance Care Planning: leading the transformation of norms*. Poster presented at the Annual Research Meeting, Seattle, US

- Ho, A.H.Y., Lall, P., **Tan, W.S.**, Patinadan, P.V., Wong, L.H., Dutta, O., Pang, W.S., Low, C.K., Cheah, J., Wong, C., Car, J. (2018, June). *Sustainable implementation of Advance Care Planning in Asia: An Interpretive-Systemic*

Framework for National Development. Poster presented at the Annual Research Meeting, Seattle, US

- **Tan, W.S.** (2018, October). *Place of death, wish and reality*. In: F. Girosi (Chair), Health services and outcomes research for policy. Symposium at the Singapore Health & Biomedical Congress, Singapore.