

## **End-of-life care beliefs values, practices and support needs of Chinese women living in the UK: A Cultural Safety approach**

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## Abstract

End-of-life care requires attention to mental health, religious practices and beliefs, and health care systems and supports to help individuals cope with the process of aging, coming to terms with death and dying and to help family members and loved ones cope with bereavement. To date, there is limited research examining end of life care and the needs of Chinese people in the UK. Understanding end-of-life care expectations in relation to this population is important for informing the development of new health policy and service initiatives, given that there are currently over 1 million Chinese people living in the UK. The purpose of this study is to explore the mental health, religious practices and beliefs, and services and support systems required by this community to cope with end-of-life and bereavement. In July 2011, Wai Yin Chinese Women's Society in Manchester, UK conducted fourteen semi-structured in-depth interviews with a group of Chinese migrants (primarily women working within the margins of UK's formal economy) to explore end-of-life care issues. The current study performed a secondary analysis of these transcripts focusing only on the stories of the eleven Chinese women. The women participants were recruited as a part of Wai Yin's Sunshine Project, which aimed to assist

Chinese migrants in improving their knowledge and understandings of their employment and immigration rights (in the UK) and to help them learn the English language. Main findings are presented in eleven broad-based themes: acculturation, culturally-specific services, death and dying, Eastern practices and beliefs, gendered effects, health and health care, hereafter, language and communication, obligations versus duties and responsibilities, personal choices, and Western practices and beliefs.

## Introduction

### Background

End-of-life care requires attention to mental health, religious practices and beliefs, and health care systems and supports to help individuals cope with the process of aging, coming to terms with death and dying and to help family members and loved ones cope with bereavement. Research indicates that end-of-life care decisions can be an arduous, painful and uncomfortable process particularly for Chinese migrants<sup>1</sup> (Bowman & Singer, 2001; Chan & Kayser-Jones, 2005; Ho, Radha Krishna, & Yee, 2010). For Chinese migrant women in the UK, challenges associated with end-of-life process are complicated by gendered social and cultural: norms, roles, expectations, behaviours, attitudes and mannerisms specific to being a Chinese woman (i.e. expected behaviours of submission and subservience to their spouse and their family members, caregiving roles, responsibilities and expectations, as well as, spiritual duties and responsibilities).

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<sup>1</sup> Chinese migrants are defined in this paper as Chinese persons living in a new cultural setting.

<sup>2</sup> Dominant culture refers to the established language, beliefs, behaviours, practices, values, religion and rituals as well as social customs and norms of a society. The dominant culture is usually maintained by those

It is important to note that attitudes, beliefs and social norms in end-of-life care decision-making are often significantly influenced by the dominant culture<sup>2</sup> of the host society<sup>3</sup> (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Bowman & Singer, 2001; Chan & Kayser-Jones, 2005; Liu et al., 1999). As such, communicating with health and social service providers about sensitive issues, in particular issues relating to death or dying can generate unnecessary stress and anxiety for ethnic minority<sup>4</sup> women (Bowman & Singer, 2001; Chan & Yau, 2009; Chan & Kayser-Jones, 2005).

In England, Chinese people make up about 1.6% of the total population and 3.5% of the population within Manchester (Office for National Statistics, 2009). When examined as a group, Chinese populations living in England less often access health care services, specifically, primary health care services such as visits to the GP office (Seymour, Payne, Chapman, & Holloway, 2007). Similarly, with respect to end-of-life care, utilization of services such as health and social support services either at home or in hospices are particularly low among this population compared to white European groups (Ahmed et al., 2004; National Council for Hospices and Specialist Care Services, 2001; Seymour et al., 2007). At present, no data are available on gender-specific usage of end-of-life services and supports among Chinese populations.

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<sup>2</sup> Dominant culture refers to the established language, beliefs, behaviours, practices, values, religion and rituals as well as social customs and norms of a society. The dominant culture is usually maintained by those in power who control social institutions such as the media, education, law, marriage, religion as well as political and economic processes (Marshall, 1998).

<sup>3</sup> Host society refers to the established, and often, dominant society (see footnote 1) within which immigrant groups seek accommodation and asylum seeker and refugee populations seek safety, security and refuge (Montgomery County Community College, 2012).

<sup>4</sup> Ethnic minority refers to a population living in a community, which has a different national origin and cultural traditions than the host society (see footnote 2). Often, ethnic minority groups become marginalized and experience social and health inequities as a result of subjections to racism and social exclusion (Marmot & Wilkinson, 2006).

Current literature suggests a need to further examine differences in the low uptake of end-of-life services by ethnic minority groups residing in England (Evans et al., 2011). Research indicates that end-of-life services in England focus heavily on primary health care (Evans et al., 2011). However, end-of-life care encompasses more than health care services alone (Hsiao, Gau, Ingleton, Ryan, & Shih, 2011). Death preparation is a process which can also include completing unfinished tasks; finding closure in life; as well as considering, preparing and undertaking traditional customs and spiritual practices (Chan & Yau, 2009). As well, it must be acknowledged that culture plays a significant role in this process. Culturally appropriate and safe end-of-life care requires consideration of cross-cultural differences and gender-specific challenges by front-line workers and governing bodies that make important decisions on health policy. For example, challenges older Chinese adults may experience include language barriers; differences in food choices; inability to effectively communicate end-of-life care supports and needs, particularly mental health-related issues such as loneliness and isolation; and differences in spiritual and cultural beliefs and customs such as practices related to appropriate funeral attire, traditional food preparation, prayer and family-centered care (Chan & Kayser-Jones, 2005). Chinese women, in particular spouses in the caregiving role or position, may experience the double- or triple-burden of having to assist in making difficult end-of-life decisions for their parents and parent-in-laws, providing care to them and their family as well as having to work in precarious jobs in UK's formal economy (Remmert, 2009).

With respect to traditional Chinese beliefs, values and practices, it must be noted that Chinese people are not a homogeneous group, and as such, Chinese culture should not be thought of and treated as a monolithic entity (Bowman & Singer, 2001). The beliefs, values and practices of Chinese people may vary by many social factors, for example, by the region or state

in which they resided prior to migration (Bowman & Singer, 2001). Understanding end-of-life care expectations within Chinese groups is important for informing the development of new, culturally safe, sensitive and appropriate health policy and health service initiatives for end-of-life care in the UK.

### **Rationale, Aims and Theoretical Lens**

To date, there is limited research exploring the end-of-life care needs of Chinese people living in England (Evans et al., 2011). A deeper understanding of end-of-life issues from the perspectives of Chinese people living in England will help improve the provision of personal care and assist health care providers in understanding the spiritual and health care needs of the dying in order to develop and implement strategies for culturally appropriate holistic care. For this paper, I seek to inquire about the spiritual practices and beliefs and end-of-life wishes from a select group of eleven Chinese women service users from Manchester's Wai Yin Chinese Women Society in order to broaden our understandings of the attitudes, values, beliefs and practices towards end-of-life decisions. I intend to do this through a Cultural Safety lens in an attempt to acquire new knowledge without furthering negative stereotypes about Chinese traditions and culture. However, it must be noted that because certain stereotypes and generalizations reflect an element of truth, some of these may surface throughout this piece in order to acknowledge particular understandings of Chinese traditions and culture so that we may seek to expand this way of thinking and inform current practice.

To do this, I propose to conduct a secondary data analysis of eleven interview transcripts using principles of Grounded Theory (Strauss & Corbin, 1990). The data were collected for an exploratory study conducted by Wai Yin Chinese Women Society in July 2011 to examine and understand traditional spiritual practices and end-of-life attitudes and beliefs in some of Wai

Yin's Chinese service users. Because Wai Yin Chinese Women Society is the largest Chinese Community Centre in the UK, the organization sought to use these data for a pilot study to initiate end-of-life care research for Chinese people living in Manchester and potentially for all of UK. Details of the exploratory study can be found in the Methods.

The theoretical framework used to guide the aims and the methodology for the exploratory study conducted by Wai Yin was informed, implicitly, by Culturalism. Culturalism refers to the process of viewing people and their everyday life through a lens of culture; however this has been narrowly defined as shared values, beliefs and practices (Browne et al., 2009). Another issue with Culturalism is that it is often conflated with ethnicity, and consequently, it has been used to explain why certain groups experience various health, social and economic outcomes. This practice can result in the stereotyping or stigmatizing of some groups, in particular, ethnic minority populations (Browne et al., 2009). Therefore, to further the current theoretical way of thinking, and to avoid popularized, stereotyped representations of culture (Browne & Varcoe, 2006; Gustafson, 2008; McConaghy, 1997), the secondary analysis attempts to re-interpret the existing data by supplementing the lens of Culturalism with the tenets and assumptions of the Cultural Safety paradigm.

Cultural Safety is a relatively new concept that emerged from the field of nursing in New Zealand to assist in providing better care for Maori communities (Browne et al., 2009). Cultural Safety recognizes that, often, the concept of culture is oversimplified and may inadvertently reinforce negative stereotypes of ethnic minority populations specifically within the context of health care and social service provision (Browne & Smye, 2002; Browne & Varcoe, 2006; Nguyen, 2008). This paradigm acknowledges and incorporates a focus on differential power dynamics and inequitable social relationships between the service provider and the client.



Cultural Safety furthers the lens of Culturalism through focusing attention towards structural inequities and disadvantages experienced by ethnic minority groups.

Although Cultural Safety was originally conceptualized based on issues arising from biculturalism between Maori and non-Maori peoples (Ramsden, 1990), several authors have applied this framework for research in various multicultural contexts, particularly within new immigrant populations (Anderson et al., 2003; Baker, 2007; Kirkham & Anderson, 2002; Kirkham et al., 2002; Ogilvie, Burgess-Pinto, & Caufield, 2008). Because the previous study was implicitly guided by Culturalism, the research questions were not designed to critically capture issues of gender and social inequities; rather, they focused on drawing out fundamental aspects of culture, such as traditional Chinese beliefs, values and practices that impacted the end-of-life decision-making process. To extricate additional issues relating to the complexity of peoples' lives and to reframe our ways of thinking about culture and end-of-life care, Cultural Safety will be used as an interpretive lens in the Results and also used to guide the Discussion and inform future recommendations.

## **Methods**

### **Study Details**

In July 2011, Wai Yin Chinese Women Society conducted an exploratory, qualitative study on end-of-life care attitudes, beliefs, values and service requirements among fourteen Chinese service users, three men and eleven women. Fourteen semi-structured in-depth interviews were conducted in Mandarin and Cantonese with a group of Chinese migrants<sup>5</sup> - primarily women working within the margins of UK's formal economy. The current secondary analysis focused only on the experiences of the women (N=11). The women participants were

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<sup>5</sup> Refer to Appendix II for the Semi-structured Interview Questionnaire (in English and in simplified Chinese).

recruited as a part of Wai Yin's Sunshine Project, which aimed to train Chinese migrants to improve their knowledge of employment and immigration rights, and language skills to enable them to access support services. Permission to access the study transcripts was granted by the Wai Yin Chinese Women Society.

## **Ethics**

For the original project, the study protocol was submitted for approval to Manchester Metropolitan University's Divisional Ethics Committee, which approved the application. The research was conducted in accordance with the British Psychological Society's (2006) ethical guidelines. Informed consent was gained from all participants in written form where possible or in verbal form. The information sheets and consent forms were translated into the appropriate languages (simplified Chinese). The project protocol ensured that the anonymity and privacy of all participants were protected.

Due to the sensitivity of the topic, confidentiality and anonymity were of the utmost priority and were guaranteed to participants. Researchers were instructed to act if signs of emotional distress were observed so participants could then be referred to appropriate support services. Researchers were supplied with lists of such support services to facilitate referral; however, no referrals were required during the research project.

For the current secondary data analysis, ethics approval was sought out and granted by the Office of Research Ethics at Simon Fraser University.

## **Analysis**

For the qualitative analysis, transcripts from Wai Yin's exploratory study were analyzed based on principles of grounded theory. Central themes relating to end-of-life care were extracted and characterized by tenets of Culturalism. Finally, to expand on and address the

criticisms of Culturalism, Cultural Safety was used as an interpretive lens in the Results and was also used to guide the Discussion and inform future recommendations.

The first, second and third layer of coding, were analyzed using HyperResearch (Version 3.5). Principles of Grounded Theory (Strauss & Corbin, 1990) were applied which included three phases, namely, open coding, axial coding and selective coding. The first layer of coding, Open Coding, required examining the text linearly for salient categories<sup>6</sup>. New categories or codes were introduced each time a new phenomenon emerged from the text. The constant comparison approach was used to ensure that the data were being coded consistently and to ensure a close connection between the categories in preparation for the second layer of coding, Axial Coding. The first layer of coding resulted in (N=69) codes. For a more detailed description of the initial set of codes, refer to Appendix I<sup>7</sup> for the Frequency Table of Codes.

For the second layer of coding, Axial Coding, I explored the relationship between the initial set of codes and examined how they could be further grouped to reveal broader themes. The process of finding connections between the codes yielded 11 broad-based themes, which demonstrated important aspects of end-of-life care for this group. The intricacies of each broad-based theme were described in the code maps below. Each code map revealed a central phenomenon highlighted in yellow – a process informed by the third phase of Grounded Theory, namely, Selective Coding, which required identifying and relating the core category to other categories.

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<sup>6</sup> In the three phases of Grounded Theory, the term “categories” is referring to the resulting codes revealed as part of the coding process.

<sup>7</sup> The Frequency Table of Codes depicts the number of times each code appears in all fourteen transcripts.

## Results

### Demographics

Details of the participants' demographic profile are shown in Table 1.

**Table 1. Participants' Profile of eleven Chinese women service users from Wai Yin Chinese Women Society, Manchester, UK.**

| Demographic Variable  | N  |
|-----------------------|----|
| Age Range in Years    | 11 |
| 25 – 34               | 7  |
| 35 – 44               | 3  |
| 45 – 54               | 1  |
| Years Lived in the UK | 11 |
| > 1                   | 1  |
| 1 – 3                 | 3  |
| 4 – 6                 | 3  |
| 7 – 9                 | 4  |
| First Language        | 11 |
| Fukien                | 1  |
| Cantonese             | 2  |
| Mandarin              | 2  |
| Hakka                 | 6  |

Most participants were younger women 25 to 34 years old. Since the topic of end-of-life is extremely taboo within Chinese culture, Wai Yin decided that it would be best to initially sample a younger generation. The sample also consisted predominantly of marginalized Chinese women because the Sunshine program was designed specifically to assist migrant Chinese women, with or without appropriate work visas, become work-ready for UK's employment system.

The length of time spent the participants spent living in the UK ranged from less than 1 year to 7-9 years. All participants were able to understand and speak Mandarin; however, with respect to the specific dialect, many participants spoke Hakka or Cantonese. The reported dialects reveal that the majority of participants were from more rural parts of China.

## Language and Communication

Theme one consisted of six codes, including the central phenomenon of, communication barrier, with the five remaining codes serving as either a predictor or an outcome of a communication barrier (Figure 1).

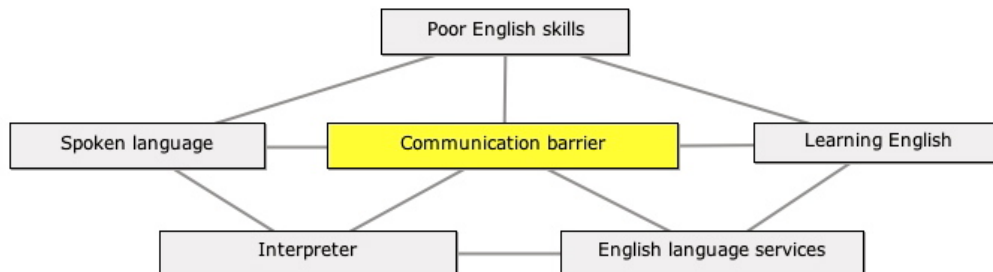


Figure 1. Depicts a code map representing the theme Language and Communication. The central phenomenon is “communication barrier.”

All participants reported English as either their second or third language and that they would prefer to speak in Chinese, either in Mandarin or Cantonese. Most participants can understand and speak either Mandarin or Cantonese and several participants indicated that they could speak either of these in addition to another dialect of Chinese. Participants revealed that they found it very difficult to communicate with health professionals and other agencies when they encountered health problems and faced making end-of-life decisions.

Like many of us don't know English. We don't know what to do if a person dies. I don't think we know where cremation should take place, who should we look for, and which places for burials. (P2, Text, 1678,3043)

Often, communication barriers resulted in frustrations experienced by both the health care provider and the health service user as indicated in the next excerpt.

... if the doctor is impatient, he doesn't want to spend a lot of time listening to us. Because we are limited in the English language, we have to depend on simple translations to describe the symptoms and other medically related inquiries... if we encounter good doctors, they will invest time in trying to understand and communicate with and as a result we feel more comfortable to try and speak; but if we meet doctors who are impatient, then they will tell us very directly to call in another time. In fact, sometimes we say to on another, “Just forget it! We won't be seeing a doctor today and so just let it be.” (P2, Text, 1678,3043)

According to Participant 2, explaining the health issue and describing symptoms was challenging due to language difficulties. However, these challenges were often dependent upon the service provision approaches of the general practitioner (GP). For example, Participant 2 described how some GPs were very patient and sympathetic to their language difficulties, while others were very impatient and abrasive. The process of seeking health care services tended to yield better results with GPs who were more sensitive to issues associated with migration and cultural barriers, with language being the most common and significant challenge experienced by the non-native English speaking participants.

When participants were asked if interpreters were offered to overcome their communication barriers, 11 participants revealed that this service was available when they visited the GP office. However, 3 participants reported using other means of communication supports such as their spouse or friends to help translate, and/or they employed Internet services or electronic dictionary devices during GP consultations to help facilitate communication.

When I take my kid to see the doctor, most of the time (the interpreter) doesn't come. But luckily that doctor is very nice, while on phone with me, he translates into Chinese to let me take a look. I type whatever question I have to let him take a look. This is better. But sometimes I still don't feel it's accurate enough.(P3, Text 1456,1784)

According to Participant 3, interpretation services were available by appointment at the GP office; however, for the most part, interpreters did not show up. Participant 3 revealed that even with the help of electronic dictionary devices, these were often insufficient to accurately translate and describe health and health-related issues.

In applying a Cultural Safety lens, it is clear that power differentials existed between the service provider and the service user. This is upheld by macro-political level dynamics of the host society with the idea that the new culture will always be secondary to which the sole responsibility of the host society is to “accommodate” by providing the option of interpretation

services, however, according to the participants, having the interpreter actually present at the time of the appointment was not strictly enforced. Consequently, the availability of interpretation services through the NHS, and the provision of cultural awareness, sensitivity, competence and safety training must be re-evaluated to ensure that, firstly, interpretation services are truly accessible and that health service providers are trained in providing necessary services to individuals experiencing language difficulties.

## Health and Health Care

Theme two is comprised of eight codes, including the central phenomenon of, British health care services, with the remaining six codes operating as either an outcome or predictor of British health care services (Figure 2).

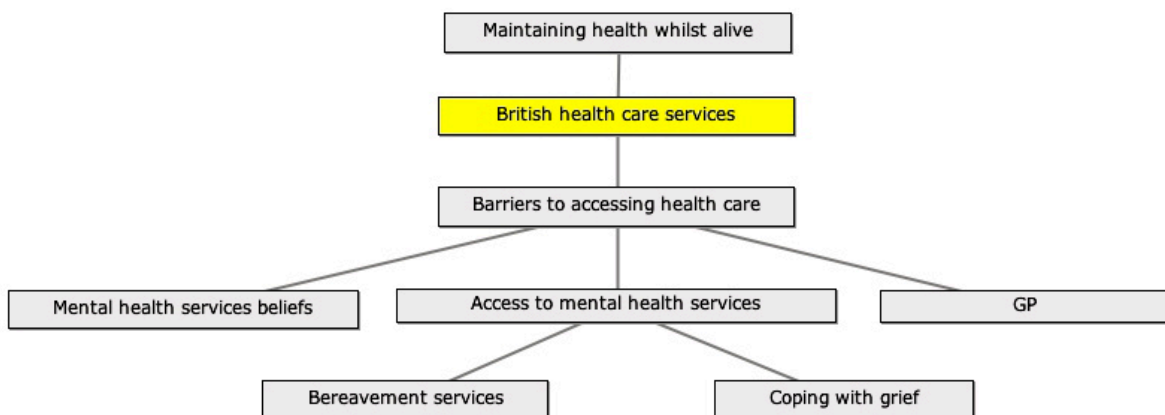


Figure 2. Depicts a code map representing the theme of Health and Health Care. The central phenomenon is “British health care services.”

The general consensus from all participants was that mental health supports and services was an essential service that should be available and accessible when needed. For example, Participant 3 stated:

I think so. Because if someone passes away at home there will be a lot of people around. But here in UK, we’ve all left our home, if a family member passes away, we will feel very depressed and will need someone to enlighten us. (P3, Text 10299,10529)

As indicated above, in China, it is common for the elderly to die at home surrounded by family members who can provide a primary means of support. Many Chinese migrants in the UK are forced to leave loved ones behind. Consequently, having someone to speak with during a time crisis is necessary and appropriate, in particular, for those with immediate family members residing in China. However, it is not customary for Chinese people to seek out services provided by mental health service providers.

...according to traditional Chinese customs, very few people would see a psychologist because people are born they get old and sick and they die, this is natural. There shouldn't be any. There is more in the West. If they're not happy, if they're not happy at work, or have post-partum depression, they all go see a doctor for psychological treatments. I feel like there's very little of that in China. (P13, Text 5314, 5790)

Many Chinese people see aging, death and grieving as a natural process and therefore bereavement services and supports are often underutilized. Mental health and illness is seen as a Western conception, often with overemphasis on the biomedical model (Watters, 2010). In the UK, mental health services are seen as being over-utilized and sought out for a variety of reasons such as work-related issues and post-partum depression.

Despite the underutilization of mental health services by Chinese people in the UK, the next excerpt reveals the importance of having access to culturally specific bereavement and end-of-life services.

When my grandmother died, I was very sad and cried a lot, but now after so much time, I'm not that sad any more. I think that I didn't pay respects to my grandma, but when my mom passes away, I'll definitely do that for her. (P14, Text 24654, 24880)

According to Cultural Safety, it is important and necessary to consistently improve the quality of care within intercultural contexts (Cameron, Andersson, McDowell, & Ledogar, 2010; Dyck & Kearns, 1995). Health care providers need to acknowledge that Chinese migrants have different pre-departure histories. It is, therefore, crucial for end-of-life services to consider the



grieving process for those that were forced to leave immediate family members behind by having prepared sufficient means of providing culturally safe services for individuals in difficult circumstances.

### Culturally Specific Services

Theme three revealed five codes, including the central phenomenon of, Manchester's Chinese supports and services, serving as the predictor of the four remaining codes (Figure 3).

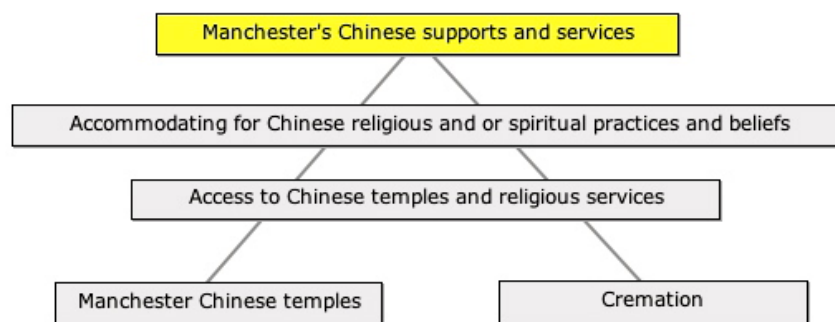


Figure 3. Depicts a code map representing the theme of Culturally Specific Services. The central phenomenon is “Manchester’s Chinese supports and services.”

In terms of culturally appropriate services, majority of the participants indicated their desire and need for having more culturally appropriate services. Specifically, participants voiced appreciating having an organization like Wai Yin, run by Chinese people who were fluent in Chinese and English.

At least I have something to rely on, either this organization or places that specifically served the Chinese and know our language. Obtaining help from them to do these things is the best. But I have never thought of or asked about these things. If they have (this kind of service), then that will be very nice, because it provides great help for us who have trouble communicating. (P2, Text 9174,9694)

The need for services that addressed the issue of communication barriers when accessing health and social services and supports was reiterated. Interestingly, it was also emphasized that service provision should come from those that embodied the culture and understood the cultural intricacies distinct to Chinese people.

Furthermore, Manchester, comparatively to other European cities, has a larger Chinese population. Hence, it would make sense to implement culturally specific health and extended health care services for Chinese people.

Manchester has the most Chinese people across Europe or in the UK, so according to common sense more temples should be built for people to worship. (P1, Text 12192,12410)

With respect to religious and spiritual services, the main argument shared by Participant 1 during the interview was that, presently in Manchester, Chinese temples were rare and did not meet the spiritual and religious needs of those that practiced traditional Chinese religions. In fact, many participants reported not knowing that such services (i.e. Chinese temples) existed in the UK.

Temple? Oh temple. Hm. I don't know. I've been here for so long, but I haven't heard of any. Maybe they don't have any here. Maybe... maybe if you want to do something in UK, it has to be approved by the government, there are lots of procedures to go through. (P7, Text 20963,21574)

In drawing from Cultural Safety, it appears that power differentials between the host and newcomer society continue to influence the lives of and opportunities for Chinese migrants. It is evident that culturally specific end-of-life care, pertaining to religion and spirituality, for Chinese people living in the UK were scarce, as revealed in the excerpts. Structural barriers, such as procedures and processes sanctioned by the UK government were possible challenges to the implementation of traditional Chinese spiritual and religious services.

## **Acculturation**

Theme four is comprised of five codes, including the central phenomenon of, difference between Eastern and Western religious practices and beliefs, with four remaining codes operating as predictors of the central phenomenon (Figure 4).

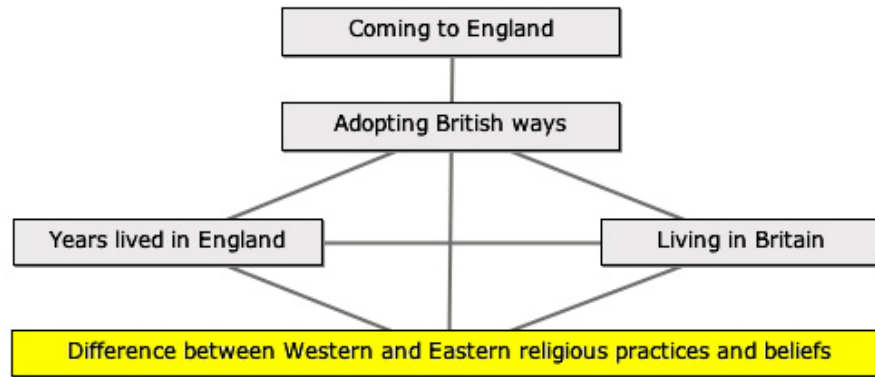


Figure 4. Depicts a code map representing the theme of Acculturation. The central phenomenon is the “difference between Western and Eastern religious practices and beliefs.”

For example, Participant 1 described her duty to adopt the English ways with particular emphasis on being a law-abiding citizen.

It’s like “when at Rome, do as the Romans do.” As Chinese you come to the UK, you follow UK laws and do what English people do. (P1, Text 4758, 4817)

The tone of this passage reveals that the process of adopting values, practices and beliefs consistent with the host culture was not a personal choice but a duty or responsibility of the migrant. The process of acculturation described in this passage, revealed the need to fully assimilate into the British culture rather than integrate it with Chinese culture. The difference between the two is that assimilating would require completely giving up the old culture, in this case, Chinese culture, and integrating would encourage new immigrants to retain the old culture whilst learning and adapting and mixing in aspects of the new culture.

Despite the fact that some Chinese people living in the UK felt an obligation to assimilate into British culture, others revealed that they were conflicted by Western customs that pertain to end-of-life care, in particular, the ways in which the British provided care to the elderly.

I think the seniors here are very courageous, based on what I saw in their ideas. The elderly parents live separately from their children, parents have their own lives and children their own. The children will visit their parents when they have time and so on. If at the end... if you can’t by yourself...if you can’t be independent, if you’re really ill and you can’t walk and have to use a wheelchair,

then you'll need to go to a home because someone will be watching over you. If you can move about by yourself, then do your best to take care of yourself. (P12, Text 9533,10120)

Coming to terms with cultural dissimilarities for end-of-life care extends past differences in provision of care for loved ones. Several participants described the bipolarities between Western and Eastern religious practices and beliefs and revealed feeling pressured to choose between Western and Eastern religions.

Christians do not put an incense burner or any image of "Guanyin" at home like us. They do not do that. So generally when they have something on their mind they go to church to pray. They are like that. Although I've come here for such a long time I haven't been there. I've never been there. Because after all, how can I say, according to them, if you believe in Buddha then you can't believe in Christianity, because the two are different. (P1, Text 9409, 9854)

There were significant differences in methods of worship and prayer between Western and Eastern religious practices and beliefs, especially between Christian and Buddhist practices. Traditional Chinese practices include burning incense, as a part of the prayer process when praying to the image of Guanyin<sup>8</sup>, while Christians show their devotion by praying, kneeling down, often in Churches.

According to Cultural Safety, it is important to note how power differentials between the host and new culture impact the agency of Chinese migrants. For example, implicitly, it is expected that they adopt the dominant religion in the UK, Christianity. A Chinese person must choose between Buddhism and Christianity because it is not possible to adopt both religions (P1, Text 9409, 9854), indicating pressures associated with acculturation; in particular, the pressures associated with assimilating into British society through increased efforts of embracing all

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<sup>8</sup> Guanyin is the Chinese Goddess of Mercy, Compassion and Love. Guanyin comes from the Buddhist religion and is an extremely important and popular entity worshipped among Chinese communities throughout East and South East Asia. Common traditional Chinese prayer practices involve the burning of joss (incense) sticks before an image or shrine of Guanyin. She is regarded, by many, as the protector of women and children (Yang, 2007).

aspects of British values, beliefs and practices in order to be socially accepted and socially included.

### Eastern Practices and Beliefs

Theme five consisted of ten codes including the central phenomenon of, living in China, with the remaining nine codes functioning as either the predictor or an outcome of, living in China (Figure 5).

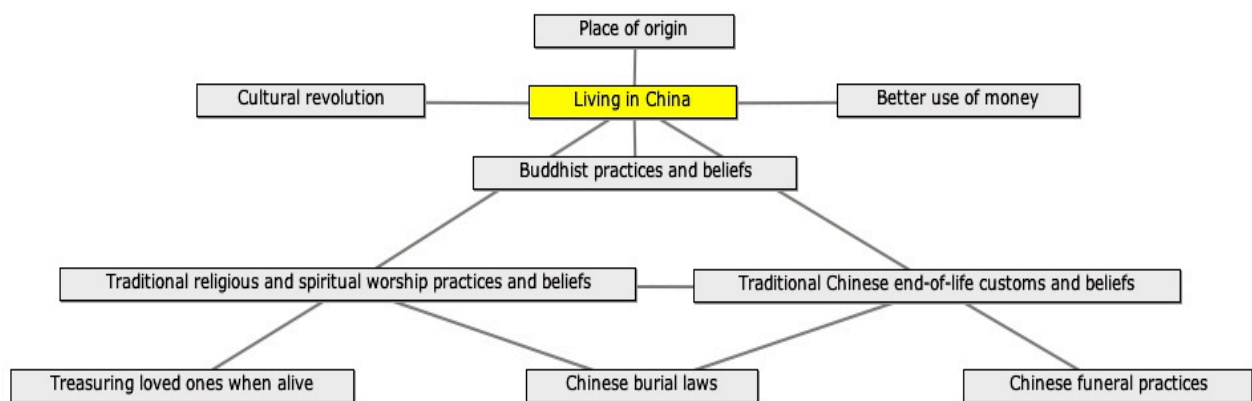


Figure 5. Depicts a code map representing the theme of Eastern Practices and Beliefs. The central phenomenon is “living in China.”

In China, Buddhist and Taoist<sup>9</sup> beliefs are the most common. Several participants indicated that they believed in Buddha because typically, “most Chinese people believe in Buddhism (P8, Text 19894,20069).”

Interestingly, a number of participants indicated that they were not particularly spiritual, religious and/or superstitious. However, they specified that if they had to choose, they would choose to pray to or worship Buddha or Guanyin.

<sup>9</sup> Taoism is a philosophical tradition emphasizing a moral set of beliefs, encompassing the concept of Wei Wu (action through non-action): naturalness, spontaneity and simplicity, as well as, The Three Treasures: compassion, moderation and humility, all of which guide Chinese people in their day-to-day life. Traditions, rituals and customs and practices associated with Taoism intertwine with Buddhism (Lao, 2009).

In terms of traditional practices and beliefs during special times of the year, such as Chinese New Year, the next passage presents some details of this occasion from the perspective of Participant 8.

Sometimes when it's the 1st day of the (lunar) year, people usually like to burn incense on the 1st and the 15th. On the 1st, they say "wow, people burn incense all the time, seems like the mountain is burning!" (laugh) Smoke is everywhere on the mountain, you can't even get into the temple, you can't even open your eyes because of the smoke. Those people might think they have to worship Buddha and burn incense on the 1st day of the year, in order for everything to go smoothly for the year or something like that. (P8, Text 19461,20158)

The first day of the lunar year is Chinese New Year and to celebrate or bring in the New Year, Chinese people would typically burn incense, around the home on the first and the fifteenth. It is also common practice to pray to Buddha either at a Chinese temple, if you are living in an urban area, or on a mountainside, if you are living in more rural parts of China. Importantly, if a Chinese person expected the following year to present good fortunes and to avoid misfortunes, then they must burn joss sticks (as a part of the prayer process) and bow before Buddha.

With respect to traditional end-of-life customs and beliefs, there are specific rituals that are considered common practice for all of China.

When our old people pass away, they will burn paper money... those (paper) houses, and they will invite some Taoist priest to come and read scriptures, stuff like that. Yeah, very extravagant. Things like the burial of the elders...not to mention the paper money, it already costs a lot just to abide those customs, (P3, Text, 5045,5220)

Typically, when a person passes away, customary Chinese end-of-life practices involve: burning incense to honour and respect the individual that has passed and burning paper representations of earthly materials such as money, paper houses, food, gold nuggets, cars and so on to symbolically epitomize the transfer of material wealth from this life to the afterlife. The

presence of a Taoist Priest to conduct rituals assists the safe passing of the individual's soul from this world to the next.

From a Cultural Safety perspective, it is important for British society to recognize, acknowledge and accommodate for traditional protocols, aspirations and wishes of Chinese migrants (such as those specified above) in order to provide effective end-of-life care for these communities.

### Western Practices and Beliefs

Theme six consisted of four codes, including the central phenomenon of, Western religious practices and beliefs, serving as the predictor of the three remaining codes (Figure 6).

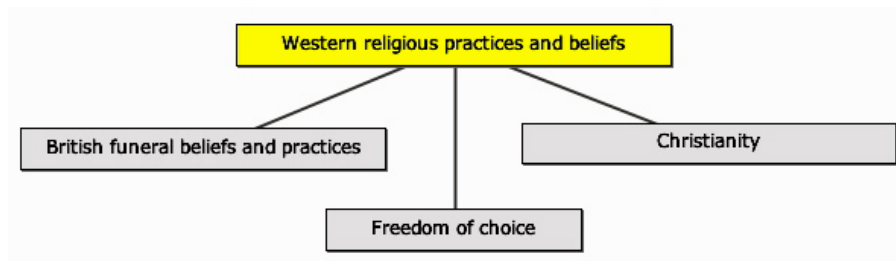


Figure 6. Depicts a code map representing the theme of Western Practices and Beliefs. The central phenomenon focuses on “Western religious practices and beliefs.”

When asked about religious practices and beliefs in the UK, it was clearly articulated that, “...in Western society, it’s Jesus (P1, Text 8878, 8975).” It is without a doubt that Christianity is the most popular religion in the UK. Several participants spoke about members of the Christian church that would rigorously and repeatedly attempt to convert them to Christianity.

On the bus there are a lot of Christian foreigners who can speak Chinese and they try to convert us. It feels...kind of controlling, to be preached and pressured into be converted. Sometimes I feel like they’re too nice, unbelievably nice. Are they really that nice? (P14, Text 6614,6874)

According to this passage, many white, British missionaries have expanded their language abilities in order to recruit members of the Chinese community to joining the Christian

church. Participant 14 indicated that she felt “pressured” during these encounters and their forward methods make them appear disingenuous. Proponents of Cultural Safety would argue that these actions are fuelled by motives to preserve power by maintaining the dominant religion by the host society.

With respect to British funeral practices, many revealed not having participated in any British funerals since moving to the UK for two main reasons: firstly, their social circle consisted of mainly other members of the Chinese community; and secondly, their older family members resided in China.

Akin to Chinese beliefs and practices, it was described that common Western end-of-life rituals that take place when someone dies serve to pay respect to and celebrate the life of the person who has passed. Common practices include: gathering of friends and family at the person’s home; arranging for a Hurd to take all immediate family members to the church, and having an open casket for people to say their farewells.

I’ve seen my neighbour die. There was a row of friends’ cars. The families just came in the usual family cars, but the coffin was a different kind of car. Then they’ll all go to the church where they’ll have visit the open casket, seeing the person one last time. After that, they’d take the body for cremation, right? After cremation, they take it to the cemetery and bury it. (P12, 6097, 6740)

During the interviews, there were many questions surrounding the actual burial process, for example, whether the body had to be cremated or buried. The reason is that, in China, everyone must be cremated, as it is the law. Some Participants indicated that this law infringes on an individual’s freedom and rights. Participant 1 emphasized that, in the UK, it was not against the law to have burials, “They will not go against your will of burying the whole body. They do not do this (P1, 6690,6772.”). According to Cultural Safety, it can be argued that the concept of “choice” presented here becomes blurry when end-of-life options are available only to those that have the financial means to exercise these rights.



## Personal Choices

Theme seven consisted of six codes, including the central phenomenon of, personal religious or spiritual practices and beliefs, with the five remaining codes operating as either predictors or outcomes of the central phenomenon (Figure 7).

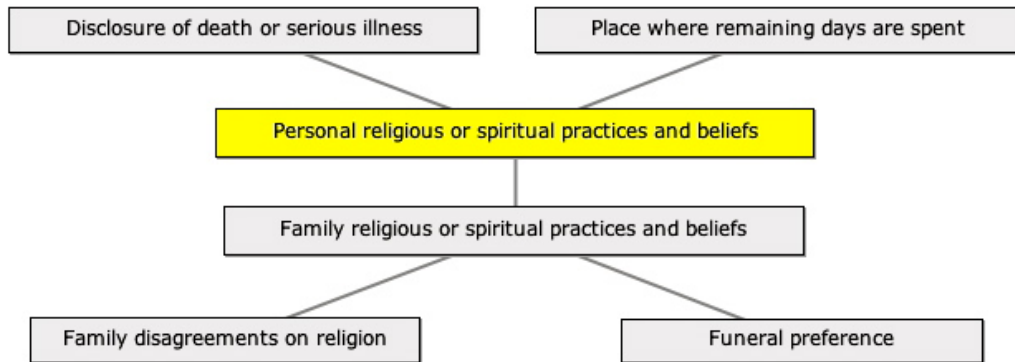


Figure 7. Depicts a code map representing the theme of Personal Choices. The central phenomenon is “personal religious or spiritual practices and beliefs.”

For many women, personal agency is often compromised upon marriage. For example, Participant 7 articulated challenges she had experienced when trying to keep her religion after she had gotten married and describes frequent and persisting arguments she had with her mother-in-law.

At first she kind of didn't want me to believe in these, my belief is different from hers, she was like...according to Chinese customs, your religion has to follow the one you marry. Chinese people are like this, kind of forceful and excessive...like “you've married my son whose family believes these, then you have to believe in these as well.” There is a saying “a woman follows her husband no matter who his family members are and what they believe in.” (P7, Text 11638,12142)

Cultural Safety privileges the standpoint of women and emphasizes that it is important to capture their voices and provide a critical lens for interpreting gendered experiences. Typically, it is expected that Chinese women adopt the religious practices and beliefs of her husband's family. Here, gendered norms and expectations restrict women's ability to choose her religion.

In general, the freedom to choose, over the years, has become an extremely personal and important issue for Chinese people, given China's political history. The freedom to choose a specific religion and/or the decision to engage or disengage in religion as an institution is controversial and has instigated conflict across many cultures all over the world. According to several participants, there is no right or wrong choice. Many reveal having doubts about the existence of a God and choose not to participate in any organized religion.

I don't know. Lots of religious people say they will go to God. I don't know about that. I don't believe in the religion and I don't understand. It doesn't matter where I go. Scientifically speaking, how do you say it... it evaporates. Religiously, people probably go to God, to heaven, or in Buddhism, people go to hell, I don't know. I don't have any religious beliefs. I think gone is gone. Like all other animals, if you die, it follows normal natural laws. The earth decomposes you. (P13, Text 364,3858)

Interestingly, there is a saying in Chinese, "returning to one's roots," which depicts the idea of returning home and can be associated, metaphorically, as returning to one's original form after death.

The Chinese say, "return to one's roots," so it's better at home. It's a very traditional Chinese concept. I don't know how to express it. Maybe Chinese people like being at home, watching their children or their parents, maybe they know it's fairly safe. (P10, Text 1358, 1740)

Cultural Safety maintains having cultural awareness in all aspects of health care provision and health research. The idea of being surrounded by family members during a person's remaining days is very important in Chinese culture. According to Participant 10, Chinese people place a lot of value and significance in dying at home because the home embodies elements of safety, security and comfort. In relation to the overall theme of Personal Choices, the option of choosing to die at home is a significant end-of-life decision that must be considered and honoured within the context of end-of-life care.

## Death and Dying

Theme eight consisted of ten codes, including the central phenomenon of, death of a family member, with nine remaining codes functioning as either a predictor or an outcome of the central phenomenon (Figure 8).

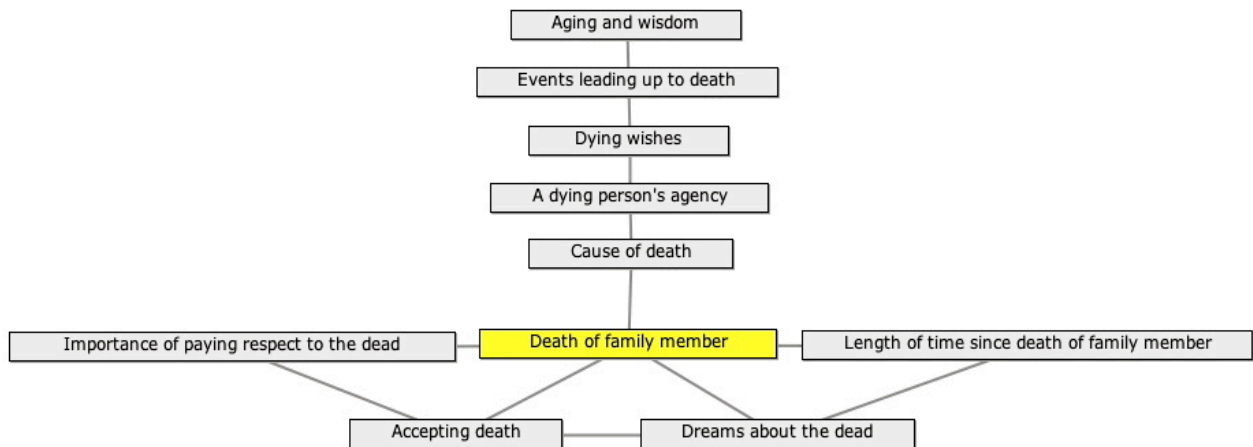


Figure 8. Depicts a code map representing the theme of Death and Dying. The central phenomenon is “death of a family member.”

From the interviews, some of the most intriguing and valuable points raised regarding death and dying focuses on facing and accepting death, respecting personal wishes and regrets as well as the importance of paying respect to ones that have passed on.

Everyone who is born dies, right? You don't know when you're going to die. That's fairly normal, I think. Of course we'll be sad: it's family, after all. If your friend or a pet dies, you'll also be sad. There are emotional attachments. No need to see a doctor. Everyone goes through that process. It's just a matter of time, sooner or later. (P13, Text 4655,5002)

Death was often described as a normal process and an inevitable outcome. The above passage reveals that since death was inevitable, it was not necessary to seek out medical attention to prolong an individual's the remaining days, despite the fact that death would bring sadness upon the family.

When participants were asked about their dying wishes, the fear of not having: completed specific life goals; learned desired skills; and ultimately, enjoyed life to the fullest were emphasized.

If I am going to pass away today, I'm thinking...(both laugh). There are so many things I haven't done yet and I would feel regretful. Why didn't I do this well? Why didn't I learn this and that? Why didn't I enjoy my life? I would feel regretful. (P3, Text, 12442, 12679)

Another dying wish frequently mentioned by participants was being honoured and respected by their children. A crucial component of Chinese culture is filial piety, which involves honouring and respecting one's parents when they are alive and after they have died, not as simply a gesture or an act of kindness, but as a part of the children's duty. The difference is that a gesture or a kindness is perceived as something that can be carried out by anyone, even a stranger, whereas, only a family member or individuals close to the family would take on and fulfill a duty.

If my children really want to pay me respects, in England, if you're buried in the ground, if your children are dutiful, they'll visit you, but if they're not, then they won't in a hundred years! If they're sincere, then they will often think, "I miss my mom." That's enough. (P12, Text 7935,8239)

Cultural Safety maintains the importance of recognizing and understanding historical origins that influence a lineage of cultural beliefs, values, practices and norms. According to Buddhist beliefs, death is a natural process of life and should be accepted as an inevitable outcome for all earthly creatures. Filial piety is a Taoist concept that has been valued by Chinese people for hundreds of years. Such eminent beliefs must be acknowledged and reflected upon when providing end-of-life care.

## Hereafter

Theme nine consisted of four codes, including the central phenomenon of, beliefs about the afterlife, with three remaining codes operating as either a predictor or an outcome of beliefs about the afterlife (Figure 9).

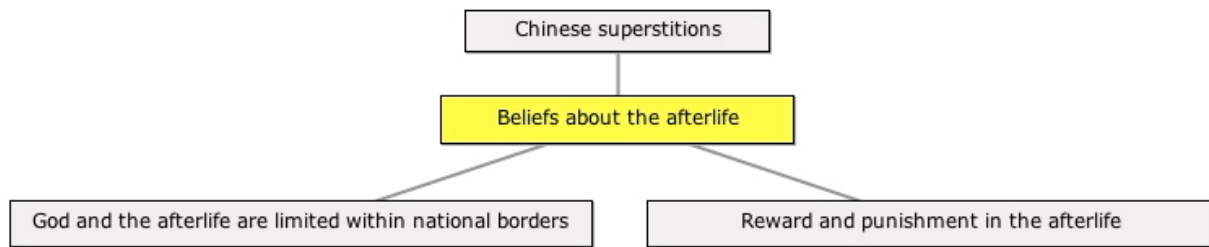


Figure 9. Depicts a code map representing the theme of Hereafter. The central phenomenon is “beliefs about the afterlife.”

The existence of heaven and hell is a significant part of the Chinese religious and spiritual belief system. Some specific intricacies include the existence of 18 levels of hell and people deemed bad would end up deep down in the lowest level and their punishment was to climb up each level until they reached the very top, in order to leave hell and reincarnate.

If you believe what they usually say, good people go to heaven and become Saints, and the bad go to hell and suffer. The Chinese believe there are 18 levels of hell. You would have to climb and climb and climb, all the way to the top before you can reincarnate. (P14, Text 14904,15318)

More importantly, the desire to live righteously in life was discussed, consistently, by the participants.

Regardless, I just try and not do bad stuff in my life, try your best to do good things within your ability, right? This way it'll be good, right? Some people are very bad and they do bad stuff everyday. When he's in trouble and he goes to the temple and burn the incense, Buddha will not bless him, right? (P2, Text 8115, 8258)

The importance of being a good person was emphasized, since people who committed acts of evil would lose the good graces of Buddha. Nevertheless, some believed that the

blessings and protection associated with traditional Chinese beliefs were limited within geographic boundaries.

I'm in UK and I dreamt that I knocked at the door of my home over and over again, but just couldn't get in. I think God is limited within national borders. When I worshipped back home (in China), I felt that it might protect me, but maybe it's only a form of reassurance. Here, even if I worshipped God, God will not hear me. And for my grandpa, I have not dreamt about him. This could mean that I'm too far away. (P3, Text 6725, 6752)

It is strongly believed by some that protection and good fortune from God ceased to exist after immigrating to the UK. In other words, God was "limited within national borders." The assumption here is that in order to regain spiritual "reassurance" and "protection," the acceptance of a new God or image in the UK was required.

According to the transcripts, there is a general consensus that Chinese people are very superstitious people. Several participants indicated significant gender differences that pertain to superstition, religion and spirituality. However, Culturally Safety cautions culturally essentialist notions, for example, notions that portray all Chinese women as being extremely superstitious people that encourage and practice unorthodox rituals. Gendered expectations and norms are discussed further in the next theme.

## **Gendered Effects**

Theme ten consisted of six codes, including the central phenomenon of, duties of a Chinese woman, with the remaining five codes serving as either a predictor or an outcome the central phenomenon (Figure 10).

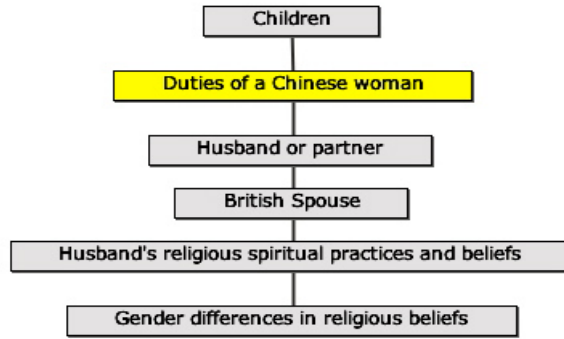


Figure 10. Depicts a code map representing the theme of Gendered Effects. The central phenomenon is “duties of a Chinese woman.”

According to several participants, Chinese men often disengage from partaking in traditional Chinese spiritual and or religious practices, beliefs and rituals. One individual revealed that, “He (her husband) didn’t believe anything” (P9, Text 3908,3935). This was a common response by the participants when asked what their spouses religious views were.

As specified, Chinese women were generally noted to be more superstitious, religious or spiritual than men.

Relatively speaking, women might believe in these superstitions more so than men. But for some men, if they believe, their beliefs are stronger than women. However, generally, women believe more than men. If they both believe, then often men believe more than women. (P2, Text 11154,11418)

It would appear that it was the social norm for women to be more superstitious, religious or spiritual than men. Men who existed outside of this stereotype were deemed to have a stronger belief system than that of women. Nevertheless, it was indicated that the duties of a Chinese woman generally resided within the home and with the children.

...could not find the time. Now the kids are older and are in school, but the two kids are both very good, they say, “mom, go learn English, you can communicate with others and talk with others. After you learn English, you have many, many friends and socialize with them.” So, I’m very happy, it’s very good. Every time when I say, “Oh, I am going to study English or I’m going to school.” They will say, “Sure, I’ll be very good at home.” So, the older one looks after the younger one, and the younger one listens to the older one. They are relatively good and so now I can find the time to go out. Now that I’m studying, it’s kind of tiring, because to start from the beginning is very tiring. (P7, Text 45,803)

Cultural Safety advocates fiercely the importance of capturing women’s voices and interpreting gendered experiences. Issues of gender were apparent during certain points of the interview process. However, it must be noted that the interview questions were not designed, as a part of Wai Yin’s exploratory study, to capture gender as a determinant of end-of-life decisions amongst Chinese women living in the UK.

### Obligations versus Duties and Responsibilities

Theme eleven consisted six codes, including the central phenomenon persons or bodies responsible for providing care, serving as the predictor of the remaining five codes (Figure 11).

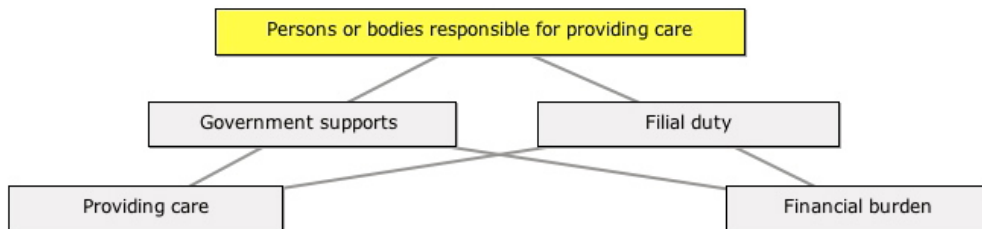


Figure 11. Depicts a code map representing the theme of Obligations versus Duties and Responsibilities. The central phenomenon is “persons or bodies responsible for providing care.”

As emphasized, family is a significant part of Chinese culture. With respect to end-of-life care, it is expected that family members, especially the children, be the primary care providers for aging parents.

For foreigners, they tend to hire nurses. It seems very rare that their children take care of them and stay with them. In China we have more children taking care of them, mostly daughters or daughter-in-laws. (P3, Text 4512,4844)

It was noted that it is the social norm in Western Society to hire nurses as primary care providers for aging parents. Conversely, in China, the children, usually daughters or daughter-in-laws are expected to care for aging parents. Here, gender, influences the woman’s responsibility, which impacts her workload, stress levels and the ability to pursue career choices. It is very common and socially accepted that caregiver duties not be shared between spouses.



Filial piety<sup>10</sup> is a strong and widely accepted belief in Chinese society. According to Participant 13 in the following excerpt, it is “the Chinese way.”

According to the Chinese way, I hope it's my children. Having your family take care of you is better than having the government do it. I don't like the Western way. When people are old and retire, their children don't have those family ties. They send them to old folks' homes. But in the homes, the nurses take care of you like automatons, everyone's the same, it's a process. In China, it's different. There's a sense of family. Westerners don't understand the concept of family. They don't understand it. Only Chinese people understand it. This is what's valuable. Family is better. (P13, Text 10697, 11293)

There was consensus that it is more important to have your family members care for you than the government. Several participants noted disdain for Western caregiving practices for aging parents, especially practices that pertain to sending seniors to retirement homes. It was strongly voiced that the concept of family was less valued in Western society than in Eastern society.

Majority of participants agreed that it was the responsibility of the children to care for the parents. In fact, this belief goes beyond responsibility, as it was described as something that is desired and hoped for by every Chinese parent.

It should be the children helping their parents. I never used to think like this, but when I was pregnant, it was very difficult, especially with my first son. I didn't have money or a house, and it was really difficult. I often tell my son, “look, your parents have worked to support you, we're not telling you that you have to take care of us, and of course, we'll have our own money, but when we're old, it doesn't mean you can say good-bye to us. You should come visit us, even if you just buy a bottle of water and come see us, we would still be happy, so as long as you have the intention, the traditional Chinese concept of filial piety.” When we can't walk any more or drive any more—that's what I'm really afraid of, when I can't buy things on my own. I don't like seeing the British elderly women pushing those walkers on the street. (P12, Text 11886,12984)

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<sup>10</sup> Filial piety is a major concept of Confucianism, which emphasizes the important virtue and primary duty of children to honour, respect, obey and care for one's parent and elderly family members. While there exists an array of religious beliefs in China, filial piety is common to all of them (Baker, 1979).

Akin to Western beliefs, the fear of losing the ability to function, to be independent in the future, and the fear of loneliness and losing family support is a grave concern. Hence, for many Chinese people, filial piety is crucial because it acknowledges the energy and hard work required by parents to raise children and recognizes the importance of being respected and honoured by them, as they get older.

According to Cultural Safety, health service provision should actively engage in learning important cultural beliefs and values. Family and filial piety are two intertwining concepts that are crucial in the Chinese belief system. As such, End-of-life care services must seek to understand filial piety and make a conscious effort to consider and include the immediate family in every aspect of the decision-making process.

## **Discussion**

This study attempted to explore and understand the beliefs, values, and practices of a select group of Chinese migrant women living in England when making end-of-life decisions and accessing end-of-life care. I strived to expand on previous research that focused on examining bereavement, spirituality, coping mechanisms and mental health, while addressing criticisms that have been raised about this research, namely, that it was implicitly guided by principles of Culturalism which infers that culture is a monolithic entity. Consequently, these data required reconceptualizing using a framework that acknowledged structural determinants of social and health inequities and the complexities that exist in people's lives, specifically those that are influenced by gendered roles and expectations. As such, I employed the Cultural Safety paradigm to gain a deeper understanding of how such complexities impacted end-of-life care decisions for Chinese women.

Firstly, with respect to accessing health care, the findings suggest that language and cultural differences hinder health service provision to immigrant Chinese women in the UK. The results reveal a strong indication for a need to redevelop and improve language and health information services, in particular the accessibility of Chinese interpreters that have strong health literacy skills in both English and in Chinese. Several participants reported that interpreters were available, but that they seldom committed to their appointments or were unable to translate the medical terms appropriately. In the UK, there are community service organizations such as Wai Yin that provide culturally specific services, such as English language support to Chinese people; however, it must be acknowledged that these organizations may not be financially and/or structurally equipped to cope with the demand (Dwyer & Brown, 2005; Zetter & Pearl, 2000).

Contemporary health care is often based on the assumption that health problems are individually located and experienced (Watters, 2001). Westernized constructions of health tend to locate solutions and place responsibilities at the individual level (Watters, 2001). This approach argues that ethnic minority groups carry with them the health issue and are therefore responsible in resolving the health problem (Watters, 2001). Often, these are persons in extremely vulnerable positions who are denied the means to take control of their health and of their life circumstances. According to Cultural Safety, the privileging of Western epistemologies and methods, and the excluding of Eastern approaches, beliefs and practices may be ineffective in addressing the underutilization of end-of-life services within Chinese groups (Cameron et al., 2010). For example, the findings indicated a conflict between: assimilating to British ways and sustaining traditional Chinese religious and spiritual practices and beliefs. Several participants highlighted the need to adopt British customs by changing religions (i.e. from Buddhist or Taoist beliefs to Christianity). The results suggest that there are those living in the UK that would prefer

to keep their traditional religious and spiritual beliefs but are unable to due to structural barriers such as the inaccessibility of Chinese temples.

The findings also suggest that Buddhist and Taoist beliefs, for some women, guided their personal thinking and influenced their day-to-day decision-making. Interestingly, these philosophies often interact with gender. For instance, one participant revealed that it is the moral duty and responsibility of Chinese women to respect and honour her husband and his parents because, “it is the Chinese way (P13, Text 10697, 11293).” Consequently, she must adopt her husband’s spiritual and religious traditions, even though these may go against her own personal beliefs. It is recommended that end-of-life strategies encourage health and social care providers to learn and understand Eastern religious and spiritual traditions, practices and beliefs, which may often enforce a particular way of thinking and decision-making.

Cultural Safety privileges the standpoint of women and emphasizes that it is important to capture their voices and provide a critical lens for interpreting gendered experiences (Anderson et al., 2009). In this study, the accessibility of health care and social supports and services, generally depended highly on English language capabilities. Often, the effects of gender may prevent some Chinese women from learning English. For example, it was indicated by one participant that her marital and maternal responsibilities, prevented her from taking English courses. She revealed having to wait until her children reached a certain age before she could commit to learning English. This gendered pathway contributes to social isolation, exclusion and marginalization for Chinese women living in the UK. When considering culturally-safe practices within the extended realm of healthcare provision, it is crucial to consider the effects of gender on the accessibility of health care and social supports, which impacts health outcomes for ethnic minority women.

Cultural Safety strives to incorporate and examine interlocking effects of other social and health determinants. Specific to Chinese women living in the UK, these may include the role of age or generation, pre-arrival histories and post-arrival challenges, political influence, dedication and/or obligation to traditional religious or spiritual beliefs, acculturation and socioeconomic status. Thus, within the context of end-of-life care research, this paradigm recognizes that access to and uptake of end-of-life services cannot be simply attributed to cultural identity but that it may be attributed to a complex network of intersecting factors such as those stated above. For example, according to filial piety, Chinese families are expected to care for and support one another according to a hierarchy of age. In particular the young are expected to respect and care for the elders until they pass on. Several participants noted that most Chinese people would prefer to die at home surrounded by their family members. It is important to acknowledge that this preference may be similar to Western notions; however, for Chinese people, often, this is not simply a wish or a preference, but rather an expected duty of the younger generation (Baker, 1979). Failure to meet these expectations may bring shame upon the family.

There are positive and negative outcomes associated with filial piety because its principles can be neglected and/or misconstrued. This depends on the combined effects of culture, gender, socioeconomic status and age. For instance, there is a common perception that Western culture prides itself on individualism, independence and libertarianism and according to one participant, “Westerners don’t understand the concept of family (P13, Text 10697, 11293).” Presumably, in Western societies, the concept of filial piety is more or less neglected or held in less esteem. Hence, either the aging parent or the government assumes caregiving responsibilities. This may lead to a myriad of detrimental mental and physical health outcomes such as loneliness, depression, physical injuries and even death. In furthering this point, I have

often witnessed “British elderly women pushing those walkers on the street (P12, Text 11886,12984)” having lived in the UK.

Interestingly, there are layers of drivers of inequity that can be extracted from this scenario, such as age, gender, culture and socioeconomic status. To contextualize this point, it is socially acceptable to have aging parents live on their own within nursing or seniors’ homes whether they choose it or not; however, seniors’ homes have varying levels of quality or standards such as having a shared accommodations as opposed to having their own suite. In this instance, access to end-of-life care may be inequitable based on an older person’s socioeconomic status. However, another layer of inequity, such as gender can be applied, which locates older women at a point of further disadvantage. Older women from Western societies may need to provide care for her aging spouse in addition to caring for herself and addressing her own health issues associated with age and gender.

Conversely, older women from Eastern societies may have assistance or support from her family such as her children or even her grandchildren. Often, Chinese families stay living together within the same household regardless of age. It is important to highlight that Eastern and Western cultures juxtapose shame when it comes to living or leaving your family. In Chinese culture, it is considered shameful to leave your family and neglect your duties to honour, respect, obey and care for your elders, however, in Western culture, it is considered shameful to live at home past a certain age. This idea stems back to filial piety and contextualizes this concept within Eastern societies and reveals how the principles within this context can be misconstrued to contribute to disadvantages that different Chinese women may experience due the interlocking effects of gender, age, culture and socioeconomic status. For example, the

meaning behind the principles of filial piety may hold different value and/or be applied differently if you are a Chinese man or woman.

According to Participant 3, “In China we have more children taking care of them, mostly daughters or daughter-in-laws (P3, Text 4512,4844).” The key point from this quote is that a Chinese man may be expected to honour, respect, obey and care for his parents and in-laws by allowing them to live in his home and provide financial support, but it is more than likely that he is not expected to spend hours making them congee, washing their sheets and/or changing their bed pans, whilst caring for the children, cleaning the house, working a part-time job and trying to learn English at the same time. Conversely, if the husband brought home a substantial income, the burden of having a multitude of tasks experienced by the wife would be alleviated through the hiring of help. Incidentally, often, the help would most likely be other Chinese women.

The interlocking effects of gender, age, and socioeconomic status, together with the culturally embedded concept of filial piety shape the position of Chinese women. Future research should expand on this knowledge through the voices of a larger group of Chinese women living in various Eurocentric societies such as Canada, US and Australia. It is important for future work to draw on differences and similarities of lived experiences to continuously improve and redevelop end-of-life strategies for Chinese women living in Western societies.

Overall, this study has emphasized the importance of understanding the values, beliefs, practices, social norms associated with philosophical and religious and/or spiritual concepts or ideas (such as Buddhism and Taoism) that shape Chinese culture. A key concept voiced by participants is filial piety. It is important for health policymakers and health care practitioners and service providers when restructuring or redeveloping end-of-life care to understand and acknowledge that Chinese families are expected to care for and support one another. Chinese

people have been characterized as having strong family values that foster intense interdependent family ties, high filial expectations, and strong intergenerational cohesiveness. Many participants revealed that Chinese family members, including spouses, children, grandchildren, and extended family members, are devoted to caring for their elderly relative. Equally important, is the recognition that this type of responsibility is often gendered.

Currently, this is the only study that examines end-of-life care among a group of Chinese migrant women in the UK by applying a Cultural Safety paradigm. However, this study is not without limitations. Firstly, it must be noted that the sample size was small and consisted of predominantly younger, more marginalized Chinese migrants, primarily because Wai Yin's services are designed to cater to underserved populations. As such, the findings and recommendations for service delivery may not be generalizable to all Chinese women living in the UK. Older Chinese migrant women and those from previous generations may have different experiences and needs. Secondly, principles of grounded theory were used only as an analytic tool to summarize the data; grounded theory was not used for theory development.

In terms of strengths, Cultural Safety has been demonstrated in this paper as a useful framework to guide research, programmatic efforts and new public policy initiatives to help improve services and supports for ethnic minority populations. It requires an understanding of the differential power dynamics between the service provider and the service user. At the very least, it is recommended that health service provision, programmatic efforts and strategies at the primary care level be guided by principles of Cultural Safety.



## Concluding Statement

End-of-life care decisions can be an arduous, painful and uncomfortable process particularly for persons living in a new cultural setting. For Chinese populations living in the UK, end-of-life care requires attention to acculturation, in particular, Western versus Eastern beliefs on religion, spirituality, burial practices and provision of care and the availability of culturally-specific care, all of which encompass issues relating to gender. In this paper, cultural safety was applied as a driver to explore in depth end-of-life care perspectives from Chinese people living in the UK; employed as an interpretive lens when analyzing the data, and used to make recommendations for future research, policy and health care provision initiatives. Findings indicated that gendered responsibilities in health care provision and women's agency associated with the constraints of marriage and culturally embedded gendered expectations on personal choice to be the key issues.

## Critical Reflection

As a public health researcher, I needed to be aware that I was entering a community that was more vulnerable, less privileged and underserved compared to the rest of the British population due to post-colonial practices and ideologies. I struggled immensely in dealing with the fact that I, too, embodied such characteristics having grown up in Canada, having acquired predominantly white friends and having adopted Western practices and beliefs. Participants of the study viewed me as an outsider because of my North American accent and my pseudo-Canadian Chinese dialect. Even though I am extremely proud of my cultural heritage, I needed to accept that some Chinese people would not see me as another Chinese person that they can trust.

To resolve this issue, I was advised by my mentors and supervisors to try and conduct my research by using a post-colonial lens and interpret the results by applying a Cultural Safety paradigm. In doing so, I recognized the different histories that shaped our views as well as the power dynamics, which existed between myself, the community staff and, the service-users. More importantly, I was cognizant of my social location (Chinese-German-Canadian woman raised in a privileged society) compared to the participants (immigrant/refugee women – those with status who were trafficked to the UK and those without status who were exploited by UK employers). By incorporating an equity-based theoretical perspective, I was able to conduct my research in a more caring and ethical way.

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## Appendix I: Frequency Table of Codes

| Code (N=69)  | Total |
|--|-------|
| British Spouse   | 2     |
| Poor English skills  | 2     |
| GP   | 13    |
| Interpreter  | 21    |
| Communication barrier  | 6     |
| Death of family member   | 30    |
| Cause of death   | 1     |
| Events leading up to death   | 3     |
| Providing care   | 6     |
| Place where remaining days are spent                                       | 34    |
| A dying person's agency  | 2     |
| Becoming British   | 5     |
| Coming to England  | 2     |
| Traditional Chinese end-of-life customs and beliefs                        | 12    |
| Importance of paying respect to the dead                                   | 3     |
| British funeral beliefs and practices                                      | 14    |
| Cremation  | 12    |
| Chinese funeral practices  | 28    |
| Chinese burial laws  | 6     |
| Freedom of choice  | 4     |
| Buddhist practices and beliefs   | 13    |
| Reward and punishment in the afterlife                                     | 2     |
| Traditional religious and spiritual worship practices and beliefs          | 25    |
| Christianity   | 22    |
| Western religious practices and beliefs                                    | 5     |
| Difference between Western and Eastern religious practices and beliefs     | 6     |
| Personal religious or spiritual practices and beliefs                      | 34    |
| Accommodating for Chinese religious and or spiritual practices and beliefs | 12    |
| Better use of money  | 6     |
| Access to mental health services   | 8     |
| Manchester Chinese temples   | 3     |
| Access to Chinese temples and religious services                           | 15    |
| British health care services   | 12    |
| Manchester's Chinese support and services                                  | 4     |
| English language services  | 2     |
| Gender differences in religious beliefs                                    | 6     |
| Place of Origin  | 12    |



|   |    |
|---|----|
| Barriers to accessing health care                         | 5  |
| Disclosure of death or serious illness                    | 16 |
| Beliefs about the afterlife                               | 18 |
| Children  | 4  |
| Spoken language   | 11 |
| Persons or bodies responsible for providing care          | 29 |
| God and the afterlife are limited within national borders | 3  |
| Chinese superstitions                                     | 5  |
| Dreams about the dead                                     | 1  |
| Funeral preference  | 3  |
| Bereavement services                                      | 4  |
| Accepting death   | 2  |
| Dying wishes  | 13 |
| Years lived in England                                    | 7  |
| Learning English  | 3  |
| Husband or partner  | 5  |
| Duties of a Chinese woman                                 | 5  |
| Length of time since death of family member               | 2  |
| Filial duty   | 16 |
| Treasuring loved ones when alive                          | 1  |
| Aging and wisdom  | 1  |
| Coping with grief   | 4  |
| Family religious or spiritual practices and beliefs       | 14 |
| Husband's religious spiritual practices and beliefs       | 2  |
| Family disagreements on religion                          | 3  |
| Financial burden  | 5  |
| Government supports                                       | 12 |
| Living in Britain   | 7  |
| Living in China   | 10 |
| Cultural revolution                                       | 1  |
| Mental health services beliefs                            | 5  |
| Maintaining health whilst alive                           | 1  |

## Appendix II: Semi-structured Interview Questionnaire

Wai Yin Chinese  
Women Society

street address  
66-68 Swan Street,  
Manchester  
United Kingdom  
M4 5JU  
Tel: 0161 833 0377  
Fax: 0161 839 3335  
Email: info@waiyin.org.uk

### Interview Questionnaire 訪問問卷

**Coping with bereavement: Exploring psychological well-being, religious practices and beliefs and support needs of Manchester's Chinese population**

**研究題目:** 應付臨終或喪痛: 探討曼徹斯特的中國人在心理健康上, 宗教習俗, 信仰和支持的需要.

**Researchers 研究員:**

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**Research Purpose 研究目的:**

The purpose of this study is to investigate the coping mechanisms of Manchester's Chinese community when encountering end of life issues. Specifically, the investigators would like to explore the mental health, religious practices and beliefs and any services and support systems needed by this community to cope with bereavement.

這個研究目的是探討華人社區對臨終或喪痛的處理, 尤其探討曼徹斯特的中國人在心理健康上, 宗教習俗, 信仰和社區支持系統的需要.

|                             |                          |
|-----------------------------|--------------------------|
| <b>Participant ID Code:</b> | _____                    |
| <b>Study Location:</b>      | _____                    |
| <b>Interview Location:</b>  | _____                    |
| <b>Date:</b>                | ____ / ____ / ____       |
|                             | Day      Month      Year |
| <b>Time:</b>                | ____ : ____ AM / PM      |
| <b>Interviewer's Name:</b>  | _____                    |

## Part I. Socio-demographics

**Q1** gender 性別

- Male 男
- Female 女

**Q2** What is your date of birth (DOB)?  
是你的出生日期什麼?

\_\_\_\_ / \_\_\_\_ / \_\_\_\_  
Date 日    Month 月    Year 年

Refused

**Q3** What is your postal code?  
您的郵政編碼是什麼?

\_\_\_\_ / \_\_\_\_

Refused 拒絕

**Q4** What language do you speak at home?  
你在家裡說什麼語言?

- English 英文
- Cantonese 粵語
- Mandarin 國語
- Hakka 客家語
- Fukien 福州語
- Other 其他 \_\_\_\_\_

Refused 拒絕

**Q5** How long have you lived in the UK?  
你住在英國有多久?

\_\_\_\_\_ years. 年

- Refused 拒絕
- Yes 是

**Q12** What part of China are you from?  
你從中國哪一個城市來的?

\_\_\_\_\_  
\_\_\_\_\_.

Refused 拒絕

## Part II. Open-ended Questions

**Q13** Are you currently registered with a GP? 您最近註冊全科醫生?

- If no, why not? 如果沒有，為什麼不呢?

**Q14** Are there interpreters offered at your GP?

您是否有翻譯在家庭醫生提供?

- If no, why  
如果沒有，為什麼

**Q15** Do you have any experience of death in the family?

**Prompt: when where, how.**

你有沒有經歷：家庭成員死亡

- Death in the family (England vs. China)
- Attended funeral services in England? China?
  - What are the differences
- Bad news from the doctor – negative diagnosis  
壞消息從醫生 - 負診斷
- Who is allowed to know the diagnosis  
誰可以知道診斷
  - Should the person died at home? If not, where 應不應該死在家裡，如果不然應在何處?
  - What is end of life care in Chinese customs 中國傳統對臨終的處理

**Q16** What are your religious beliefs and practices?

你有什麼宗教的信仰和習俗?

- Specifically what religion 具體是什麼宗教
- Practices/traditions conducted when some dies in the family  
實踐 /時進行一些傳統家庭中死亡
- What is believed to happen when someone dies (i.e. afterlife)  
什麼被認為是發生在人死後 (即來世)

**Q17** Do you know of any culturally appropriate funeral services available in the UK? 你知道的任何文化上適當的殯儀服務可在英國?

- Religious death services 宗教死亡服務
- Culturally competent grief counseling / community groups
- Religious temples in the area  
在該地區宗教寺廟

**Q18** What services do you feel are required or should be offered in the UK to help Chinese people cope with bereavement?

你覺得什麼樣的服務需要或應提供在英國，以幫助中國的人們應付喪?

- Support groups for terminal illness diagnoses in  
支援小組在診斷為絕症
- Mandarin/Cantonese 普通話/粵語
- Culturally appropriate funeral services (i.e. Taoist, Buddhist)  
文化上適當的殯儀服務 (即道教，佛教)
- Community prayer groups

**Q19** What are your expectations in preparation of death?

- Where would you like to die (i.e. at home or in hospital; best place to die)
- What sort of burial service would you like
- Would you like to be sent back to China
- End of life wishes

**Q20** Do you expect your children to look after you when you are older?

- When do you think your children should start looking after you (under what conditions – i.e. terminal illness)?
- Do you think it's a Chinese tradition; part of the culture?
- Is this expectation same in England?
- Would you expect this more if you lived in China?
- How is it different in England?
- Responsibility of government or the children?