

**The experiences of death and dying for Chinese people in Australia: A qualitative study
for cultural competency**

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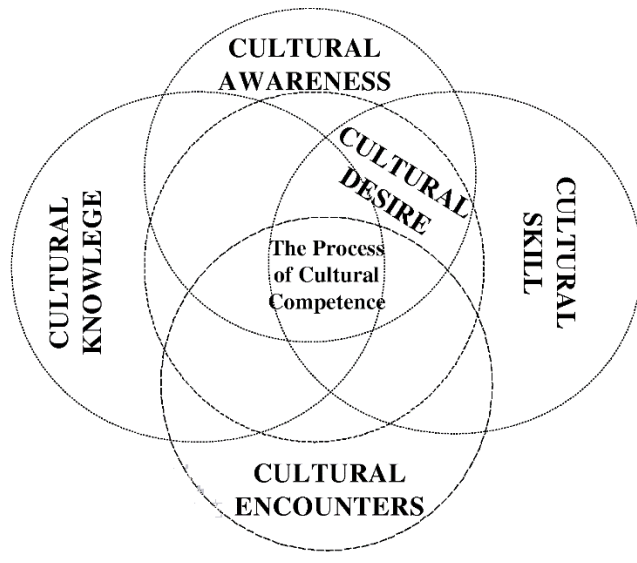


Figure 1. The Process of Cultural Competence in the Delivery of Healthcare

(Campinha-Bacote, 2002, p. 183)

Abstract

Census data have shown the emergence and predominance of Chinese communities in Australia. Health care professionals need to be competent in recognizing and respecting different cultural perspectives when working with patients and their families. A major differentiating cultural understanding for Chinese people is the conceptualisation of death and dying. Current research on Chinese culture regarding end of life highlights attitudes reflecting cultural and religious roots, and a taboo view towards discussions about death. This means research on this topic with Chinese people is challenging and few studies have been conducted in an Australian context. Given the cultural diversity of Australia and its Western approach to health care, this study aims to contribute to existing literature about the cultural perspectives of Chinese people in Australia towards health care, specifically regarding death, dying and end of life. Given the cultural sensitivity of discussing death and that many older Chinese people are non-native English speakers, interpreters can offer insights about end of life experiences with patients, rather than speaking directly with the patient, which may cause distress. A purposive sampling approach was employed to recruit Chinese interpreters, who participated in qualitative interviews. An inductive approach of thematic analysis identified four overarching themes: 'Healthcare is different (for Chinese people)', 'Family as influential', 'Death and dying as taboo', and 'Changing attitudes of Chinese people'. Findings from this study serve to raise awareness of the differing cultural perspectives of Chinese people in Australia towards death and dying and highlight the need for cultural competency for health care professionals, to deliver culturally appropriate patient care.

Presentations based on this thesis

Low, W, L, G. (2018, July). *The experiences of death and dying for Chinese people in Australia: A qualitative study for cultural competency*. Oral and Poster presentation at the 4th University of Adelaide Undergraduate Research Conference, Adelaide, South Australia. (see Appendices F, G, and H).

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and to the best of my knowledge, this thesis contains no materials previously published except where due reference is made.

I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search, and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

Gregory Low Wei Liang

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CHAPTER 1

1.1 Background

According to the most recent Census of Australia (Australian Bureau of Statistics, 2017), there was a distinct growth of Australian residents who were Chinese, with China being the third most common country of Australian residents born overseas, and Mandarin as the second most common language spoken at home, aside from English (Cantonese, a Chinese dialect, trails not far behind at fourth place). To this extent, the emergence and predominance of Chinese communities in Australia highlight the need for healthcare professionals to recognize and incorporate Chinese cultural perspectives when treating Chinese patients, in addition to increasing cross-cultural education in health professional curricula, that focuses on being culturally competent.

1.2 Death and Dying

According to Gire (2014), the communality of varying cultures lies in being brought to life (i.e., being born), and the loss of life (i.e., death and dying). However, the conceptualising of death and dying differs across cultures and is subjected to cultural norms, values and belief systems (Gire, 2014; Hsu, O'Connor, & Lee, 2009). The Western model of death and dying emphasises individual freedom and autonomy and is the implicit and explicit framework guiding clinicians in areas such as treatments and communications (Beaty, 2015; Gire, 2014). This Western model is not necessarily shared across cultures: the cultural needs and priorities of individuals should be considered when providing patient care in non-Western cultures (Sneesby, Satchell, Good, & Van der Riet, 2011; Yu, 2007). Sneesby et al. (2011), in their study on death and dying with a Sudanese community in Australia, identified distinctive cultural understandings, such as a collective framework of decision-making by the

community on an individual's health issues. A notable finding in the Sneesby et al. (2011) study was the religious connotations of God, Bible and prayers in Sudanese culture reflecting an intertwining of religion with culture. Likewise, Beaty (2015) describe the deep-rooted influences of Islam and Christianity in the cultures of Turkish people and Americans respectively on approaches to dying; for example, the commonplace discourse of death in both countries due to an Islamic and Christian belief of life after death (i.e., heaven and hell). Additionally, cultural norms such as autonomy and individualism were valued in the United States, but not evident in Turkey. These cultural differences were evident in behaviours relevant to death and dying, for instance, decision-making was left to patients in the United States but to physicians and families in Turkey (Beaty, 2015).

Thus, religion, which is inextricably linked with culture, as well as cultural norms, affect cultural approaches towards death and dying; how these aspects are apparent in Chinese culture is discussed next.

1.3 Cultural perspectives of Chinese people

For Chinese people, traditional philosophies such as Confucianism and ancestor worship, as well as the religions of Taoism and Buddhism influence how death and dying are perceived (Hsu et al., 2009). Misfortune and bad luck, as well as retributions and geomancy (*Feng Shui*), are commonplace notions of Taoist beliefs associated with illnesses and death, as are the Buddhism beliefs of Karma (prior sins) (Hsu et al., 2009; Yeo et al., 2005). Therefore, Chinese people, wherever possible, shun thinking or talking openly about death and dying or any associated notions (Yu, 2007). A study conducted by Chan and Yau (2010) with Chinese adults in Singapore revealed participants viewed death as a superstitious taboo

and avoided situations associated with the dead (e.g., funerals) for fear of bad luck and misfortune.

This taboo nature of death and dying can be a challenge for health professionals, predominantly in communications with Chinese patients and their families. For example, oncology medical professionals in China were found to be cautious in their conversations with patients and their families (e.g., careful consideration was given towards using expressions like ‘end-of-life’) (Zheng, Guo, Dong, & Owens, 2015), and they avoided explicit conversations about death with cancer patients as well as used deception or modified terminologies (Dong et al., 2016). Similarly, this cultural avoidance towards death and dying can impact researchers, serving as limitations (e.g., lack of discussion) and recruitment challenges (e.g., declining participation for fear that conversations would bring about misfortune) for studies into the health care of Chinese people (Huang, Liu, Zeng, & Pu, 2015; Yeo et al., 2005).

Cultural aspects relating to autonomy and the importance of family also affect how death and dying are perceived, particularly in decision-making. Chinese people do not view autonomy as necessary, with families taking a more significant role than the individual in the decision-making process of illnesses, such as end of life decisions (Hsu, Connor, and Lee, 2005; Huang et al., 2015; Zheng et al., 2015). This collectivism and family-oriented nature of Chinese culture can be attributed to the influence of Confucianism in Chinese culture, which relegates Chinese families as central to the decision-making process of an individual’s illness. In Confucianism, the interweaving of relationships is core, whereby illness is seen as an event that affects the individual’s network of relationships (i.e., family), thus the prominence of familial involvements and considerations (Ho, Krishna & Yee, 2010; Krishna, 2011). Gu, Chen, Liu, Zhang, & Cheng (2016), in a pioneer study of decision-making among end of life cancer patients in China, found that a significant portion of patients had transferred their right

to make medical decisions to their family members prior to their death. Familial involvements also extend towards the domain of truth-telling, where families routinely keep unfavourable medical information from patients to avoid psychological distress, and a preference by professionals for disclosing diagnosis through or with family members (Chiang et al., 2015; Gu, Chen, Liu, Zhang, & Cheng, 2016). Zheng et al. (2015) reported that medical professionals in China routinely seek family permission before discussions with the patient. Similarly, Dong et al. (2016) found that discussions about cancer were directed towards family members more often than to the patient.

Filial piety features prominently in Chinese culture and is a foundational concept in Confucianism where family (notably, elders and parents) is prioritised through efforts of care, such as at times of illness (Ho et al., 2010; Hsu et al., 2009; Krishna, 2011). A study by Chan and Yau (2010) emphasized the Confucian philosophy of filial piety that emerged in participants discourses where filial piety (e.g., providing end-of-life care) was an expected responsibility as a Chinese person. Filial piety is a commonly cited reason behind familial decision making in a Chinese person's health care as well, where care preferences and treatment options are discussed readily with one's family (Gu et al., 2016; Krishna, 2011). Furthermore, the importance of family in Chinese culture is more salient at end of life, where patients worry about giving hardships to their family as well as being with family in their final days (Ho & Sanders, 2015; Lee, Hinderer & Alexander, 2018).

Likewise, religions prominent in Chinese culture encompass concepts such as embracing nonaction in Taoism, which entrusts the decision-making to others and abstaining from excessive desires in Buddhism by not imposing an individual's preferences on families (Ho & Sanders, 2015).

While there have been numerous studies about Chinese culture in health care, many of them have been conducted in China (e.g., Huang et al., 2015) or countries with a majority Chinese population, e.g., Singapore (Chan & Yau, 2010). However, only a few studies have been conducted in an Australian context; these studies include those conducted in areas such as oncology (Chiang et al., 2015; Yeo et al., 2005), mental health (Wong et al., 2017), and palliative care (Heidenreich, Koo & White, 2014), where it was highlighted that traditional Chinese Confucian emphasis on the family led to family carers to decline professional support services. Thus, it is important to continue exploring the topic of death and dying in Chinese culture and health care, and in the context of Chinese people in Australia; doing so adds to cross-cultural knowledge and may aid in the development of cultural competency in health care professionals working with Chinese people in Australia.

1.4 Cultural Competency

Cultural competency is a concept commonly cited as “a set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situation” (Cross et al., 1989, p 6). Betancourt and Green (2010) highlighted the contemporary evolution of cultural competency as an approach that considers the influence of sociocultural factors towards cultivating skills of patient care. In the literature, there is a consensus that clinician should acknowledge the impact of sociocultural factors relating to a patient’s values, beliefs and behaviours on patient care. The importance of developing culturally appropriate attitudes, knowledge and skills in health care professionals has been well established (Heidenreich et al., 2014; Marcinkiw, 2003; O’Connor et al., 2010).

For this study, *The Process of Cultural Competence in the Delivery of Healthcare Services* by Campinha-Bacote (2002) was adopted as a framework, which viewed cultural competency as an ongoing process of development with five major constructs. These constructs are interconnected with each other and whose intersections signify the process of cultural competency (see *Figure 1*). Briefly, these five constructs are: 1) cultural awareness, which invites health care providers to explore and conduct self-analysis of their own culture in order to avoid committing cultural imposition (enforcing one's own culture on another); 2) cultural knowledge, the active seeking and development of one's knowledge about other cultural groups; 3) cultural skills, which emphasises the collection of cultural data and the carrying out of cultural assessments to aid in accurate (medical) assessments and interventions; 4) cultural encounters, which encourages providers to engage in direct cultural interactions with patients; 5) cultural desire, the inclination for providers to want, rather than need, to engage in the abovementioned processes (Campinha-Bacote, 2002). This framework has been developed primarily for transcultural nursing (Albougami, Pounds, & Alotaibi, 2016), and has been used extensively as a guideline in nursing education (Marcinkiw, 2003; Law & Muir, 2006) as well as in areas such as raising the awareness of disparities in health care of minority populations (Campinha-Bacote, 2009).

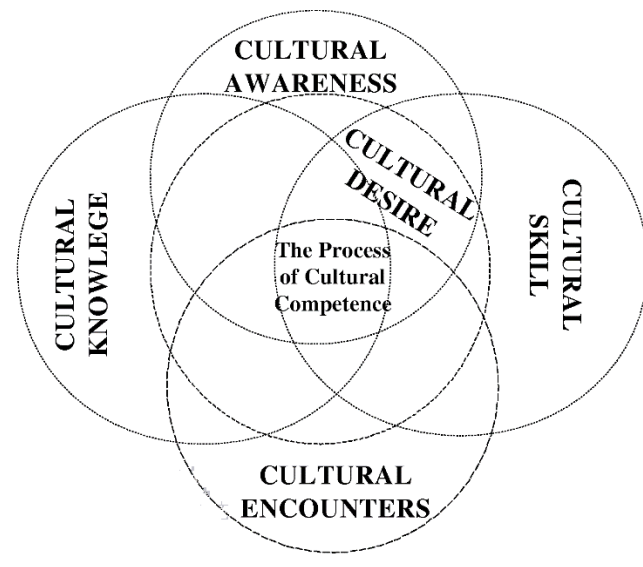


Figure 1. The Process of Cultural Competence in the Delivery of Healthcare
(Campinha-Bacote, 2002, p. 183)

1.5 Scope of the study

The present study draws upon the perspectives of professional Chinese interpreters in Australia, with a focus on how palliative care is viewed and utilised among Chinese patients at end of life in Australia to provide insight into how death and dying are perceived in Chinese culture.

1.5.1 Professional Interpreters

Effective communication between professionals and patients is a key component in health care (Silva et al., 2016). However, effective communication is impaired when language barriers and cultural differences exist, and this can lead to serious clinical consequences such as diagnostic and medication errors, as well as misunderstandings (Cohen,

Rivara, Marcuse, McPhillips, & Davis, 2005; Silva et al., 2016). Therefore, interpreters serve as a bridge of communication in health care interactions while taking on a multifaceted role that encompasses more than language assistance, such as “cultural brokers” (e.g., providing cultural insights) and “mediators” (e.g., actively joining the doctor-patient interaction) (Gartley & Due, 2017; Kirby, Broom, Good, Bowden, & Lwin, 2017; Wu & Rawal, 2017). Furthermore, the usage of interpreters in health care has been associated with improving the quality of care for culturally and linguistically diverse (CLAD) patients (Gartley & Due, 2017; Karliner, Jacobs, Chen, & Mutha, 2007).

Additionally, nonprofessional interpreters (ad-hoc interpreters such as family members) may alter information as they see fit for the patient, thereby affecting the patient’s preferences (which is a part of patient care) (Krystallidou, Devisch, Van de Velde, & Pype, 2017). Professional interpreters, on the other hand, are trained and certified, exhibit fewer interpretation errors and adhere to a strict code of ethics that prevents personal beliefs from interfering with the interpretation (Karliner et al., 2007; Silva et al., 2016). Therefore, the present study utilised interpreters who, aside from having experiences in interpreting, possessed relevant professional training in interpreting.

1.5.2 Palliative Care

Palliative care is an approach in health care that focuses on improving the quality of life for patients with serious illness – that is, terminal and life-limiting conditions for patients (O’Connor et al., 2010; Van Mechelen et al., 2013). Palliative care addresses the physical, emotional, and social duress experienced by patients and families during their illness (and for families of the patient, palliative care continues after the patient dies) (Strand, Kamdar, & Carey, 2013; Vincent, 2015). Thus, as a holistic process of care, palliative care is multi-

disciplinary and is a team-based effort with a primary emphasis on symptoms management through pain reduction (Strand et al., 2013; Van Mechelen et al., 2013).

Death and dying are central to palliative care, due to the life-limiting nature of patients' illness, thus to facilitate quality health care for Chinese patients at end of life, it is paramount to understand how these patients perceive palliative care, and in a broader context, death and dying (O'Connor et al., 2010).

1.6 Aims and Objectives

The present study aims to contribute and expand on existing literature about the cultural perspectives of Chinese people in Australia towards health care, specifically regarding death, dying, and end of life; the focus on cultural competency extends the relevance of this study to different areas of health care. The objectives of this study are twofold: 1) to enquire about and explore the cultural perspectives of death and dying in Chinese people in Australia, and 2) the implications of having this knowledge for the cultural competency of health care providers working with end of life patients. Information derived from this study may inform health care professionals in Australia about understanding Chinese culture and how to provide culturally appropriate and quality patient care to Chinese people in Australia. This study utilised a qualitative research paradigm to gather data and develop findings.

CHAPTER 2

Methodology

2.1 Participants and Recruitment

A purposive sampling approach was employed to recruit participants. Participants were NAATI (*National Accreditation Authority for Translators and Interpreters*) certified professional interpreters with specialisation in any Chinese language including dialects, e.g., Cantonese. Eligibility criteria for the study included being aged over 18 years, and with a professional background interpreting for clients in palliative care or facing end of life.

Participants were recruited from the Australian Institute of Interpreters and Translators (AUSIT); a recruitment flyer (Appendix A) detailing the study was sent to the AUSIT for dissemination to its members through its monthly electronic magazine. The AUSIT is a national professional association for interpreters and translators in Australia and covers every state and territory in Australia, as well as being closely intertwined with the NAATI (Maruca, 2017). Interested members were asked to contact the researcher through email or phone. Additionally, passive snowball sampling was employed where existing participants invited other potential participants to contact the researcher.

Sample size was guided by data saturation, which is when no new information (e.g., themes) is attainable with further participants (Guest, Bunce, & Johnson, 2006). With the recruitment process outlined above, a total of 9 participants responded, with 2 participants declining after further correspondence, citing lack of time. Thus, the final sample size was N=7, whereby data saturation was evident.

2.2 Ethics

The University of Adelaide Human Research Ethics Subcommittee approved this project (Ethics no. xxxx). Consent forms (Appendix B) and participant information sheet

(Appendix C) were sent to eligible participants for their signature and review prior to the interviews; participants were informed that this study was carried out as part of the researcher's Honours thesis and may be used for future research or publication or both. Participants were assured that they would not be identified in any reports, and neither would their place of work or the identity of clients be revealed.

2.3 Data Collection

Eligible participants were invited for an interview face to face or by phone or video, as preferred by the participant. Five interviews were conducted by phone, and two interviews were conducted face to face. The researcher conducted all interviews over a period of 3 months from May to July 2018. Each interview lasted for approximately an hour and was conducted in English.

Interviews were unstructured and consisted of open-ended prompt questions to ensure the flexibility and exploratory nature of participants' responses (see Appendix D); this ensured the richness of data collected (Braun & Clarke, 2013). Questions were in no order and omitted, expanded upon or adjusted in accordance to participants' responses. The interview questions were focused around the topic of death and dying from a Chinese cultural perspective, including palliative care and end of life issues. Questions were also asked regarding participants' thoughts on cultural competency for health care professionals.

2.4 Data Analysis

With participants' written consent, interviews were audio-recorded. The recordings were transcribed verbatim by the researcher and line numbers added to each transcript. Great

care was taken to ensure the confidentiality and anonymity of participants in the transcripts by removing identifying characteristics of participants such as names, workplaces and case-specific details. The de-identified transcripts were emailed to participants to ascertain satisfactory de-identification and accurate representation of the interview. Providing participants with an opportunity to view their transcripts allowed for a process known as member reflections.

Member reflections constitute as an integral component of qualitative credibility; credibility is one of the eight criteria for excellence in qualitative research (Tracy, 2010). This process involves presenting participants with their transcripts as well as initial findings whereby participants could contribute feedbacks, comments and questions to the researcher; this established correspondence and collaboration between the researcher and participants, ensuring the accuracy of the research and potential for new data to surface. All participants expressed satisfaction with their transcripts.

Interviews were analysed with thematic analysis (TA) to establish, evaluate and report patterns of themes within the qualitative data (Braun & Clarke, 2006, 2013). An inductive (bottom-up) form of thematic analysis with a focus on latent (implicit/interpretative) themes, was employed to address the exploratory aims of this study (Braun & Clarke, 2006). Upon transcription of each interview, preliminary themes were identified; this served as preparation for subsequent interviews as well as to monitor data saturation (Guest et al., 2006).

The analytic approach for this study was based on Braun and Clarke (2006) 6-phases framework; the framework functioned recursively, with movements alternating as necessary, throughout phases. The framework encompassed as follows: 1) familiarization with the data (the transcription of interviews and repeated readings of the data while identifying preliminary themes; 2) encoding data (a process of generating initial codes by systematically

reviewing the entire data set); 3) establishing themes (analysing and organising codes and coded data extracts into possible themes and sub-themes); 4) evaluating themes (refinement of themes in relation to the coded data extracts and the entire data set for coherence and meaningfulness); 5) defining themes (conducting a detailed analysis of themes on their own and amongst each other for support of the data); 6) producing a report of the TA conducted, in a clear, concise and vivid manner (this constitutes the 'Findings' section of the thesis). To visualise the network of themes and sub-themes derived from the data, a thematic map (Appendix E) was developed. Interview data were coded around the research question, 'What are the experiences of Chinese people in Australia at end of life as reported by interpreters?'.

An audit trail was maintained throughout the study. By documenting the research decisions and activities involved in the development of the study, the audit trail served to facilitate transparency and trustworthiness of the process (Carcary, 2009; Tracy, 2010). Pertinent information was included in the audit trail such as: the recruitment process, interactions with participants, interview notes, preliminary coding of themes and reflective thoughts. Regular discussions with one of the researcher's supervisors were held to review the analysis to ensure it was reflective of the data and to manage any assumptions.

Reflexivity - the researcher's active reflections on their role in the research (e.g., insider and outsider positions, personal stake) - enhances transparency and consequently extends sincerity to the study and credibility to findings (Braun & Clarke, 2013; Carcary, 2009; Tracy, 2010). The researcher is from a Chinese cultural background with a keen interest in cross-cultural psychology as well as death, dying and end of life, which inspired the commencement of the current study. The researcher intends to train and practise as a psychologist, working in an area related to healthcare, in the future.

CHAPTER 3

Findings

3.1 Participant Characteristics

Participants were all women, with five originally from China and two from Hong Kong. Years of experience as a professional interpreter ranged from two years to fourteen years; four participants were NAATI-certified Mandarin interpreters whereas three were NAATI-certified Mandarin as well as Cantonese interpreters. All participants had experiences interpreting for Chinese people at end of life, with one who specialised only in medical interpreting. Additionally, all participants provided freelance interpreting services through the phone or in person, and two were also in-house interpreters for hospitals. Participants were based in Adelaide, Sydney, Melbourne, and Perth.

3.2 Overview

Analysis of interview data yielded four themes: 'Healthcare is different (for Chinese people)', 'Family as influential', 'Death and dying as taboo', and 'Changing attitudes of Chinese people'; each theme had corresponding subthemes. A thematic map was developed to visualise the network of themes and sub-themes (see Appendix E). These themes are examined in detail in the following sections.

3.3 Health care is different (for Chinese people)

Participants expressed health care as consisting of many layers of complexities, whereby health care is viewed as positively changing the welfare of patients and health care professionals as supporting this change. For example, depending on the medical condition,

treatment plans differ and involve different types of medical professionals. According to participants, being a minority population in Australia, Chinese people perceive and experience health care differently from the general population, which ultimately affects the quality of care received. The following five sub-themes embodies the experiences between Chinese people and health care as denoted by participants' role as interpreters for Chinese people in Australia.

3.3.1 Language as barrier

With English being the primary language of communication in Australia, Chinese people, many of whom are non-native speakers of English, perceive language as a barrier in health care in Australia. Without a common language for communication, Chinese people are greeted with a sense of unfamiliarity and are subjected to dependence on others for communication; this can lead to negative emotions.

they (patients) don't understand anything and they rely on someone to tell them what's the story and they would feel frustrated (Participant 1, lines 58-59)

To counter the language barriers, interpreters serve as a bridge for communication in the healthcare of Chinese people in Australia, and subsequently as an effort towards patient-centred care. Participants reported that the usage of interpreters was viewed as a positive process in the health care system in Australia.

they felt a lot of respect first of all they have the interpreters there for you and they feel very much respected to overcome the language (Participant 2, lines 111-112)

The Chinese language is diverse, and as in any language, words carry emotive meaning; there are many regional differences in how words are conveyed and interpreted for meaning. Participants, as interpreters, acknowledged the challenges of translation especially for medical concepts. For example, while palliative care has a singular meaning in English, when translated to Chinese, there are several translations that convey different meanings in English.

one is called 安寧治療 that is to bring peace to you treatment and another one is 姑息... but 姑息 in Chinese has also got other meanings its not on the positive side on the negative side you just let it rest as much as possible (Participant 3, lines 169-172)

3.3.2 Interactions with healthcare professionals

Interpreters serve as the medium of communication between Chinese people and health care professionals in Australia; as such, participants are uniquely positioned to observe how healthcare professionals in Australia work with Chinese people. There was a consensus that health care professionals understand the challenges of Chinese people in a linguistically foreign health care system; this was expressed through positive actions, such as being supportive.

They (healthcare professionals) are very supportive they tell them everything in the system from what they can get this is the crucial things make them realise their options are their rights (Participant 1, lines 137-139)

However, there were instances where it was evident that health care professionals possess limited cultural knowledge of Chinese culture and respond disrespectfully.

He (doctor) wasn't just making remark he was laughing about the Chinese medicine to the lady (Participant 2, lines 145-146, 159)

Such negative experiences may result in a reluctance of Chinese people in sharing information with professionals from a different culture, compounded by the emphasis Chinese people place on trustworthiness as a trait, given that trust is a core ethical component in Confucianism (Lei, Ying, Tie, & Rubienska, 2015). Participants highlighted the importance of obtaining the client's trust in the interpreting service to facilitate patient-doctor consultations.

sometimes if they don't trust you it actually also interferes with the doctor appointment because the Chinese people sometimes they don't like to give out information (Participant 2, lines 57-58)

3.3.3 Age

Chinese people's interactions with health care professionals were also influenced by their age, particularly in how they approach their health. Participants reported that elderly Chinese people tend to self-medicate and avoid seeking care.

the old people they don't like to go and see doctor they would do their own therapy they just don't like taking any medicine and they don't like any examinations (Participant 2, lines 199-200)

Medical information was also perceived differently across ages. For elderly Chinese people, medical information was viewed to be confidential and thus not to be shared openly whereas younger Chinese people were seen to be more open-minded and did not exhibit such tendencies.

its takes them (elderly Chinese people) a while to get used to an interpreter there and the interpreter find out such things, the younger ones don't have such problems

(Participant 7, lines 109-111)

3.3.4 Medical Systems, Australia versus China

Participants highlighted differences and compared the medical systems of Australia and China, which is where most Chinese people in Australia have originated from. The medical system in Australia prioritises the concept of autonomy in patients, for example, through open disclosure (Allan & Munro, 2008), as well as undertaking a holistic approach to healthcare, for instance, the utilisation of allied health professionals (Philip, 2015).

they (Australia) respect the rights of the patient to know what's happening and they very much need the patient to be the one to make the informed decision about the treatment ... in here the medical team would have allied health professionals to advise on different fronts not just the condition (Participant 3, lines 146-149)

On the other hand, the health care system in China was viewed to be rigid and lacking in enabling individual freedom for patients.

In China it is more of the doctor making the decision you can't really say to the doctor I don't want to do this and they will be like tell you off... ... in China its more they just force

you and in China when you have cancer they just do whatever they need to do they don't let you make a choice (Participant 2, lines 109-121)

3.3.5 Reaction to diagnosis

A diagnosis of terminal illness usually leads to negative emotions for patients, for example, anger (Houston, 1999). For some patients, participants observed a gradual acceptance.

at the beginning the patient was so shocked and painful about this news but eventually he accepted and said it was part of his life (Participant 6, lines 26-27)

Likewise, a diagnosis of terminal illness does not usually affect just the patient; the family are also impacted by the diagnosis (Lee & Bell, 2011), and this can lead to an attitude of blame-seeking to explain the diagnosis and prognosis (Houston, 1999). In Chinese culture, the family tend to be influential in the health care of the individual; this is explained more in the next section, where family in Chinese culture presents itself as a theme.

most of them don't take it easily the death when the doctor tell them they look so shattered their family don't take it easy they say their doctor delay this or they say you haven't treat me properly (Participant 4, lines 100-102)

3.4 Family as influential

The construct of family is deeply rooted in Chinese culture (Huang et al., 2015), and for many Chinese people, it would be unheard of to separate family aside. Drawing from

experiences interpreting for Chinese patients as well as their own experiences as Chinese persons, participants described the role of family in Chinese culture, explaining that the family is influential in the health care decisions of Chinese people; this is represented by the following three sub-themes.

3.4.1 Importance of family in healthcare

For many Chinese people, there is a fundamental belief that family serves as a crucial pillar of support in times of difficulty, for example, when one is terminally ill. Participants noted that patients tend to associate family with support.

in an Asian community the network of support would be bigger stronger in a way like you would be in a family unit so the family would look after you... .. the core values family support and things is still quite strong so you might have support from your family (Participant 3, lines 156-165)

Likewise, as a Chinese person, family is always on one's mind, and there is always concern for the wellbeing of one's family. This was explicitly communicated to participants by patients at end of life.

make sure that your children or your families are taken care of and as a Chinese you are always thinking of looking after your family even at death you want to make sure that your family is taken care of (Participant 5, lines 64-67)

3.4.2 Family's involvement with patients' health care

As mentioned above, the family is influential in the healthcare of Chinese people and this manifests as the family taking on an active role in the decision-making process of an individual's health care arrangements, for example, in the uptake of medical treatment. Seeking approval from the family was repeatedly expressed by participants.

in the treatment of the patient they (family) like to have their say so if somebody wants to go to a palliative care centre he or she will have to talk it through to their loved ones and ask them for their agreement before they can go (Participant 7, lines 224-226)

Another matter where the family is highly involved in the health care of individuals is during consultations. Participants, in their observations, noted how the family stepped in to influence the interpreting service provided to patients; this was regarded as a common incidence and often served to prevent the disclosure of information to patients.

the families come stand up you can just tell me don't mention to him yes and that happens all the time (Participant 4, lines 116-117)

3.4.3 Disclosure of illness

An area of health care where the family is actively involved is the communication of diagnosis and medical information to patients. Chinese families adopt a communication approach that emphasises non-disclosure of information to patients; this is perceived to contribute to the wellbeing of the patient (Liu, Yang, Da, Fan, and Gao, 2018). Participants

voiced that in their interactions with family members of patients, keeping patients in the dark was a favourable approach and perceived to be beneficial for the patient.

the family worry that the diagnosis all these talking would worry the patient, so they prefer not to have the patient told about their condition treatment or diagnosis

(Participant 3, lines 87-89)

In societies where the Chinese culture is dominant, for example in China, the deep-rootedness of family is reflected in how professionals communicate information and their cooperation with families. Participants with experiences in health care settings in China illustrated the routine practice of keeping patients uninformed about their diagnosis, particularly with a terminal illness.

(in China) many people who have terminal cancer the doctor will take the daughter or son outside and talk to them ... and then the patient doesn't even know he has terminal cancer the doctor will come in and say everything is okay to the point that they don't even know they are dying (Participant 2, lines 244-247)

3.5 Death and dying as Taboo

This non-disclosure approach can be understood in the context of how life and death are perceived in Chinese culture; death and dying are regarded as symbolic of adversity for Chinese people, and so any discussion is deliberately shunned. The following four sub-themes illustrates the negative embodiment of death and dying in Chinese culture and the health care of Chinese people.

3.5.1 Avoidance of discussion

Because of how death and dying are perceived in Chinese culture, discussions of these topics are explicitly avoided. For example, medical issues such as terminal illness, which inevitably leads to the death of the patient, are not openly talked about. In some instances, unaware and evasive attitudes towards medical issues are preferred, with denial observed by participants, especially among the elderly.

some old people they don't really want to do all these things if I don't know about it then it is not a problem if I am going to die then I am just going to die so I don't need to know about it (Participant 2, lines 192-193)

In particular, death and dying are associated with misfortune. Participants expressed an explicit desire to avoid the topic even where the person is aware that they are at the end of life.

Chinese you know that, because it (death) is bad luck things choi choi choi and we don't touch any bad subject though we know that was happening just avoid it bad spirit (Participant 1, lines 113-114)

3.5.2 Religion

The avoidance thinking about and discussing death and dying in Chinese culture can be attributed to religion where the existence, or lack of, religious beliefs affected perceptions of life and death. The belief of life after death or life ending at death was viewed to be one such factor, according to participants.

Western culture is more Christian ... they will still have the hope of life after death so that way probably makes it better for you to overcome, in China...most of the people are atheist means they don't believe in anything like life stops at death so if that's your belief I think it will make talking about death alot more harder (Participant 2, lines 257-261)

Religion also affects rituals and ceremonies associated with death; different religions have their own practices. Buddhism is a religion prevalent in Chinese culture and has its own set of practices that were perceived to be different from the usual practices in Western culture.

when the person dies or even just planning for that because it is very different practice (to Australia) like some of them are Buddhism and they need to get a monk or someone from the temple to do the chanting right after the death (Participant 3, lines 66-69)

3.5.3 Quality/Perception of Life

The negative embodiment of death and dying is reflected in how life is perceived in Chinese culture, and consequently in health care approaches, where there is a concerted effort to preserve life. Participants observed that Chinese people demand continual medical efforts for patients at end of life to prolong life, even though quality of life could be compromised.

That (ceasing treatment) is another term is very difficult to accept for the Chinese people to say just going to let this person die ... they just say okay do the feeding tube I don't care must keep them alive (Participant 2, lines 282-284)

One explanation is a Confucian belief in Chinese culture relating to filial piety, the obligation to one's parents and elders; this is conveyed through the family's efforts to prolong the life of their elderly relative.

when a patient is terminal if the offspring do not try their best and spend all they can to pursue active treatment it is considered ... the closest English translation is filial piety ... it just seems to be for everybody else that you are valuing money more than you do your parents and that's looked down upon (Participant 7, lines 54-59)

3.5.4 End of Life approaches (Palliative care)

A related area of health care where the perceptions of death and dying are important is the understanding and receptiveness towards medical approaches regarding improving the quality of life of terminally ill patients. Palliative care is a concept of care that focuses on improving quality of life for patients with life-limiting illnesses and provides a continuum of care throughout the course of a serious illness (Strand et al., 2013). Participants explained that there is a limited understanding of the concept among Chinese patients; palliative care was observed to be commonly associated with death and dying and thus negatively responded to by Chinese patients.

as soon as he heard palliative care why are you here I am not even dying you have to explain we don't just take care of dying people we are here to help you to see if any care we can provide but they don't like the term like you say to them you are dying or

about to die something like that anything to do with that they don't want to know about it (Participant 2, lines 221-225)

As already explained, the family plays a significant role in a Chinese patient's health care, and treatment decisions tend to require family approval. With palliative care, treatments may be ceased to improve quality of life for patients at end of life. Participants expressed that palliative care and its focus on quality of life was also commonly associated with giving up hope.

somebody of a Chinese background choose palliative care there is also the family to content with the family members might not agree and think it is giving up (Participant 7, lines 219-222)

3.6 Changing attitudes of Chinese people

As seen in the previous theme, death and dying are viewed negatively in Chinese culture. However, participants described a gradual shift of attitudes among Chinese people towards death and dying; mindsets of Chinese people are moving away from the negative outlook of death and dying and showing acculturation towards so-called Western medical models of conceptualisation. Participants highlighted this shift in mentalities as affecting the communication approaches in health care, where patients must be informed of their medical conditions.

not many of them are so narrow-minded in past might be no one want to talk about it and even not to disclose the real situation in front of patient but now the patient has

the right to know everything and the doctor will tell the patient directly ... people open their mind more easier now (Participant 1, lines 105-109)

This shift in mentalities is also reflected in increased open-mindedness and acceptance towards medical conditions, particularly with terminal illnesses and decisions relating to health care approaches. However, participants noted that the elderly were not as responsive to these changing attitudes as younger people.

Yea more open not everybody is on the same level but definitely more open well from my experiences as an interpreter coming across patients with terminal illness the younger ones tend to accept it better obviously most of the old people eventually accept it as well but I think the young ones tend to be more rational about it and they do think about palliative care (Participant 7, lines 215-218)

CHAPTER 4

Discussion

4.1 Overview

The present study explored the cultural perspectives of Chinese people in Australia towards health care, specifically regarding death, dying, and end of life, in relation to a cultural competency framework in health care. A novel finding of this study is the changing attitudes of Chinese people towards health care in an Australian context, which are characterised by greater open-mindedness and receptiveness towards Western medical approaches. This finding highlights a disconnect with commonly held cultural understandings of Chinese people, which is consistent with recent research (Chen et al., 2017; Huang, Zeng, Jing, & Liu, 2018) illustrating greater desire for information-disclosure and autonomy among terminally ill Chinese patients, as well as towards open discussions about death and dying.

A possible explanation for this finding is acculturation, which can be broadly understood as cultural changes occurring in individuals due to continuous exposure to a second culture (Lee, Chen, He, Miller, & Juon, 2013; Wu & Smith, 2016). For this study, this suggests that Chinese people's exposure to the Western culture in Australia has affected their attitudes towards health care. Additionally, generational differences influence levels of acculturation, where older adults possess lower acculturation to the host culture (Dong, Bergren, & Chang, 2015). This supports the present study's finding that while Chinese people's attitudes are changing, older Chinese patients in Australia tend to be more traditional and adhered to aspects of the Chinese culture more closely than younger Chinese patients. However, while acculturation has been associated with changes in health behaviours and attitudes that follow the host country's culture (Lee et al., 2013), mixed findings reporting positive (Dong et al., 2015; Lee et al., 2013) and negative (Wu & Smith, 2016) health behaviours and outcomes suggest the complexities of understanding the role of acculturation

in health care. Notably, acculturation is subject to cultural and linguistic influences, and culturally sensitive and appropriate care is recommended for CALD adults with low levels of acculturation (Dong et al., 2015).

Other major findings in this study are consistent with previous literature, indicating that health care is different for Chinese people due to salient features of Chinese culture influencing how Chinese people approach health care (Chen & Fan, 2010; Chiang et al., 2015; Ho & Sanders, 2015; Hsu et al., 2005; Li, Davis, & Gamier, 2011; Yu, 2007). The findings relating to the cultural avoidance and negative embodiment of death and dying align to previous research (Chan & Yau, 2010; Hsu et al., 2005; Hsu et al., 2009; Huang et al., 2015; Li et al., 2011; Yu, 2007; Zheng et al., 2015). Notably, prevalent beliefs among Chinese people of Confucianism, as well as the religions of Taoism and Buddhism serve as cultural influences, for example, Confucian thoughts urge staying clear of supernatural incidences, death and dying included, to aid moral development, as do Taoist's understandings that perceive death and dying as distractions from the goal of immortality (Hsu et al., 2009; Ke, Huang, Hu, O'Connor, & Lee, 2017). These cultural perspectives of death and dying affect Chinese people's understandings of life and consequently treatment decisions, where, aligning with this study's and that of previous research, Chinese people advocate continual medical treatments because of philosophical and religious influences, for example, the pursuit of immortality in Taoism advocate efforts towards extending physical life, as well as the concept of filial piety in Confucianism, where efforts to prolong life of elders are guided by the familial bonds of respect (Chen & Fan, 2010; Ho et al., 2010; Hsu et al., 2009; Krishna, 2011).

This study's findings of language constituting as a barrier for the positive health care experiences of CLAD people, is consistent with previous research (Chiang et al., 2015; Green, Bradby, Chan, & Lee, 2006; Hyatt et al., 2017; Kirby et al., 2017) where language

differences are understood to hinder effective communication. For Chinese people, the Chinese language has multiple dialects and varying translations of English terminologies which are understood to be linked to cultural meanings and understandings of the Chinese culture (O'Connor et al., 2015).

Findings in this study, as well as that of previous research (Chan & Yau, 2010; Gu et al., 2016; Ho & Sanders, 2015; Huang et al., 2015; Lin, Kan, & Chen, 2012), point to a family-oriented collectivist nature of the Chinese culture that engages a differentiating understanding of the concept of autonomy, that is expressed through the importance of family as well as the familial involvement with patients' health care. This is expressed during times of illness, where the family is regarded as a form of support with patients' concern directed towards family over self, the family takes on a dominant role in the decision-making process, as well as the family withholding medical information and decisions from patients (Chen & Fan, 2010; Rui, 2015; Heidenreich et al., 2014; Kagawa-Singer & Blackhall, 2001; Krishna, 2011; Lee & Bell, 2011; Pang, 1999). The understandings of family among Chinese people have often been attributed to the Confucian ethics prevalent in Chinese culture, where the family is a critical, fundamental and inseparable construct of an individual, and which cultivates in the practice of familism (Chen & Fan, 2010; Rui, 2015). For example, the common cultural understanding of illness as a familial event for Chinese people (Gu et al., 2016). Rui (2015) describes this familial involvement as a routine and implicit practice in Chinese culture, that takes into thorough consideration of patients' wellbeing; patients have been known to willingly relegate decision-making to family members (Gu et al. 2016; Ho & Sanders, 2015). Additionally, Pang (1999) describes the lack of truth-telling as a tradition in Chinese culture, termed as "protective truthfulness", where paternalistic consideration permits truth-telling only if it benefits the patient. The following section further discusses these findings in relation to the cultural competence framework of this study.

4.1.1 The Process of Cultural Competence in the Delivery of Healthcare Services

According to the cultural competency framework of this study, Campinha-Bacote (2002) advocates cultural competency as a lifelong process of development where health care professionals aim to work effectively in a culturally diverse environment that is within the cultural context of the patient. Health care professionals can use this model as a framework for establishing and executing culturally appropriate and quality health care services for culturally and linguistically diverse patients. For this study, the cultural characteristics of Chinese culture, as identified through the findings, serve as a contextual setting for grounding the core tenets of this model (see, *Figure 1*). Four constructs (awareness, skills, knowledge, and encounters) are discussed below.

Cultural awareness represents the self-examination and self-exploration of one's own cultural background to avoid imposing facets of one's culture onto another from a different culture (i.e., cultural imposition), as well as being self-aware of the differences in cultural backgrounds of oneself and another (Campinha-Bacote, 2002). A practitioner exercising self-reflection enables the recognition and management of personal biases with an aim to prevent stereotypical views and attitudes towards another culture, thereby enhancing imposition-free interactions with patients (Campinha-Bacote & Campinha-Bacote, 2009). Additionally, cultural awareness is essential because actions that are viewed as unusual or questionable in one's own culture may be the norm in other cultures, and practitioners who lack thorough cultural consideration of patients may unintentionally exacerbate the problem (Christopher, Wendt, Marecek, & Goodman, 2014; Ong-Flaherty, 2015). In the context of this study, the medical system in Australia prioritises individual autonomy, as a product of the individualistic nature of Australia's dominant Western culture (Beauchamp & Childress,

2013; Dove et al., 2017; Jo Delaney, 2018). Autonomy, as framed in the lens of individualism, relates to decision-making as self-choosing, independent from external influences, and informed (Dove et al., 2017). Therefore, according to the cultural characteristics of Chinese people towards health care, practitioners in Australia may find some Chinese practices problematic. An example of this is group decision-making. Without developing cultural awareness, practitioners may find group decision-making among Chinese patients and their families as unnecessary and time-consuming, and consequently emphasise the patient's individual right in decision-making which may be construed as inappropriate by the patient and their family; this suggests practitioners may be prone to commit unintended mistakes that negatively affect the health care experiences of Chinese people (Ong-Flaherty, 2015).

Cultural skills refer to the ability of practitioners to collect cultural data and conduct cultural assessments of the patient in a culturally appropriate and sensitive manner (Campinha-Bacote, 2002). Cultural assessments are important in understanding and bringing out patients' cultural beliefs, values, and practices to devise mutually acceptable and culturally responsive treatment plans (as well as to avoid cultural assumptions) (Ingram, 2011; Marcinkiw, 2003). Cultural assessments involve learning about the patient's interpretations of their illness as well as determining the patient's level of cultural influence, for which Kagawa-Singer and Blackhall (2001) recommend an ABCDE mnemonic that encompasses the cultural *attitudes* related to the medical specialisation, religious and spiritual *beliefs*, historical and political *context*, individualistic or family-oriented *decision-making style*, and *environment* of the patient. Additionally, conducting a cultural assessment prevents practitioners from involuntarily offending the patient and fosters favourable relations (Kagawa-Singer & Blackhall, 2001). Without conducting the necessary cultural assessments with each patient, practitioners working with Chinese patients may persist in full disclosure

of medical information to patients, thus inadvertently ignoring the cultural values of truth-telling in Chinese culture, which may be perceived to be disrespectful and uncaring by the family and result in mistrust that affect future correspondence with patients and their families. Similarly, practitioners may perceive a terminally ill Chinese patient's lack of asking questions about death as acceptance, where it may be because this topic is not openly discussed in Chinese culture (Yu, 2007).

Cultural knowledge is defined as practitioners pursuing and attaining factual and relevant information about cultures to understand patients' varying worldviews towards their health, illnesses and treatments (Ingram, 2011). Therefore, obtaining a competent cultural assessment is crucial for developing a foundational base for cultural knowledge as patients' cultural beliefs, values, and practices contribute to cultural understandings (Campinha-Bacote, 2002). Aside from understanding the multifaceted and varying nature of cultures towards health care, practitioners should also focus on the similarities between cultures as there are universal concerns in health care, such as the improvement of one's health (Law & Muir, 2006). In the pursuit of cultural knowledge, practitioners should take into consideration intra-cultural variations and be mindful of stereotyping by not essentializing individuals according to their culture (Marcinkiw, 2003; Yeo et al., 2005). Practitioners working with Chinese patients, particularly for those at end of life, should understand that while discussions about death and dying are taboo in Chinese culture, these are attributed to varying religious and philosophical understandings (Ke et al., 2017; Yu, 2007). Likewise, practitioners should also factor in that attitudes of Chinese people may be affected by acculturation, which affects the level of influence of patients' heritage culture (Dong et al., 2015). Practitioners should not assume that every patient who is Chinese does not want to be informed of their diagnosis or that they would like their families involved in consultations. Therefore, attaining adequate cultural knowledge will better equip practitioners to understand

and tailor care to patients' cultural requests and approaches, thereby facilitating more positive interactions and health outcomes (Ingram, 2011).

Cultural encounters are platforms for cultural interactions to occur, where direct encounters allow practitioners to refine or modify their existing cultural understandings of a particular culture as well as to build experiences working with patients from different cultural backgrounds through familiarity with linguistic terms and communication patterns, and thus lowers the risk of possible stereotyping (Campinha-Bacote & Campinha-Bacote, 2009; Marcinkiw, 2003). Importantly, continual interactions are advised where this is possible as interactions with a few culturally and linguistically diverse individuals do not denote cultural expertise (Campinha-Bacote, 2002). Additionally, encounters also provide an opportunity for practitioners to assess patients' linguistic levels and needs, as language differences can complicate communications between practitioners and patients, which may lead to negative health outcomes (Campinha-Bacote, 2002; Silva et al., 2016). Cultural attitudes also affect language usage (O'Connor et al., 2015). For example, practitioners without proper understanding of the linguistic nuances and meanings in the Chinese culture, may inadvertently communicate terms that patients regard as offensive because of their cultural relation to death and dying. Additionally, the utilisation of professional interpreters to enable and improve communication, as well as to overcome language barriers is recommended in health care, where the role of professional interpreters is associated with positive clinical care (Gartley & Due, 2017; Karliner et al., 2007). This supports a finding in this study that the utilisation of interpreters was well-received by Chinese patients. Furthermore, Chiang et al. (2015) recommend written information in patients' native language to serve as language aids beyond the usage of professional interpreters; this implies practitioners should also work together with interpreters to further improve patients' interactions.

4.2 Strengths

The present study has several strengths that meet Tracy's (2010) as well as Braun and Clarke's (2013) checklists for excellence in qualitative research. Given the increasing Chinese population in Australia and the global cultural diversity of patients, research towards enabling culturally congruent health care is important (Albougami et al., 2016), for which the present study constitutes as a relevant and worthy topic (Tracy, 2010). Likewise, research on this topic that is in the context of Australia, and with interpreters as participants, is limited, and thus findings of this study serve as a significant contribution to literature (Tracy, 2010).

Relevance of this study was achieved through the use of a well-supported and established cultural competence framework. Campinha-Bacote's model for cultural competence was chosen, among several cultural competence models, because it is adequately in-depth to guide research as well as for developing interventions for culturally and linguistically diverse individuals (Albougami et al., 2016). Furthermore, the use of Campinha-Bacote's model of cultural competence provides empirical support for successfully increasing levels of cultural competence and remains widely used in research to guide culturally competent practice among practitioners (Albougami et al., 2016; Brathwaite, 2005).

Data saturation was achieved following the seventh interview, suggesting adequate data were collected to support claims, and the inclusion of participants from several states around Australia improved the rigour of findings by pushing the sample beyond convenience (Tracy, 2010). As the researcher maintained an audit trail, sincerity was enhanced through transparency and supported the researcher's self-reflexivity practices (Tracy, 2010). For example, the researcher's cultural background constituted as an "insider" role and may have assisted in eliciting greater discussions from participants. However, the researcher was self-

reflective by ensuring that his existing knowledge of the topic did not affect interviews and the coding process. The supervision process aided analysis, including reflexivity.

Furthermore, the choice of using thematic analysis in this study allowed a flexible approach to enable in-depth exploration of findings (Braun & Clarke, 2006, 2013). Given the exploratory nature of the present study, this flexibility was advantageous, and contributed to the study being meaningfully coherent (Tracy, 2010).

4.3 Limitations and future research

While practitioners' use of professional interpreters is recommended during medical consultations with culturally and linguistically diverse patients with limited English proficiency, Krystallidou and Pype (2018) highlighted that interpreters exhibit verbal and non-verbal cues that influence patients' participation during interaction and may consequently affect practitioners' ability to provide patient-centered care. Additionally, there is a tendency for professional interpreters to make alterations, such as omissions, which may lead to interpretation errors as well as clinical consequences if inaccurately understood by patients or practitioners (Sleptsova et al., 2017). For Chinese people, given that illness is perceived to be a familial event, professional interpreters are likely to be viewed as outsiders and information may not be readily shared, thereby affecting the quality of clinical interactions (Gu et al., 2016). To address this limitation, future research could triangulate perspectives of interpreters with practitioners such as nurses and doctors as well as patients, to further refine and ascertain the quality of findings.

Given that the influence of acculturation on Chinese people in Australia has been offered as a possible explanation of a finding in this study, there is a paucity of literature surrounding the effects of acculturation to Australian culture on this topic. In acculturated

societies such as Singapore, where there is a fusion of “East” and “West” cultures, negotiations of Chinese cultural values take place to accommodate the rising shift of individualistic autonomy (Ho et al., 2010). Therefore, further research in this area may provide greater insights into improving the health care of Chinese people in Australia.

4.4 Implications

The findings from this study present important implications for practitioners working with Chinese people, particularly with those who are terminally ill, and the uptake of palliative care among these patients. Given that palliative care encompasses care of the patient together with the family, familial involvement would seem natural (Krishna, 2011; Strand et al., 2013). However, because of its perceived connotations with death and dying, family members may not inform patients about palliative care or potentially interfere with patients who wish to take up palliative care (Bai et al., 2010; Huang, 2015). These may be attributed to a lack of proper understanding regarding palliative care and the association of palliative care with surrendering to death as well as acknowledge impending death. This is supported by findings in this study as well as recent research that found misconceptions about palliative care as a major barrier in the refusal or reluctance to choose palliative care (Huang, 2015; Lu, Gu, & Yu, 2018). Additionally, given that the taboo view of death and dying extends to language usage, translations of palliative care in Chinese language may impede its accessibility (O’Connor et al., 2015). Furthermore, the goals of palliative care may result in halting treatments that negatively impact quality of life while offering no tangible benefits, as well as discouraging excessive treatments; these may not sit well with Chinese people who view continual treatments as a form of filial piety by prolonging life, and the misconception of associating palliative care with surrendering as lacking filialness (Bai et al., 2010; Krishna,

2011; Lu et al., 2018). Therefore, core tenets of the Chinese culture including the taboo view of death and dying, “protective truthfulness”, the virtue of filial piety, as well as the bearing of familial autonomy in decision-making, may complicate palliative care as a viable approach for Chinese patients.

As this study focused on cultural competence, this may provide useful suggestions for practitioners in improving the health care experiences of Chinese people. Given the importance of family in Chinese culture, practitioners may consider involving family members in medical interventions and assessments, while also widening the focus of interventions that alleviate the patient’s stress related to the illness to include family as well (Lee & Bell, 2011). Likewise, the dominance of familial involvement in the decision-making process may suggest that practitioners can provide families with additional knowledge to ensure optimal decision-making for the patient’s health care (Ho & Sanders, 2015). Understanding the linguistic needs of individuals, as shaped by culture, is pertinent to enhance cultural competency during cultural encounters (Ingram, 2011). Therefore, to prevent misunderstandings, practitioners are advised to use culturally adapted language, as well as modifying or simplifying medical terminologies to suit cultural preferences of patients (Ingram, 2011; Krystallidou et al., 2017). Furthermore, to further develop cultural competence, practitioners should consider the impact of their own cultural beliefs on their practices, for example, that Western medical models are laden with individualistic approaches (Christopher et al., 2015). The role of reflective practice is evident here (Sandeem, Moore, & Swanda, 2018)

4.5 Conclusion

Given that the majority of studies surrounding Chinese culture in health care have been conducted outside of Australia, this study contributes to the paucity of literature in Australia concerning the health care of Chinese people. This study has met its aims of exploring the cultural perspectives of Chinese people in Australia on death and dying. While most findings are congruent with existing literature on Chinese culture, there is evidence that the cultural attitudes of Chinese people are changing. This presents as a novel finding in this study where the influence of acculturation of Chinese people to Australian culture is considered as a possible explanation. Further research is recommended with practitioners as well as patients to further expand perspectives and refine findings. Findings from this study have important implications for the uptake of palliative care among Chinese people, as well as other end of life approaches. Importantly, through the use of a well-established cultural competence framework, this study is applicable to different areas of health care, and findings may guide practitioners in the further development of their cultural competency to deliver culturally appropriate patient care to Chinese people in Australia.

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Appendix A

Recruitment Flyer



Participants needed for research project!

As part of an Honours degree in Psychological Science at the University of Adelaide, this qualitative research project aims to contribute and expand on existing literature about the cultural perspectives of Chinese people in Australia towards their healthcare, specifically pertaining to death and dying. In particular the project focuses on contributing knowledge towards the area of palliative care.

Objectives of this project:

1. To enquire about and explore Chinese interpreters' experiences working with people of Chinese background at end of life in Australia
2. Chinese interpreters' views regarding the cultural competency of healthcare professionals in Australia when working with Chinese people at end of life

Participants must be:

1. Over the age of 18
2. Fluent Chinese speakers (including any dialects)
3. A professional interpreter with experiences interpreting for Chinese clients in palliative care and/or about end of life issues

If this is you, you are invited to take part in a **1-hour interview**.

To learn more about this project, or to participate in this project, please contact:



The study has been approved by the Human Research Ethics Subcommittee at the University of Adelaide (approval number [redacted])

Appendix B

Consent Form



Human Research Ethics Committee (HREC)

CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	The experiences of Death and Dying in Australia for Chinese people: A qualitative study for cultural competency
Ethics Approval Number:	██████████

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.
3. Although I understand the purpose of the research project, it has also been explained that my involvement may not be of any benefit to me.
4. I agree to participate in the activities outlined in the participant information sheet.
5. I agree to be:
 Audio recorded
6. I understand that I am free to withdraw from the project at any time; answering of questions is voluntary and I can choose not to answer if I do not want to.
7. I have been informed that the information gained in the project is part of an Honours Thesis for the degree of Psychological Science (Honours) at the University of Adelaide.
8. I have been informed that in the published materials I will not be identified, and pseudonyms will be used for de-identification. At no point of time will any identifying details be included.
9. My information will only be used for the purpose of this research project and it will only be disclosed according to the consent provided, except where disclosure is required by law.
10. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: _____ Signature: _____ Date: _____

Researcher/Witness to complete:

I have described the nature of the research to _____
(print name of participant)

and in my opinion she/he understood the explanation.

Signature: _____ Position: _____ Date: _____

Version 1

Date: 30 March 2018

Appendix C

Participant Information Sheet



PARTICIPANT INFORMATION SHEET

PROJECT TITLE: The experiences of Death and Dying in Australia for Chinese people: A qualitative study for cultural competency
HUMAN RESEARCH ETHICS SUBCOMMITTEE APPROVAL NUMBER: H-2018-37
PRINCIPAL INVESTIGATORS: Anna Chur-Hansen
STUDENT RESEARCHER: Gregory Low Wei Liang
STUDENT'S DEGREE: Honours (Psychological Science)

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This research project is about exploring Chinese interpreters' cultural perspectives of death and dying in Chinese people in Australia, and their implications on a cultural competency framework for healthcare professionals in Australia. This project aims to contribute to existing literature concerning the cultural perspectives of Chinese people in Australia towards health care, specifically on the topic of death and dying and towards palliative care. As such, we would like for an interview with you to discuss the cultural perspectives of Chinese people on the topic of death and dying as well as palliative care, and your thoughts on its implications for healthcare professionals and cultural competency. This interview will take approximately an hour.

Who is undertaking the project?

This project is being conducted by Professor Anna Chur-Hansen, Professor Gregory Crawford and Gregory Low. Interviews will be conducted by Gregory Low. This research will form the basis for the degree of Psychological Science (Honours) at the University of Adelaide under the supervision of Professor Anna Chur-Hansen and Professor Gregory Crawford.

Why am I being invited to participate?

You are being invited as you are:

- Fluent in a Chinese language (including any dialects)
- Over the age of 18
- A professional interpreter with experiences interpreting for clients in palliative care and/or about end of life issues

What am I being invited to do?

You are being invited to participate in an interview that will last about an hour. The interview will be conducted one-on-one in a booked facility at the University of Adelaide North Terrace campus at a time of your convenience; should this not be possible, we can conduct the interview at a location at your choosing, such as your office. Should you be unavailable to meet, we can also conduct the interview through the phone, at a time of your convenience. If you are not in South Australia, a phone or video interview can be arranged. Participation is voluntary, and you could choose to withdraw your consent at any time. We will ask for your consent to audio record the interview, so the interview can be

transcribed. The recording and the transcriptions will be strictly confidential-- only Gregory Low will hear the recordings and only he and the supervisors will see the full transcripts.

How much time will my involvement in the project take?

The interview is expected to last for an hour.

Are there any risks associated with participating in this project?

There are no foreseeable risks.

What are the potential benefits of the research project?

The research may result in a better understanding of Chinese culture for healthcare professionals working within the Chinese communities. There are no immediate benefits to you.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time.

What will happen to my information?

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law. Pseudonyms will be used for de-identification and at no time will any information that can identify you or any other person or place, be included.

Only the researchers will have access to the data obtained in the project, and data will be given to the School of Psychology for storage for 7 years on a password protected computer and then deleted. Raw audio data will be destroyed after transcription has occurred.

Information from the interview will be used to produce an Honours thesis, and at the end of the project, publications may be submitted to peer reviewed journals and conferences.

Interview transcripts as well as a short summary of the research upon completion, will be sent to you through email.

Who do I contact if I have questions about the project?

For any questions about the project, you can contact:



What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Subcommittee at the University of Adelaide (approval number: [redacted]). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish

to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

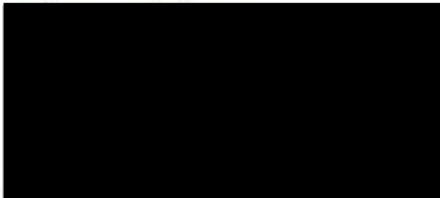
Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

Should you be interested in participating, please contact Gregory Low

(gregory.low@student.adelaide.edu.au)

Yours sincerely,



Appendix D

Examples of open-ended questions asked

The following are some of the open-ended questions asked, in no particular order.

What are your professional experiences as an Interpreter in Australia?

What are some challenges working as an Interpreter and how do you overcome these challenges?

What are your experiences interpreting for Chinese clients in palliative care?

- What would you say are some of the challenges?
- How do you overcome these challenges?

Can you please tell me about a recent experience you have had, interpreting for a Chinese person at end of life, in Australia? Please do not mention their name or anything that might identify them.

Do you have other experiences working with Chinese patients that you are able to share?

In your view, what is a “typical” way for a Chinese person to approach their death?

In your experiences, how do healthcare professionals in Australia generally discuss death and dying with Chinese patients?

- What are some interesting examples?

How do you think healthcare professionals should approach a terminally ill Chinese patient?

- What are some of the common mistakes or misunderstandings?

Appendix F

Email of acceptance for Undergraduate Research Conference



Gregory Benzi Low <gregorybenzil@gmail.com>

Undergraduate Research Conference Notification - Response required by Thursday 5 July

2 messages

Helen Nagel <helen.nagel@adelaide.edu.au>
To: "gregorybenzil@gmail.com" <gregorybenzil@gmail.com>

Tue, Jul 3, 2018 at 5:22 PM

Dear Gregory

Thank you for your interest in presenting a poster at the [2018 Undergraduate Research Conference](#) and for your abstract: *Cultural perspectives of Death and Dying in Chinese people: A qualitative study for cultural competency*

On behalf of the panel, I am delighted to invite you to present on Friday 27 July. Congratulations!

You originally applied for a poster presentation, however, our panel were impressed with your topic and abstract and would be interested to hear more about it in an oral presentation format. Please confirm by COB **Thursday 5th July** as to whether you would like to accept the offer of doing an oral presentation instead, or continue to present a poster over the lunch period (you can do both if you wish!)

1. Information if you choose to do an oral presentation:

Your PowerPoint presentation is due no later than **9am Monday 23 July**. Please email your slides in .ppt or .pptx format to daseevents@adelaide.edu.au with the subject line: URC PowerPoint Presentation. You **must** use the template which can be found [here](#). This is of a specific slide ratio and includes all relevant branding for the University and this event.

You will have a total of 20 minutes (this includes 10 minutes for your presentation, 5 minutes for questions, and a 5-minute allowance for changing presenters). There will be an academic judge and a student judge in your room to assist with keeping time. Please note that conference delegates may leave during question time in order to attend a presentation in a different room.

The presentations for this year's conference will not be recorded. Should you wish to record your presentation, you may ask your supervisor, or a friend in the audience to do so using a phone. Some students find it helpful to watch their presentation prior to attending future conferences.

A presentation time and room number will be provided to you over the next few days in a separate email. A presentation time and room number will be provided to you over the next few days in a separate email.

Appendix G

Poster presentation for Undergraduate Research Conference



The experiences of death and dying in Australia for Chinese people: A qualitative study for cultural competency

adelaide.edu.au

Gregory Low Wei Liang

Supervisors: Professor Anna Chur-Hansen

What are the experiences of Chinese people in Australia at end of life as reported by interpreters?



Background

Different cultures conceptualise death and dying differently; the Western model predominantly prescribed by clinicians is not always appropriate for providing care to patients from non-Western cultures.



Aims

This study aims to contribute and expand on existing literature about the cultural perspectives of Chinese people in Australia towards death and dying in healthcare with a focus on cultural competency.

Method

Seven Chinese interpreters took part in qualitative in-depth interviews on their experiences interpreting for Chinese people at end of life.

Interpreters were recruited through the Australian Institute of Interpreters and Translators.

Participants were:

- Women
- Born in China or Hong Kong
- Long-term residents of Australia

Interviews were transcribed verbatim and data analysed using thematic analysis.

Findings

“for Chinese it is *bad luck* and we don't touch any bad subject though we know that was happening *just avoid it bad spirit* that kind of things”
- 'P1', Mandarin Interpreter

Death as Taboo
Death and dying are regarded as a symbolism of adversity and are ingrained in Chinese culture as a conservative traditional viewpoint.

“death can be quite confronting so yea ... but because *Chinese people don't want to offend the patient or their family* so I think they wouldn't be so upfront about if you are about to die *they just try to maybe not talk about it*”
- 'P5', Mandarin/Cantonese Interpreter

“in Australia they respect the rights of the patient to know what's happening and they very much *need the patient to be the one to make the informed decision*”
- 'P3', Mandarin/Cantonese Interpreter

Individualism VS Collectivism
Western culture is viewed as individualistic, focusing on the individual's needs as opposed to Chinese culture which is collectivistic and prioritise group needs over the individual.

“if somebody wants to go to a palliative care centre they will have to talk it through to their loved ones and *ask them for their agreement* before they can go”
- 'P7', Mandarin Interpreter

“*things are changing not many of them are so narrow-minded* in past might be no one want to talk about it but now the patient have the right to know everything and the doctor will tell the patient directly now it is different and *people open their mind more easier now*”
- 'P1', Mandarin Interpreter

Changing Mentalities
Chinese people are gradually becoming more accepting at discussing death.

Discussion

- Persistent cultural avoidance towards death and dying
- Family essential and influential in Chinese culture
- Healthcare approaches affected and problematic for patient-care
- Alleviated by Chinese people exposure and receptiveness to Western concepts

Healthcare cultural competency

● Cultural factors ● Life experiences ● Cultural Knowledge → Cultural Awareness, Skills, Desire

Appendix H

PowerPoint presentation for Undergraduate Research Conference

UNDERGRADUATE RESEARCH CONFERENCE

Cultural perspectives of death and dying in Chinese people: A qualitative study for cultural competency


Gregory Lou Wei Liang

Supervisor: Professor Anna Chiu-Hansen

BACKGROUND

Most common language spoken at home aside from English?

TOP 10 COUNTRIES BY BIRTH




1. Mandarin
2. ---
3. ---
4. Cantonese

ABS Census 2015

University of Adelaide

Imperative for healthcare professionals to:

- recognise & incorporate Chinese cultural perspectives when treating Chinese patients
- Increase cross-cultural education



Communality of varying cultures lies in beginning of life and **end of life**. (i.e. death and dying) (Gire, 2014)


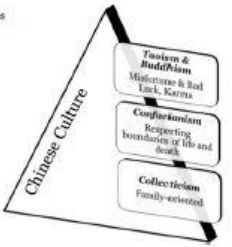



Research Question

What are the experiences of Chinese people in Australia at end of life as reported by interpreters?


Death/Dying

- Conceptualisation different across cultures
- Western model dominant
 - Individual freedom & autonomy (Beatty, 2015)
- Unable to generalise across cultures

Example

- Mrs Lee is a 40 year old terminally ill cancer patient who is thinking of ceasing cancer treatments to spend her remaining time with her family.
- Her parents, originally from China, migrated to Australia when she was 15 years old.
- Whenever she brings up the topic of death and dying, her parents get very flustered and apprehensive; this had made discussions about end of life issues very challenging.
- Mrs Lee's doctor informs her that the decision for treatment is her choice.
- Mrs Lee feels very conflicted and stressed; this has led to the worsening of her health.



Methodology

Seven Chinese Interpreters

- All women, born in China or Hong Kong
- Mandarin and/or Cantonese native speakers
- Residents of Australia >10 years

Eligibility Criteria:

- NAATI (National Accreditation Authority for Translators and Interpreters) certified interpreters specialising in any Chinese languages

- Interpreted for clients in facing end of life issues (e.g. in palliative care)

In-depth qualitative interviews

- Audio-recorded and transcribed verbatim
- Thematic Analysis



Findings

Death as Taboo

“for Chinese it is **bad luck things** and we don't touch any bad subject though we know that was happening **just avoid it bad spirit** that kind of things

- 冯, Mandarin Interpreter

death can be quite confronting — but because **Chinese people don't want to offend the patient** or their family so I think they wouldn't be so upfront about if you are about to die they just try to maybe not talk about it

- 冯, Mandarin/Cantonese Interpreter

its just a very old concept we don't have the education about death when we are younger so Chinese people tend to **don't want to talk about it** and if anyone mentions about it it's considered **not auspicious** of

- 冯, Mandarin Interpreter

Changing Mentalities

“in Australia you **conform to the culture** and they do realise it's a good way compared to not knowing what is happening to your own body it's silly **they prefer to know so that way they take control**

- 冯, Mandarin Interpreter

because people **thinking is changing** and the **new generation over the previous one and their thinking are all different** all open people can openly talk about wills now not in old days

- 冯, Mandarin Interpreter

Individualism and Collectivism

“if somebody wants to go to a palliative care centre they will have to talk it through to their loved ones and **ask them for their agreement** before they can go

- 冯, Mandarin Interpreter

Australia they respect the rights of the patient to know what's happening and they very much **need the patient to be the one to make the informed decision about the treatment**

- 冯, Mandarin/Cantonese Interpreter

as a Chinese you **are always thinking of looking after your family** even at death you want to make sure that your family is taken care of

- 冯, Mandarin/Cantonese Interpreter

Discussion

Changing mentalities

- More open
- Exposure towards Western concepts

Language (Chinese)

- Emotive affect
- Region-dependent and fluid

Congruency with existing literature

- Cultural Avoidance towards death
 - Death preparations
 - Treatments
- Chinese culture as collectivist
 - Family needs prioritised

