



**Understanding Palliative and hospice service needs of
East Asian Peoples in Christchurch:
With Communities, for communities**

BIBLE LEE KATE REID

2012

Disclaimer

Published research reports, which result from studies endorsed by Partnership Health Canterbury are produced by independent researchers. The content of the reports and the opinions expressed by the author/s should not be assumed to reflect the views, opinions or policies of Partnership Health Canterbury. Information within the report may be freely used provided the source is acknowledged. This is subject to the material being reproduced and attributed accurately and not being used in a misleading context. Every effort has been made to ensure that the information in this report is correct. Requests and enquiries concerning the reproduction on information for any purpose other than personal use, requires the permission of the authors.

Suggested Citation

Lee, B., & Reid, K. (2012) Understanding palliative and hospice needs of East Asian peoples in Christchurch: With communities, for communities. Christchurch: Partnership Health Canterbury, 2012

Acknowledgement

The principle researcher would like to acknowledge Partnership Health Canterbury for supporting this research project.

The principle researcher would also like to acknowledge and thank Dr. Blackhall for allowing the original questionnaire from the 1995 study to be viewed, adapted and utilised. It has been a privilege. Thank you.

Special thanks must go to the participants of the study. This project would not have been possible without you.

Special gratitude must also go to the Canterbury Society of Japan for your tremendous support. Thank you especially to Mrs. Chie Brook for your wonderful communications.

Thank you also to Christchurch Chinese church and the members of Cedar and Evergreen group.

Thank you also to the Christchurch Korean Society and especially to the Christchurch Korean Presbyterian Church. Thank you very much to Mr. Na Gyung Hyun and to the members of your group. Thank you also to the Christchurch Korean School and Han Yang supermarket.

My gratitude must also go to the following people: Wayne Reid, Ray Kirk, Philippa Drayton, Jenni Ravenscroft, Pat Coope, Kim Lee, Song Eugene, Yoon Judy and Cynthia Mo, Jenny Han.

Last but not least, thank you to a dear friend for your memory, may many families like yours learn that help is available in this country for those who grieve.

List of figures

Figure		Page
1.1	Asian ethnic groups in Christchurch City 2006	11
4.1	Area of residence for the Japanese respondents (n=100)	18
4.2	Number of years lived in New Zealand by the Japanese respondents (n=100)	19
4.3	Age groups of the Japanese respondents (n=100)	19
4.4	End-of-life-care services: Place of preference for the Japanese respondents	22
4.5	Area of residence for the Chinese respondents	23
4.6	Number of years lived in New Zealand by Chinese respondents (n=50)	24
4.7	Country of birth by Chinese respondents (n=50)	24
4.8	Age groups of the Chinese respondents (n=50)	24
4.9	Key factors considered important for the Chinese respondents, should they receive palliative or hospice services in New Zealand	26
4.10	Area of residence for the Korean respondents (n=56)	28
4.11	Number of years lived in New Zealand by the Korean respondents (n=56)	29
4.12	Age groups of the Korean respondents (n=56)	29
4.13	End-of-life-care services: Place of preference for the Korean respondents	32

Contents

Disclaimer.....	1
Acknowledgement	3
List of figures.....	4
EXECUTIVE SUMMARY	7
Background.....	7
Research methods.....	7
Key Results	7
Section 1: INTRODUCTION.....	8
1.1 End of Life services: Palliative care, Hospice services	8
1.2 Culture.....	8
1.3 Positioning palliative care: The Global context	9
1.4 The New Zealand context: Asian peoples and palliative needs	10
1.5 Asian peoples in Christchurch: Demography.....	11
Section 2: OBJECTIVES	12
Section 3: METHODOLOGY.....	13
3.1 Research paradigm.....	13
3.2 Ethics.....	13
3.3 Research method: Self-complete questionnaire	14
3.4 Research process.....	14
<i>Japanese</i>	15
<i>Chinese</i>	15
<i>Koreans</i>	16
3.5 Data Analysis	16
Section 4: RESULTS.....	17
4.1 Introduction	17
Japanese	18
Background information	18
Awareness of palliative and hospice services available in New Zealand	20
Interest in palliative and hospice services	20
End of life decision making.....	21
Place for end-of-life services: Preferences	22

Chinese	23
Background information	23
Awareness of palliative and hospice services available in New Zealand	25
Interest in palliative and hospice services	25
End of life decision making.....	26
Place for end-of-life services: Preferences	27
Koreans	28
Background information	28
Awareness of palliative and hospice services available in New Zealand	30
Interest in palliative and hospice services	30
End of life decision making.....	31
Place for end-of-life services: Preferences	32
4.2 Summary	33
Section 5: DISCUSSION	34
5.1 Introduction	34
5.2 Background	34
5.3 Awareness of palliative and hospice services available in New Zealand	35
5.4 Interest in palliative and hospice services	35
5.5 End of life decision making	36
5.6 Place for end-of-life services: Preferences.....	36
5.7 Further recommendations.....	38
A. <i>Policy levels</i>	38
B. <i>Local health organisations</i>	38
C. <i>Ethnic communities</i>	39
5.8 Limitations and strengths	39
5.9 Conclusion.....	40

EXECUTIVE SUMMARY

Background

Palliative care may be defined as a holistic form of health service that aims to improve the quality of life of patients and friends, when faced with problems associated with life-threatening illnesses (World Health Organization, 2012). Hospice care is often referred to as a model of palliative service across western countries.

The New Zealand population is changing. It is diversifying. It is also ageing. While it is commonly perceived that the Asian population has a younger age structure (Statistics New Zealand, 2009, p. 12), statistics show that that Asian peoples will comprise the second largest share of the 65 years and over cohort in New Zealand over the next decade (Statistics New Zealand, 2009, p. 17). Asian peoples are ageing. The young migrants from the 1980s and 1990s influx are also ageing.

Attitudes and beliefs associated with dying, death and end of life care can be different across different cultural groups (Blackhall, Murphy, Frank, Michel, & Azen, 1995). However, research about the palliative and hospice needs of minority groups in New Zealand remains scarce.

Research methods

The Ethnicity and Attitudes Toward Advance Care Questionnaire, originally by Blackhall (1995) was adapted and translated. The self-complete questionnaires were distributed to Japanese, Chinese and Korean residents of Christchurch. The distribution of the questionnaires involved an active participation from members of the Japanese, Chinese and Korean communities.

Key Results

195 questionnaires were returned. Results from the study revealed that Japanese, Chinese and Korean respondents were most likely to report little familiarity with the existing palliative and hospice services in New Zealand. The East Asian migrants were also most likely to report not knowing about the existence of related services, such as free translation services at hospices. However, the East Asian migrants were most likely to report high levels of interest in receiving more information about palliative and hospice services.

Section 1: INTRODUCTION

1.1 End of Life services: Palliative care, Hospice services

Palliative care may be defined as a form of health service that aims to improve the quality of life of patients and friends, when faced with problems associated with life-threatening illnesses (World Health Organization, 2012). It is also a holistic form of health care that recognises prevention and relief from pain and suffering, and considers the importance of psychological, social and spiritual aspects of patient care (Murray, Boyd, Sheikh, Thomas, & Higginson, 2004). Hospice services are often understood as a form of palliative service across Western countries (Bosma, Aplan, & Kazanjian, 2010).

In New Zealand, people may be referred to hospice services while undergoing treatments for illnesses, not only at the very end of life (Hospice New Zealand, 2012a). However, people are usually referred to hospices at a time when it is acknowledged that the illness is incurable (Hospice New Zealand, 2012b). Hospice New Zealand defines hospices as not limited to just buildings. Rather, *hospice* has been defined as a philosophy of care that believes caring for people should not be limited to addressing the physical needs, but also the emotional, spiritual and importantly, cultural needs (Hospice New Zealand, 2012a).

1.2 Culture

Perspectives associated with terminal illnesses, death and dying vary across countries. Such perspectives can also vary across different cultures within the same country (Voltz, Akabayashi, Reese, Ohi, & Sass, 1998). A collection of shared meanings, values and modes of interacting with others, culture determines how people view and make sense of the world (Krakauer, Crenner, & Fox, 2002, p. 184). On everyday basis, cultures are conceptualised, embedded and applied (Baker, 2002). Cultures influence peoples' communication methods, expression of emotions and decisions making. Cultural beliefs can also influence peoples' reactions to terminal illnesses and choices regarding end-of-life-care (Werth, Blevins, Toussaint, & Durham, 2002).

1.3 Positioning palliative care: The Global context

Worldwide, caring for terminally ill patients have been part of the human history (Sheehan & Forman, 1996, p. 2) . However, it is only within the last few decades that the movement for modern palliative and hospice services began. Even until the early 1950s, the focus of health care across western countries was on curative treatment (Clark, 2007). At best, patients diagnosed with a terminal illness such as cancer, were told nothing more could be done (Clark, 2007, p. 431). However, a major political phenomenon would result in a shift of this paradigm: World War II. With a rapid rise of terminally ill patients, the notion that the incurable should be left untreated would be quickly challenged (Sheehan & Forman, 1996). With a growing concern that, “the fact...palliative treatment is not understood, and hospitals appear to be trying to cure all their patients and failing...” (Aitken-Swan & Paterson, 1955, p. 627), studies on the psychosocial aspect of caring for the terminally ill would expand.

The 1960s will be remembered as the era where research on truth-telling and bereavement support first expanded across Britain and the United States (Brauer, 1960). However, the 1990s was also a significant era for the global development of palliative and hospice services. During the 1990s, many western countries found themselves facing another major social phenomenon: immigration and multicultural populations (Crawley, 2005). Gradually, it would be noted that while ethnic communities were rapidly increasing, the statistics of those utilising the health services did not reflect this social shift (Stevens & Cousineau, 2007). This would lead to a growth in researches worldwide, on improving such situation. Since the 1990s, there has been a growing awareness on the importance of promoting cultural competence of health professionals and communications with ethnic communities have rapidly expanded across North America, the United Kingdom and Europe (Blackhall et al., 1999; Clark & Centeno, 2006; Cleeland, Gonin, Baez, Loehrer, & Pandya, 1997; Fallowfield, Jenkins, & Beveridge, 2002; Randhawa, Owens, Fitches, & Khan, 2003). In particular, research about attitudes on diagnosis of terminal illnesses; and utilisation of end of life care services has generated much interest (Blackhall, et al., 1995; Thomas, Wilson, Justice, Birch, & Sheps, 2008).

Australia has also gained much awareness about the importance of promoting culturally competent palliative care since the 1990s (Centre for cultural diversity in ageing, 2010b, p. 81; Cleeland, et al., 1997). Following the commissioning by national and local agencies for a report for multicultural

palliative care guideline for Australia during the late 1990s (Taylor & Box, 1999), a national guideline for multicultural palliative care has been developed (Centre for cultural diversity in ageing, 2010b). Multilingual palliative care resources has been printed across 21 languages(Palliative Care Australia, 2011). As Australia continues to grow as a multicultural nation, stakeholders at national, local and community levels are being encouraged to collaborate, to continually promote culturally competent palliative care (Centre for cultural diversity in ageing, 2010b; Ethnic communities' council of Victoria Inc, 2012; Palliative Care Australia, 2011).

1.4 The New Zealand context: Asian peoples and palliative needs

The New Zealand population is also changing. It is diversifying. It is increasing in numbers. It is also ageing. It has been predicted that over the next decade, all four major ethnic groups in New Zealand (European, Maori, Pacific and Asian) will grow in numbers, but also experience a rise in the median age (Statistics New Zealand, 2009, p. 4). While it is commonly perceived that the Asian population has a younger age structure (Statistics New Zealand, 2009, p. 12), statistics show that that Asian peoples will comprise the second largest share of the 65 years and over cohort in New Zealand over the next decade (Statistics New Zealand, 2009, p. 17). By 2026, it has been shown that the number of Asian peoples aged 65 years and over is expected to be five times the size it was during 2006 (Statistics New Zealand, 2009). In addition, those aged 40-64 years is expected to account for 30 percent of the total Asian population over the next decade (Statistics New Zealand, 2009, p. 17). Asian peoples are ageing. The young migrants from the 1980s and 1990s influx are also ageing. However, specific guidelines on how the palliative and hospice needs of this diverse population may be met, is lacking in New Zealand (Ministry of Health, 2001, 2009).

Attitudes and beliefs associated with dying, death and end of life care can be different across different cultural groups (Blackhall, et al., 1995). However, research about the palliative and hospice needs of minority groups in New Zealand remains scarce (Schwass, 2005; Windsor et al., 2008). Literature shows that although a research about diverse groups' perspectives on death and dying was first commissioned by the Ministry of Health during 1987(Schwass, 2005), further research did not follow until 2005. This has not been followed by further studies on specific ethnic groups, nor minority groups' lack of use of end-of-life services. Failure by ethnic groups to utilise health services though, should not be taken to mean that services are not needed (Payne, Chapman, Holloway, Seymour, &

Chau, 2005, p. 111). Rather, eliciting the views of such groups in designing and implementing culturally appropriate services is needed to contribute to equity in health (Payne, et al., 2005). With sporadic evidence of research suggesting that New Zealand health professionals and Asian migrants are already facing numerous challenges, research about Asian peoples' end-of-life service needs is urgently needed (Bray & Goodyear-Smith, 2007; Hathaway, 2009; Windsor, et al., 2008).

1.5 Asian peoples in Christchurch: Demography

The Canterbury region represents 12 percent of the total New Zealand population, making it the second largest region in the nation by population size (Canterbury District Health Board, 2011, p. 15). Asian peoples have been reported to be the fastest growing population group in the region (Canterbury District Health Board, 2011, p. 15). Of the total Asian population in the Canterbury region, approximately 95 percent resides within Christchurch city (Reid, 2009). The term *Asian* is used in New Zealand to refer to a diverse group of peoples (Ministry of Health, 2006). Within this diverse group, it has been found that three East Asian groups: Chinese, Japanese and Koreans constitute 72 percent of the total Asian population in Christchurch (Reid & Zhang, 2009, p. 5).

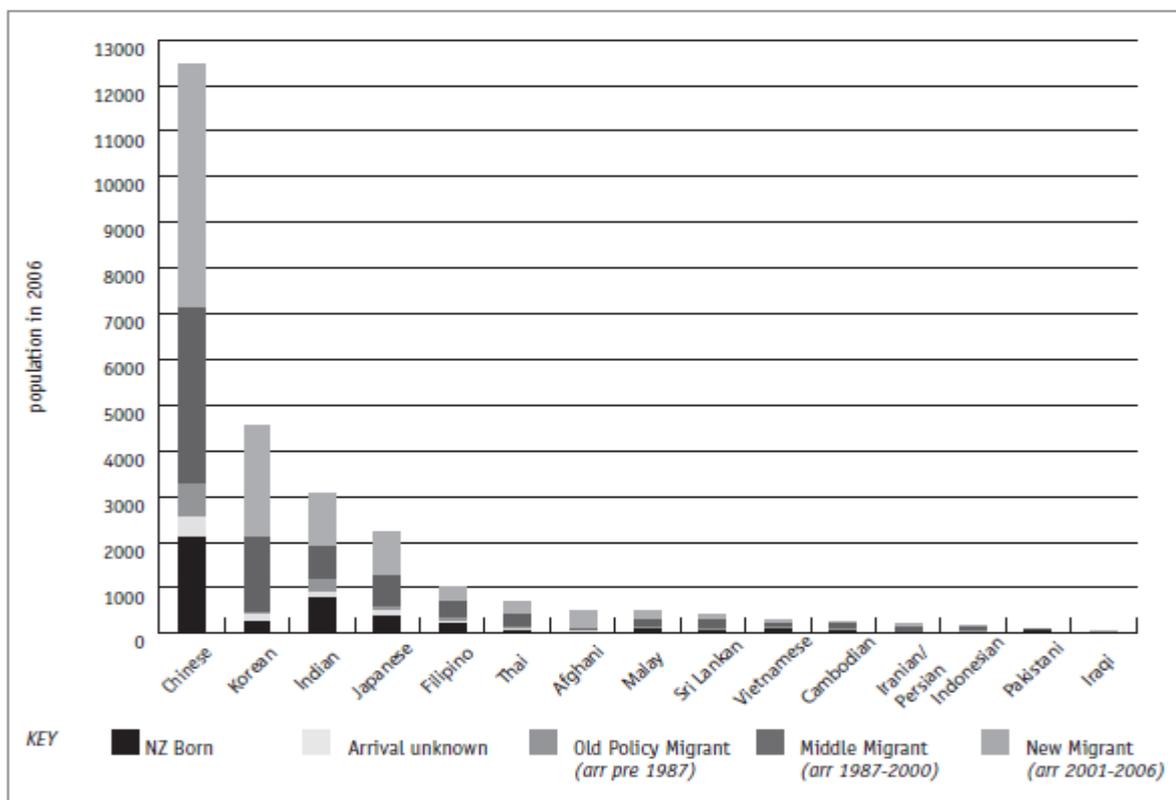


FIGURE 1.1 Asian ethnic groups in Christchurch City 2006 (Source: Friesen, 2008)

Section 2: OBJECTIVES

Guided by Reid & Zhang (2009), this study was limited to three predominant groups of East Asian background, residing in Christchurch. The overall aim of this research was to understand the perspectives of the Japanese, Chinese and Korean migrants about end-of-life health services. The specific objects were:

1. To gauge the migrants' awareness of palliative and hospice services available in New Zealand.
2. To gauge the migrants' interests of the existing palliative and hospice services.
3. To understand the migrants' perspectives on end-of-life decision making, including the communication of "bad news"; and the use of life sustaining technology.
4. To understand the migrants' preferences about where to receive end-of-life care services.

Section 3: METHODOLOGY

3.1 Research paradigm

Community profiling may be defined as a research means of describing the needs of a defined population, by directly involving the community (Hawtins & Percy-Smith, 2007, p. 5). Driven by the purpose of improving the quality of the life of the community, community profiling focuses on steering the research with an inclusive and participatory approach (Hawtins & Percy-Smith, 2007, p. 7).

Community profiling has the benefit of helping to build trust between the researcher and the community (Hawtins & Percy-Smith, 2007). The researcher is encouraged to directly consult with the community leaders for local information on existing community networks (Hawtins & Percy-Smith, 2007; Queensland Government, 2004, p. 43). This can help both parties to overcome suspicion, resulting in collection of a more extensive data (Hawtins & Percy-Smith, 2007, p. 37).

In community profiling, different research methods may be used to best meet the research objects, according to the appropriate social context (Queensland Government, 2004). Quantitative methods, including social surveys have previously been used to obtain consistent, extensive data about preferences for end-of-life care by different cultural groups across developed countries (Blackhall, et al., 1999; Blackhall, et al., 1995; Caralis, Davis, Wright, & Marcial, 1993; Voltz, et al., 1998). Social surveys have the advantage of allowing extensive data to be drawn from a large group of people. An important strength of social surveys is that it allows participants' anonymity to be preserved. The effect of interview bias is removed. Such factors can be important for research investigating questions of sensitive nature (Hawtins & Percy-Smith, 2007, p. 59). This may especially be so, when conducting research in smaller communities.

3.2 Ethics

The ethics approval for this study was received from the University of Canterbury Human Ethics Committee (re: HEC 2011/104/LR). Each survey sheet distributed was attached with an additional sheet containing written background information of the study and the contact details of the researcher.

3.3 Research method: Self-complete questionnaire

Permission was given by Blackhall (1995) to the researcher to adapt, translate and utilise the Ethnicity and Attitudes Toward Advance Care Questionnaire. Originally used in a pioneering study at California during 1995 (Blackhall, et al., 1995), this research instrument has previously been adapted for similar studies (Blackhall, et al., 1999). The original study by Blackhall (1995) has since been cited extensively by other researchers worldwide (Thomas, et al., 2008; Voltz, Akabayashi, Reese, Ohi, & Sass, 1999, p. 144; Voltz, et al., 1998). The Ethnicity and Attitudes Toward Advance Care Questionnaire by Blackhall (1995) was developed after an extensive review of anthropological and medical literatures and consultations with clinicians, anthropologists and other health professionals (Blackhall, et al., 1995, p. 820).

For the Christchurch study, the questionnaire was adapted and reviewed by a palliative physician, a former nurse, and the principle researcher. The questionnaire was then further reviewed by a former nurse aid, a nurse and a counsellor of Japanese, Chinese or Korean background. The questionnaire was then translated into Japanese, Simplified Chinese, Traditional Chinese and Korean. The Christchurch Japanese Society, a Chinese church and a Korean church were contacted to consult for most suitable translators. The final questionnaire was translated by the following: a former counsellor of Taiwanese-Chinese background; a nurse aid of Chinese background; and a former nurse aid of Korean background.

3.4 Research process

The translated questionnaires were distributed by three different means. The most appropriate distribution methods were chosen after consultations with members of the Christchurch Japanese Society and the Korean Society. Two Chinese societies in Christchurch were contacted between the period of December. 2011- January. 2012. However, contacts could not be established due to the festive seasons of Christmas and the Chinese New Year. Members of a large Chinese church were contacted and consulted instead. Several members of this church reported being members of the two Chinese societies.

Japanese

Between the period of December. 2011- January. 2012, extensive communication took place between a representative of the Japanese society of Canterbury and the researcher. After consultations between the representative and other leaders of the Japanese Society, it was advised that a paper copy of the translated questionnaire should be distributed to 350 households registered with the Society. The researcher was advised that this would allow both the members of a Japanese elderly social group and the wider households to participate. The questionnaires were distributed with a community newsletter printed by the Society. All questionnaires were distributed with an information sheet, and a self-stamped envelope. All questionnaires were numerically coded. Participant confidentiality was maintained in accordance with the conditions of the ethical approval obtained from the University of Canterbury Human Ethics Committee (re: HEC 2011/104/LR). No monetary incentive was offered.

Chinese

In the original study by Blackhall (1995), research took place at senior citizen centres, targeting four ethnic groups. However, this method could not be exactly replicated due to the different social context. Senior citizen centres are not found in Christchurch. Furthermore, New Zealand nursing homes and hospices currently remain underutilised by the Asian population (Hathaway, 2009). However, contacts were established with the leaders of two community social groups for the Chinese elderly. This took place between the period of December. 2011 - January. 2012. Communication with the leaders of the two social groups was established after contacting a Chinese church well known to the Chinese community of Christchurch. The questionnaires were previewed by leaders of the two social groups. Upon request, 50 paper copies of the questionnaires (Simplified or Traditional Chinese) were printed and distributed to the leaders of the two groups. The questionnaires were distributed at the groups' monthly social meeting. The questionnaires were distributed to both the members of the social groups; and their families. All questionnaires were distributed with an information sheet, and a self-stamped envelope. The distribution of the questionnaires was considerably delayed due to the festive activities of the Chinese New Year, where it was advised that discussions about death and dying are not culturally appropriate around such festive seasons. All questionnaires were numerically coded. Participant confidentiality was maintained in accordance with the conditions of the ethical

approval obtained from the University of Canterbury Human Ethics Committee (re: HEC 2011/104/LR).

No monetary incentive was offered.

Koreans

Through the ethnic liaison officer of Partnership Health Canterbury, the researcher was able to establish contact with a key member of the Christchurch Korean Society. Through this contact, the researcher was able to consult with the leaders of a community social group for the Korean elderly. Unlike the Chinese groups, the researcher was informed that those 65 years and over only, constitute the elderly social group. Upon invitation, the researcher was able to attend a meeting hosted by the Korean group to answer enquiries about the project. Upon invitation, paper copies of the questionnaire were distributed at the meeting to the elderly attending the meeting. In addition, the questionnaires were distributed by community leaders at the Korean language school and a Korean supermarket. This took place between December, 2011- February, 2012. In total, 90 copies of the questionnaires were distributed. All questionnaires were distributed with an information sheet, and a self-stamped envelope. All questionnaires were numerically coded. Participant confidentiality was maintained in accordance with the conditions of the ethical approval obtained from the University of Canterbury Human Ethics Committee (re: HEC 2011/104/LR). No monetary incentive was offered.

3.5 Data Analysis

Returned questionnaires were numerically coded. Data collected were entered into a spreadsheet using Excel, before being transferred into a Statistical Package for Social Sciences (SPSS) format version 19.0. The descriptive statistics included frequencies and percentages of responses. Chi-square was then used to further assess correlations between the respondents' cultural groups (Japanese, Chinese, Korean) and whether the respondents were more likely to rank religious leaders highly when needing to consult another party for end-of-life care. Chi-square test was also used to further assess relationships between the respondents' cultural groups (Japanese, Chinese, Korean) and whether the respondents thought information about diagnosis and prognosis of a terminal illness should be disclosed to families, in addition to the patient. An alpha level of $p < .05$ was adapted for all statistical tests (Santosh & Crampton, 2009, p. 261)

Section 4: RESULTS

4.1 Introduction

This section reports the results from a self-complete questionnaire completed during the period of December. 2011- February. 2012. The overall aim of this research was to understand the perspectives of Japanese, Chinese and Korean migrants on end-of-life health services, such as palliative and hospice services. Therefore, the migrants were first asked to indicate their level of understanding of palliative and hospice services in New Zealand. The migrants were also asked if they had used palliative or hospice services within New Zealand. In addition, the migrants were asked if they were aware of the existence of other related services (translation services, home visits by district nurses, bereavement support). The second objective was to gauge the migrants' interests of the palliative and hospice services. Therefore, the migrants were asked about their interest in receiving further information about palliative services. The migrants were also asked if they perceived palliative and hospice services to be useful for them and their families. In addition, the migrants were asked to describe why they may potentially be not interested in utilising palliative and hospice services in New Zealand. The migrants were also asked what key factors may be important for them, should they utilise palliative and hospice services. The third objective was to understand the migrants' perspectives on issues related to end-of-life decision making. Full disclosure of information to the patients is considered important in Western societies (Windsor, et al., 2008). However, some studies have shown that a full disclosure of news about diagnosis with a poor prognosis directly to the patients could be inappropriate for patients from Asian cultures (Blackhall, et al., 1995; Windsor, et al., 2008). Therefore, the migrants were asked about their attitudes toward disclosure of the diagnosis and prognosis of a terminal illness. In addition, the migrants were also asked about their views on the potential use of life sustaining technologies. The last objective was to understand the migrants' preferences about where they may like to receive end-of-life care services. Therefore, the migrants were asked should they or their family members be diagnosed with a terminal illness in New Zealand, where they would feel most comfortable being cared for.

Japanese

Background information

From a total of 350 questionnaires distributed, one hundred questionnaires (n=100) were returned. A summary of the respondents' locations are presented below (Figure 4.1). All of the respondents reported being born in Japan (n=100). Nearly half reported having resided in New Zealand between 11-20 years (n=53). A summary of the length of years lived in New Zealand is summarised below (Figure 4.2). The respondents were predominantly female (n=84). The questionnaires were most returned by those aged 41-50 years (Figure 4.3). Nearly a quarter of the respondents were aged between 51- 75 years (n=23). Majority of the respondents reported having a bachelor's degree (n=66).

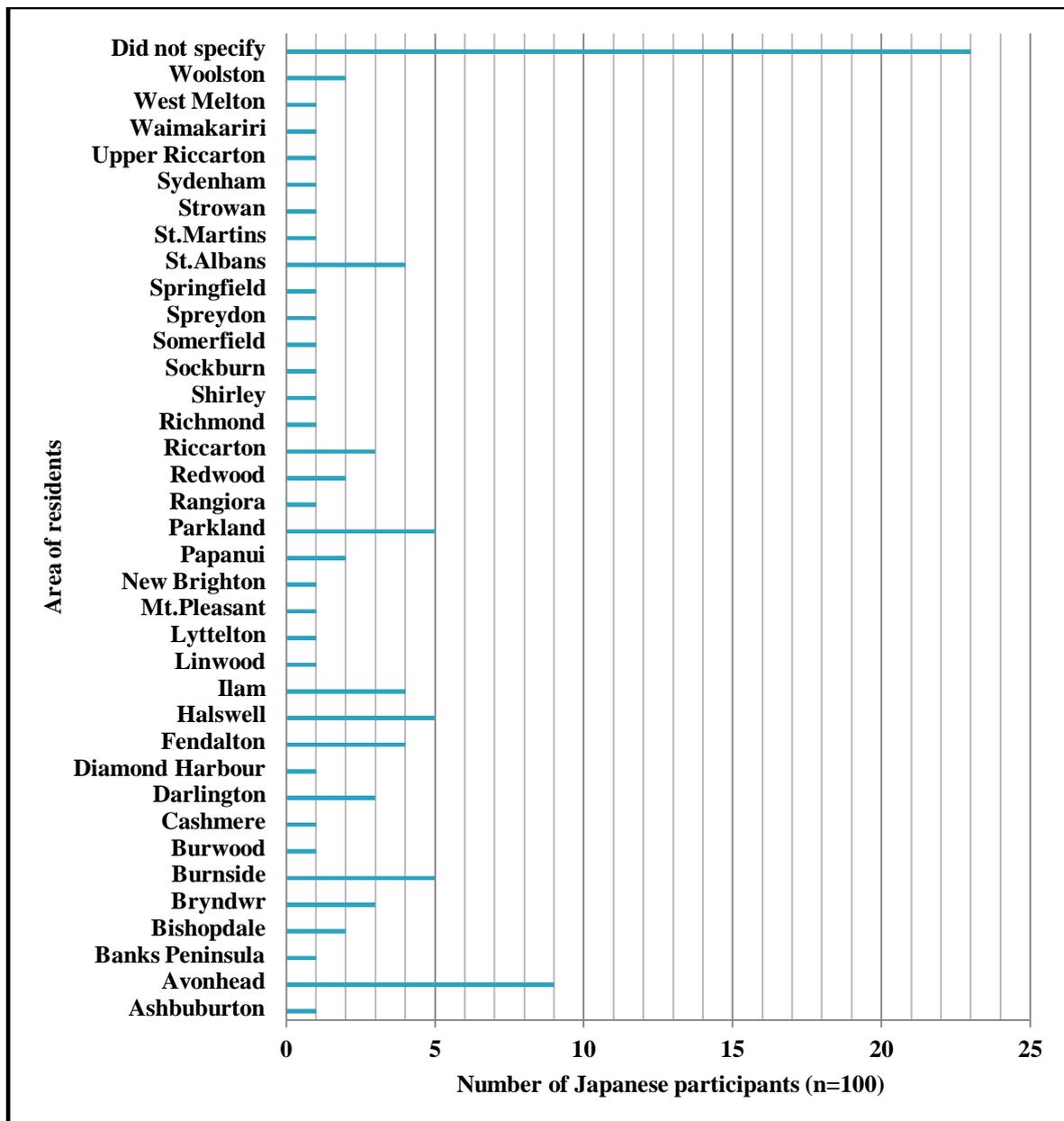


FIGURE 4.1 Area of residence for the Japanese respondents (n=100)

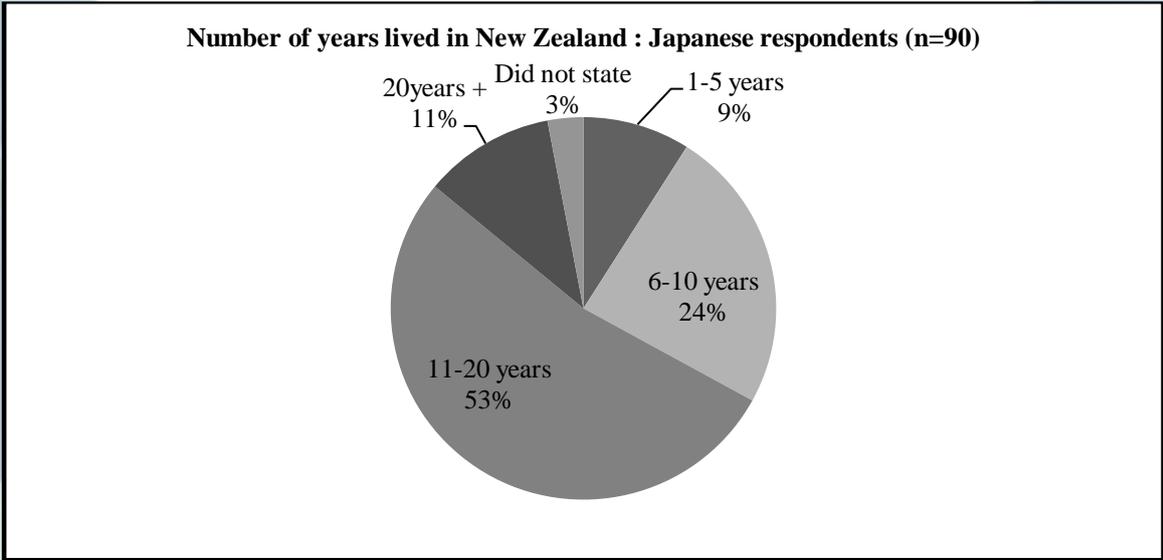


FIGURE 4.2 Number of years lived in New Zealand by the Japanese respondents (n=100)

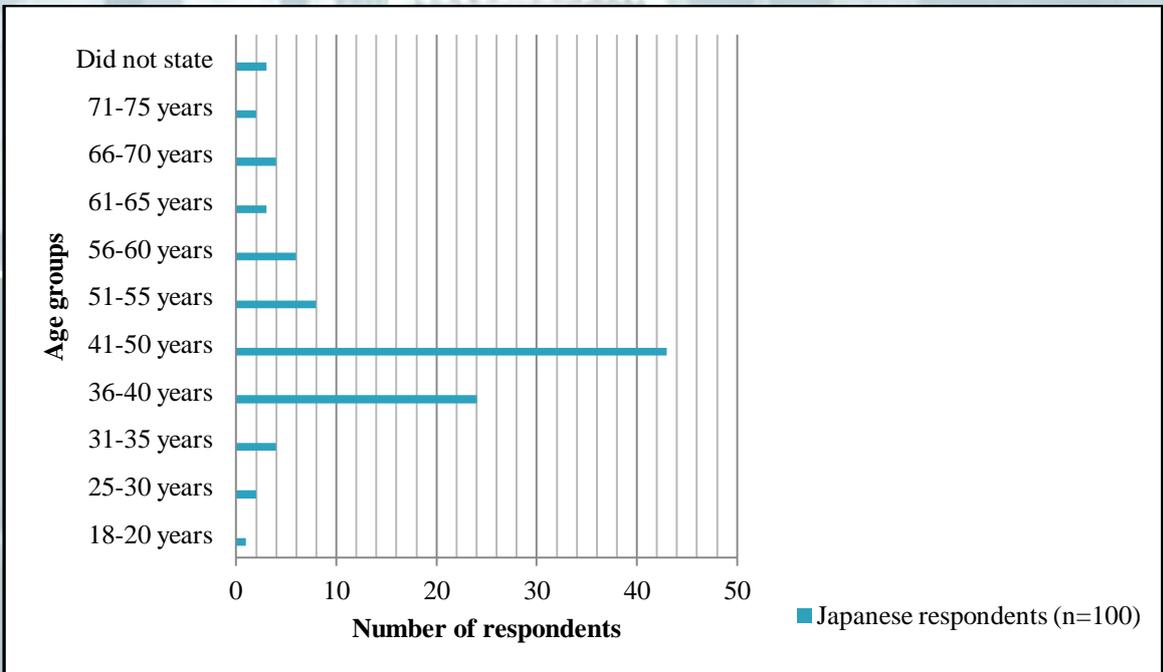


FIGURE 4.3 Age groups of the Japanese respondents (n=100)

Nearly all of the Japanese respondents (n=97) answered “yes”, when asked if they would like to receive information about palliative services. Not knowing much information was cited as the key reason as to why the respondent would not use palliative services.

Awareness of palliative and hospice services available in New Zealand

The first object was to gauge the migrants’ awareness of palliative and hospice services available in New Zealand. The Japanese respondents were most likely to indicate their level of understanding of palliative services in New Zealand as *not familiar* (n=69). The respondents were also most likely to indicate their understanding of hospice services in New Zealand as *not familiar* (n=72). The migrants were also asked if they were aware of the existence of other related services (translation services, home visits by district nurses, bereavement support). While the majority reported knowing the availability of free translation services at hospitals (n=66), the majority also reported that they did not know free translation services are also available at hospices (n=91). The majority of the respondents reported that they did not know that district nurses can be asked to visit people’s homes, should a patient be diagnosed with a terminal illness (n=67), nor that bereavement support services were available in New Zealand (n= 94).

Interest in palliative and hospice services

The second objective was to gauge the migrants’ interests of the existing palliative and hospice services. Nearly all of the respondents (n= 97) reported that they would be interested in receiving more information about palliative services in New Zealand. Most of the respondents thought that palliative services could be useful for themselves and their families (n= 96). All of the respondents thought that hospice services could be useful for them and their families (n= 100). When the Japanese respondents were asked to describe why they thought palliative services in New Zealand are currently under utilised by people of Asian backgrounds, the language barrier was the most cited factor (68%), followed by cultural barriers (12%) and religious differences (3%). The respondents could give more than one answer for this question. However, none of the Japanese respondents thought there is no need for palliative services for Asian peoples in New Zealand (n=100).

When asked why they may not want to use palliative and hospice services in New Zealand, the Japanese respondents were most likely to cite lack of information (38%), followed by being worried about communicating with the health professionals in English (31%). This was followed by being concerned that the health professionals may not understand the patients’ cultural values (12%) or

other (9%). Japanese respondents were least likely to be concerned that the New Zealand health professionals may not respect their religious beliefs (2%)..

The migrants were also asked what key factors may be important for them, if they were to receive palliative and hospice services in New Zealand. The respondents were asked to rank (1=most important; 6= least important) different factors. The total number of counts does not add up to 100, as the respondents were able to rank more than one factor as highly important or least important. The Japanese respondents were most likely to rank the following factors highly (value of 1 or 2 given): conversing with the health professionals in mother tongue (n=68), being offered information about translation services by the New Zealand health professionals (n=58). This was followed by a wish to have the health professionals respect the patients' culture (n=37). However, a wish for the New Zealand health professionals to be knowledgeable about the Japanese culture (n=27) or the traditional Japanese religion (n=4) was not as valued highly.

End-of-life-decision making

The third objective was to understand the migrants' perspectives on issues related to end-of-life decision making. Therefore, the Japanese migrants were first asked if a physician should disclose information about diagnosis of a terminal illness to the patient and their families. Most of the respondents thought that a doctor should directly inform the patients of the diagnosis (n=82). However, only a few of the Japanese respondents thought that their families should also be informed (n=15). The migrants were then asked if a doctor should disclose information about prognosis of a terminal illness. Most of the Japanese respondents thought that a doctor should directly inform the patients about an advanced, non-curable terminal illness (n=69). Nearly a quarter of the respondents thought that a doctor should also inform such prognosis to their families (n=25).

The migrants were then asked about their views on the potential use of life sustaining technologies. They were first asked whose decision it should be to decide whether or not a patient should be placed on such machines. The Japanese respondents most likely thought the decision should be solely up to the patient (n=67), followed by either families (n=48) or doctors (n=17). A small number of respondents reported other (n=3). They were then asked if they had to make a decision about the

potential use of life sustaining technologies, to whom they would turn to for advice. As in Blackhall's questionnaire (1995), 6 different people were listed. The respondents were asked to rank to whom they would be most or least likely to ask for advice (1=most likely; 6= least likely). The respondents could rank more than one person as highly likely or least likely to turn to for advice. The Japanese respondents were most likely to rank the following highly (value of 1 or 2 given): family members (89.8%), doctors (84.4%) followed by friends (21%). A smaller number of the respondents ranked other parties as highly (value of 1 or 2 given): a nurse (13.8%), a religious leader (5.5%) and a social worker (5.3%).

Place for end-of-life services: Preferences

The last objective was to understand the migrants' preferences about where they may like to receive end-of-life care services. The migrants were asked should they or their family members be diagnosed with a terminal illness in New Zealand, where they would feel most comfortable being cared for. The total does not add up to 100, as some respondents selected more than one place. The figure below summarise the findings (Figure 4.4). The Japanese respondents were similarly likely to select their own home, followed by hospitals and hospices. Only a few of the respondents selected age residential care facility.

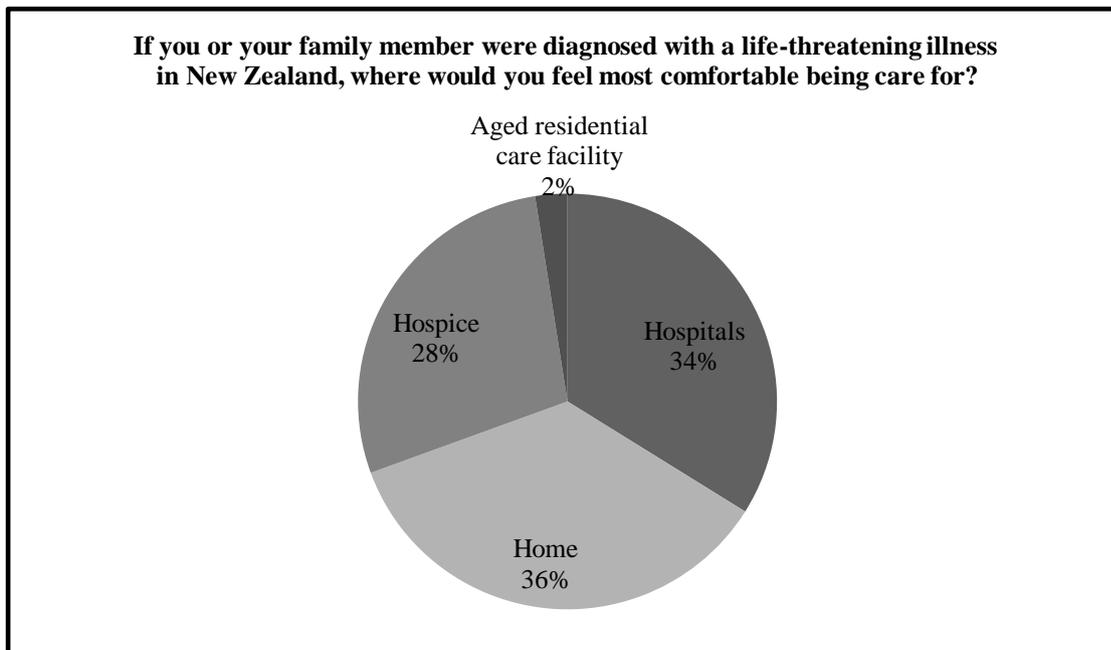


FIGURE 4.4 End-of-life-care services: Place of preference for the Japanese respondents

Chinese

Background information

From a total of 50 questionnaires distributed, thirty nine questionnaires (n=39; 78%) were returned. All of the respondents reported their location as within Christchurch city. A summary of the respondents' locations are presented below (Figure 4.5). All of the respondents reported being born outside New Zealand (n=39). Nearly half of the Chinese respondents reported years of residency in New Zealand as between 11-20 years (n=19; 48.7%) A summary is presented below (Figure 4.6). The birth country of the Chinese respondents varied from mainland China to Taiwan (Figure 4.7). All of the respondents however, identified themselves as a member of two social groups in Christchurch for the Chinese elderly, or family members of the elderly. Half of the total Chinese respondents were male (n=19), half were female (n=19). One respondent did not state. A third of the respondents were aged between 41-55 years (n=14; 34.2%). Nearly another third were aged more than 60 years (n=10; 25.7%). A summary is presented below (Figure 4.8). While nearly half of the total respondents reported having a bachelor's degree (n=19; 48.7%), nearly a quarter also reported no formal education (n=8; 20.5%). All of the respondents who reported no formal education were aged more than 60 years old and reported their birth country as mainland China (n=8).

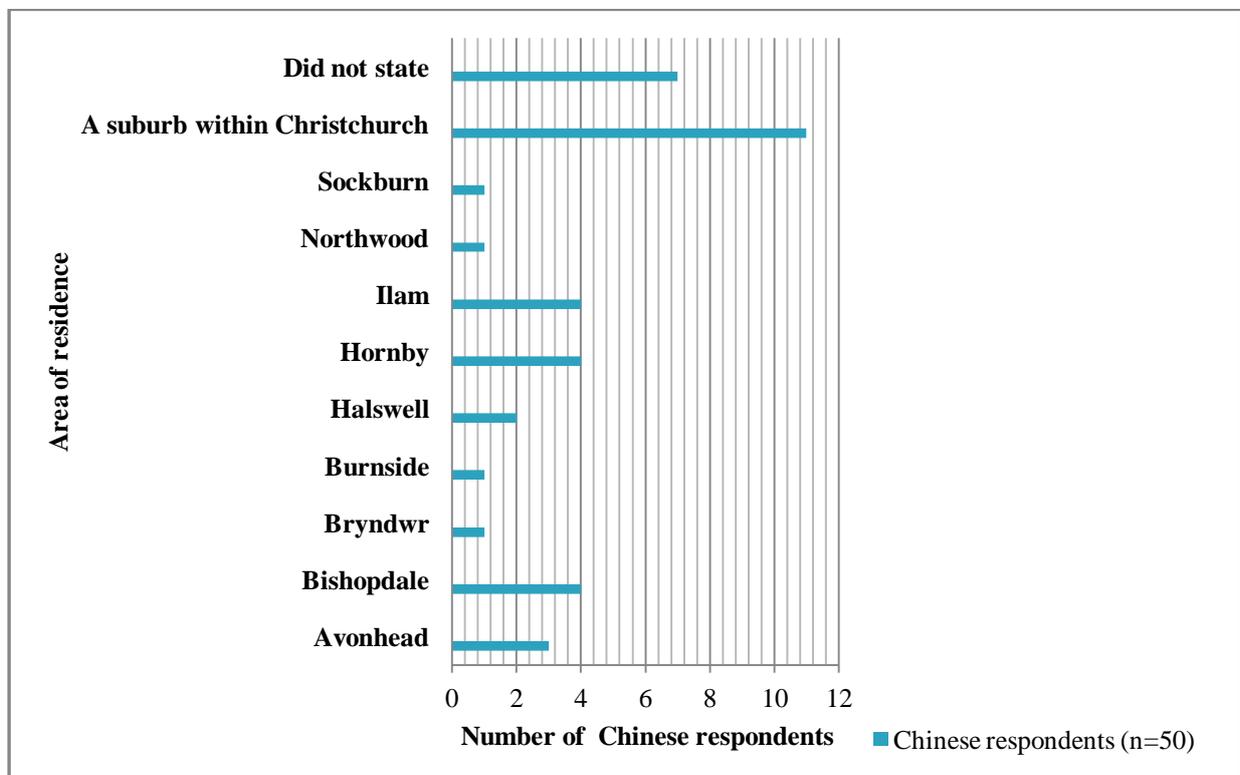


FIGURE 4.5 Area of residence for the Chinese respondents

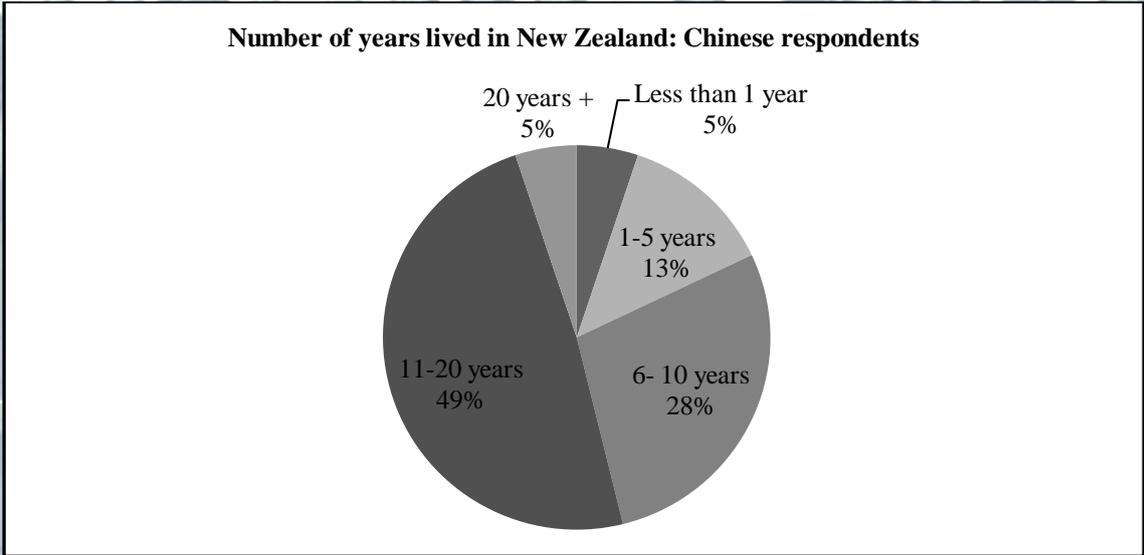


FIGURE 4.6 Number of years lived in New Zealand by Chinese respondents (n=50)

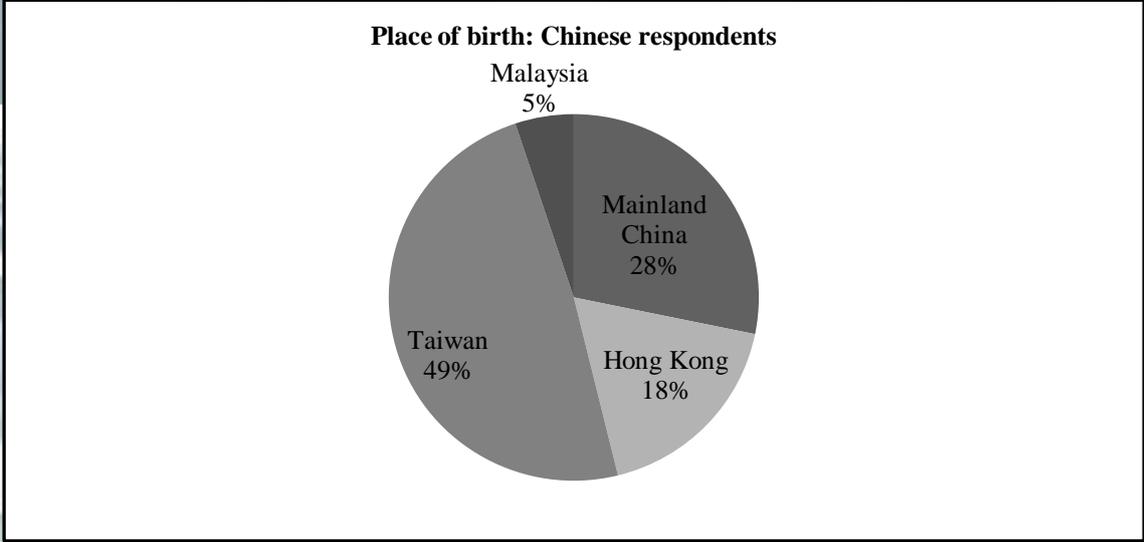


FIGURE 4.7 Country of birth by Chinese respondents (n=50)

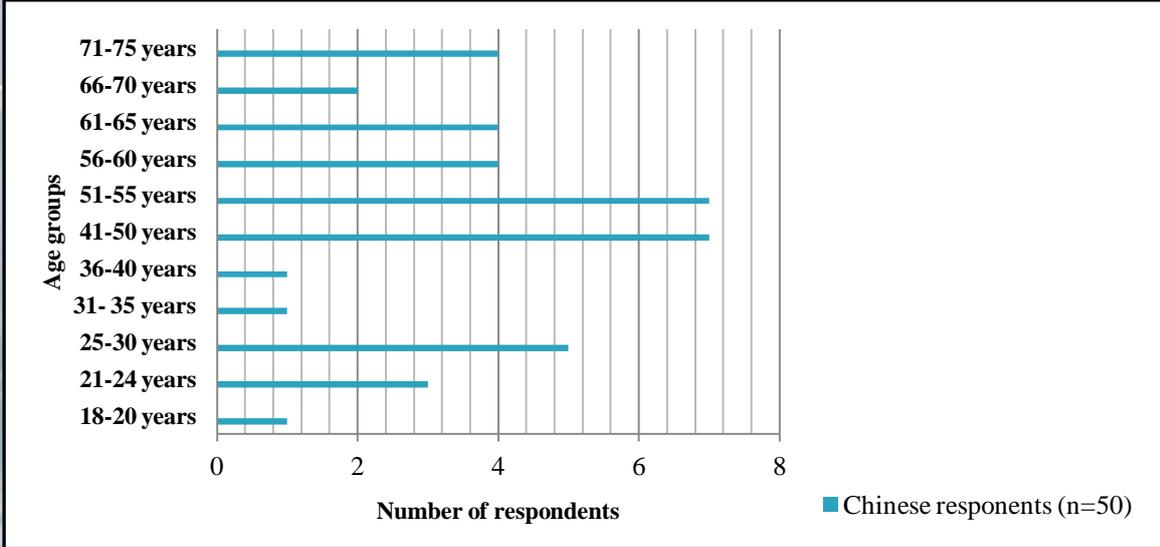


FIGURE 4.8 Age groups of the Chinese respondents (n=50)

While more than half of the Chinese respondents reported knowing that free translation services are available at hospitals, most reported that they did not know free translation services are also available at hospices.

Awareness of palliative and hospice services available in New Zealand

The first object of this study was to gauge the migrants' awareness of palliative and hospice services available in New Zealand. The Chinese respondents were most likely to indicate their level of understanding of palliative services in New Zealand as *not familiar* (n=30; 76.9%). The Chinese respondents were also most likely to indicate their understanding of hospice services in New Zealand as *not familiar* (n=26; 66.7%). The migrants were also asked if they were aware of the existence of other related services (translation services, home visits by district nurses, bereavement support). While more than half reported knowing the availability of free translation services at hospitals (n=24; 61.5%), most of the respondents reported that they did not know free translation services are also available at hospices (n=29; 74.4%), nor that district nurses can be asked to visit people's homes, should a patient be diagnosed with a terminal illness (n=29; 74.4%). Most also reported not knowing that bereavement support services were available in New Zealand (n=24; 61.5%).

Interest in palliative and hospice services

The second objective was to gauge the migrants' interests of the existing palliative and hospice services. Most of the respondents (n= 31; 79.5%) reported that they would be interested in receiving more information about palliative services in New Zealand. Nearly all of the Chinese respondents thought that palliative services could be useful for themselves and their families (n= 37; 94.9%). Nearly all of the respondents thought that hospice could be a useful services for them and their families (n= 37; 94.9%). When the Chinese respondents were asked to describe why they thought palliative services in New Zealand is currently under utilised by people of Asian backgrounds, the language barrier was the most cited factor (71.8%), closely followed by cultural barriers (46.2%) . Religious differences were also cited (7.7%). One respondents thought there was no need for palliative services for Asian peoples in New Zealand (n=1).

When asked why they personally may not want to use palliative and hospice services in New Zealand, lack of information was the most cited factor (figure 4.9). The percentages do not total 100 as respondents could give more than one answer for this question. More than half of the respondents thought not knowing enough information about palliative and hospice services was a barrier for them (n= 25; 64.1%). Nearly half of the respondents also reported being worried about communicating with the health professionals in English (n=19; 48.7%).

When asked what key factors may be important if the respondents were to receive palliative and hospice services in New Zealand, the Chinese respondents were most likely to rank the following factors highly (value of 1 or 2 given): conversing with the health professionals in mother tongue (61.8%), being offered information about translation services by the New Zealand health professionals (58.8%). This was then equally followed by a wish to have the health professionals respect the patients' traditional religion (45.2%) and culture (45.2%). For the Chinese respondents, having the health professionals knowledgeable about Chinese religion (30%) or culture (27.6%) was also seen as desirable. The total number of counts do not total 39, as the respondents could choose multiple factors as equally important or least important to them (figure 4.9).

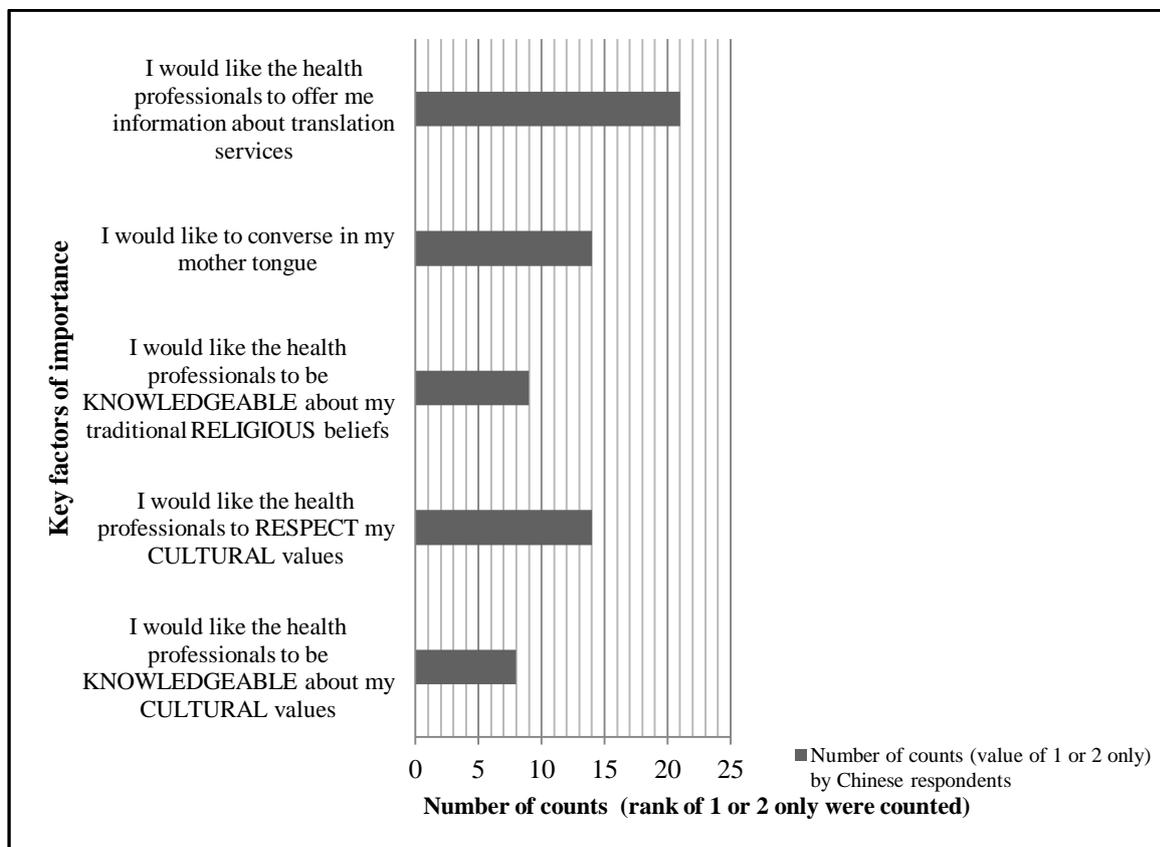


FIGURE 4.9 Key factors considered important for the Chinese respondents, should they receive palliative or hospice services in New Zealand

End-of-life-decision making

The third objective was to understand the migrants' perspectives on issues related to end-of-life decision making. Therefore, the migrants were first asked if a physician should disclose information about diagnosis of a terminal illness to the patient and their families. Most of the Chinese respondents

thought that a doctor should directly inform the patients of the diagnosis (n=35; 89.7%). Most of the Chinese respondents also thought that families should also be informed (n=34; 87.2%). The migrants were also asked if a doctor should disclose prognosis of a terminal illness. Most of the Chinese respondents thought that a doctor should directly inform the patients about an advanced, non-curable terminal illness (n=34; 87.2%). Most Chinese respondents also thought that a doctor should also inform such prognosis to the families (n= 33; 84.6%). Chi-square test showed a statistical significant relationship could be found between a respondent's cultural affiliations (Japanese, Chinese, Korean) and whether a respondent thought a doctor should disclose information about a patient's prognosis to the patient's families ($p= .001$; $df= 24$).

The migrants were then asked about their views on the potential use of life sustaining technologies. They were first asked whose decision it should be to decide whether or not a patient should be placed on such machines. The Chinese respondents most likely thought the decision should be made by the patient (n=27; 69.2%), followed by the family members (n=9; 23.1%). The respondents were then asked if they had to make a decision about the potential use of life sustaining technologies, whom they would turn to for advice. The respondents were asked to rank parties they would most or least likely to ask for advice (1=most likely; 6= least likely). The respondents could rank more than one person as highly likely or least likely to turn to for advice. The Chinese respondents were likely to rank the following highly (value of 1 or 2 given): doctors (82.4%), family (76.7%), a religious leader (44%). This was followed by friends (30.8%), nurses (30.8%) and a social worker (7.7%). Chi-square test showed a statistical relationship could be found between the migrants' cultural affiliations (Japanese, Chinese, Korean) and how they would seek religious leaders when needing advice about the potential use of life sustaining technologies ($p= .000$; $df= 30$).

Place for end-of-life services: Preferences

The last objective was to understand the migrants' preferences about where they may like to receive end-of-life care services. Therefore, they were asked should they or their family members be diagnosed with a terminal illness in New Zealand, where they would feel most comfortable being care for. The total does not add up to 39, as respondents could select more than one place they would like to receive such services. The Chinese respondents were most likely to select their own home (n=21;

53.8%), followed by hospice (n=11; 28.2%) and hospitals (n=9; 23.1%). Only one respondents selected age residential care facility.

Koreans

Background information

From a total of 90 questionnaires distributed, fifty six questionnaires (n=56; 62.2%) were returned. All of the respondents reported their location as within Christchurch city. A summary of the respondents' locations are presented below (Figure 4.10). All of the respondents reported being born in Korea (n=56). Nearly half reported having lived in New Zealand between 6-10 years (n=25; 44.6%). This was followed by between 11-20 years (n=21; 37.5%) A summary is presented below (Figure 4.11). Just over half of the Korean respondents were female (n=31; 55.4%). This questionnaire was most returned by people aged between 76-80 years (n= 12; 21.4%). A full summary of the Korean respondents' age groups are presented below (Figure 4.12). Nearly half of the Korean respondents reported having a bachelor's degree (n=19; 48.7%). However, a small percentage also reported no formal education (n=8; 14.3%). All of the respondents who reported no formal education were aged more than 70 years.

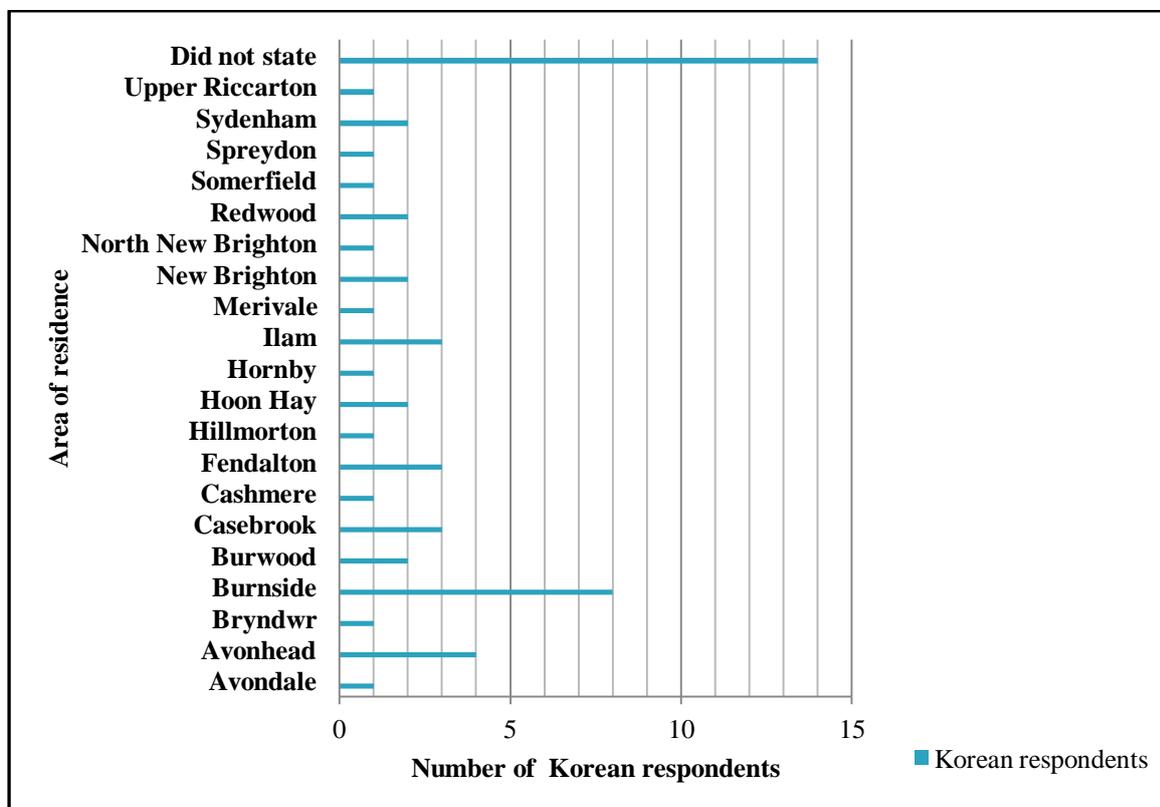


FIGURE 4.10 Area of residence for the Korean respondents (n=56)

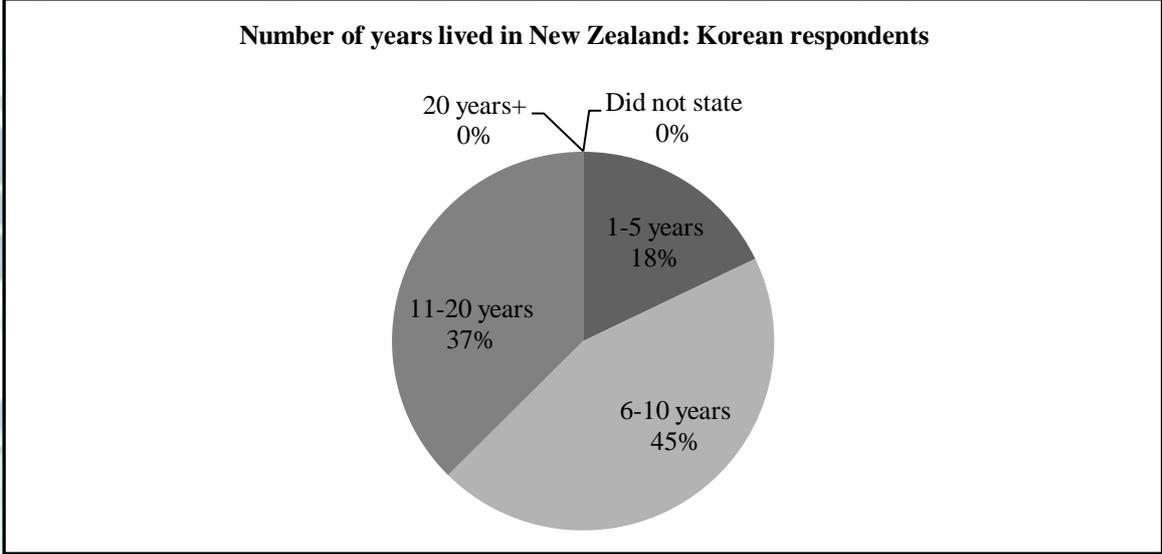


FIGURE 4.11 Number of years lived in New Zealand by the Korean respondents (n=56)

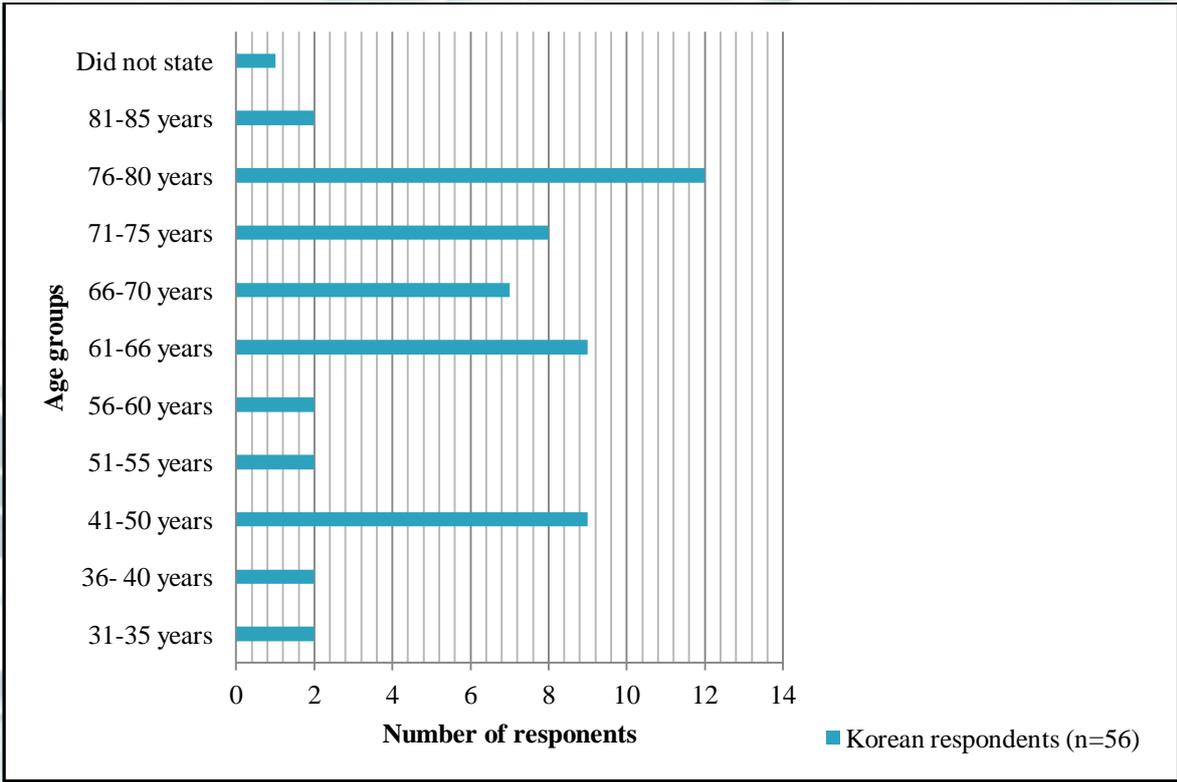


FIGURE 4.12 Age groups of the Korean respondents (n=56)

Awareness of palliative and hospice services available in New Zealand

The first object was to gauge the migrants' awareness of palliative and hospice services available in New Zealand. The Korean respondents were most likely to indicate their level of understanding of palliative services in New Zealand as *not familiar* (n=38; 67.9%). The respondents were also most likely to indicate their understanding of hospice services in New Zealand as *not familiar* (n=37; 66.1%). The Korean migrants were asked if they were aware of the existence of other related services (translation services, home visits by district nurses, bereavement support). While the majority knew that free translation services were available at hospitals (n=42; 75%), less than half reported knowing that free translation services are also available at hospices (n=23; 41.1%). Less than half reported that they know that district nurses can be asked to visit people's homes, should a patient be diagnosed with a terminal illness (n=22; 39.3%). Only a quarter of the respondents knew that bereavement support services were available in New Zealand (n= 14; 25%).

Interest in palliative and hospice services

Nearly all of the Korean respondents (n= 46; 82.1%) reported that they would like to receive information about palliative services in New Zealand. Nearly all of the Korean respondents thought that palliative services could be useful for themselves and their families (n= 50; 89.3%). Nearly all of the respondents thought that hospice could be a useful services for them and their families (n= 53; 94.6 %). When the Korean respondents were asked to describe why they thought palliative services in New Zealand is currently under utilised by people of Asian backgrounds, language barrier was the most cited factor (87.5%). A small number of the respondents cited cultural barriers (16.1%). Religious difference was not cited by any of the Korean respondents (0%). None of the Korean respondents thought there is no need for palliative services for Asian peoples in New Zealand (0%).

When asked why they personally may not want to use palliative and hospice services in New Zealand, the Koreans were most likely to cite being worried about speaking with the health professionals in English (67.9%). This was closely followed by the report of not knowing enough information about the existing services (64.1%). A small number was concerned with the health professionals not understanding their cultural values (16.1%). None of the Korean respondents cited being worried that the health professionals would not respect their religious beliefs.

Most of the Korean respondents thought that a doctor should disclose information about diagnosis of a terminal illness to the patient, but also to their families.

When asked what key factors may be important, if the respondents were to receive palliative and hospice services in New Zealand, the Korean respondents were most likely to rank the following factors highly (value of 1 or 2 given): speaking to the health professionals in mother tongue (94.1%), being offered information about translation services by the New Zealand health professionals (78.9%). A small number reported a wish to have the health professionals respect the patients' cultural values religion (19.4%). A very smaller number of the Korean respondents reported a wish to have the health professionals respect traditional religion (9.7%) or be knowledgeable about traditional religion (12.9%).

End-of-life-decision making

The third objective was to understand the migrants' perspectives on issues related to end-of-life decision making. The Korean migrants were asked if a physician should disclose information about diagnosis of a terminal illness to the patient and their families. Most of the respondents thought that a doctor should directly inform the patients of the diagnosis (n=50; 89.3%). Most of the respondents also thought that their families should also be informed (n=44; 78.6%). The migrants were asked if a doctor should disclose information about prognosis of a terminal, non-curable illness. Most of the Korean respondents thought that a doctor should directly inform the patients (n= 50; 89.3%). Nearly a quarter of the respondents thought that a doctor should also inform such prognosis to their families (n=46; 82.1%).

The migrants were then asked about their views on the potential use of life sustaining technologies. The migrants were asked whose decision it should be to decide whether or not a patient should be placed on a life sustaining machine. Four parties were listed. The respondents could select more than one party as their answer. The respondents thought that the decision should be solely up to the patient (n=26; 92.9%) or their families (n=17; 89.5%). This was followed by either the doctor (n=17; 30.4%) or other (n=1; 1.8%). The migrants were then asked if they had to make a decision about the potential use of life sustaining technologies, to whom they would turn to for advice. The respondents were asked to rank to whom they would be most or least likely to ask for advice (1=most likely; 6= least likely). The respondents could rank more than one person as highly likely or least likely to turn to for advice. The Korean respondents were most likely to rank the following highly (value of 1 or 2

given): family (76.7 %), doctors (68.2 %) and nurses (29.6%). This was followed by a religious leader (20%), friends (14.3%) and social worker (11.5%).

Place for end-of-life services: Preferences

The last objective was to understand the migrants' preferences about where they may like to receive end-of-life care services. The migrants were asked should they or their family members be diagnosed with a terminal illness in New Zealand, where they would feel most comfortable being care for. The total does not add up to 100, as some respondents selected more than one place. The figure below summarises the findings (Figure 4.13). The Korean respondents were most likely to select hospitals. This was followed by hospice, then home. One respondent selected aged residential care facility.

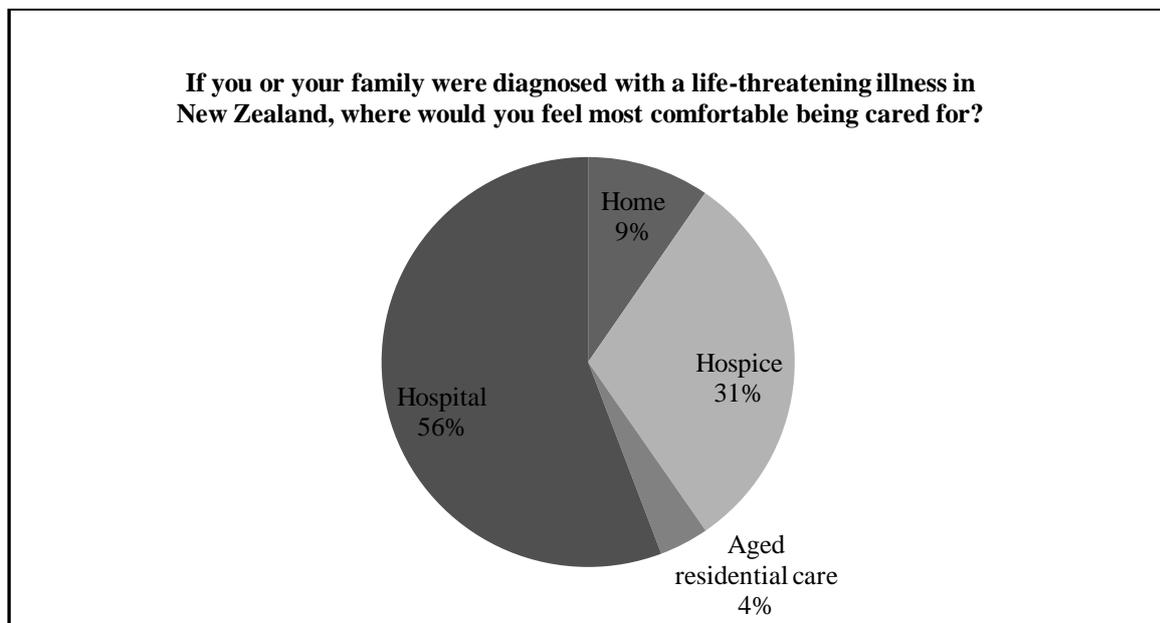


FIGURE 4.13 End-of-life-care services: Place of preference for the Korean respondents

4.2 Summary

This section reported the findings from a self-complete questionnaire that was completed by Japanese, Chinese and Korean residents of Christchurch between December. 2011- February. 2012. The purpose of the questionnaire was to meet four research objectives. The four objectives were: to gauge the migrants' awareness of palliative and hospice services available; interests in the existing palliative and hospice services; perspectives on end-of-life decision making; and preferences about where to receive end-of-life care services. The results found that Japanese, Chinese and Korean residents were all most likely to report little awareness of the existing palliative and hospice services, but report high levels of interests in receiving information about such services. Japanese, Chinese and Korean respondent were also most likely to be worried about communicating with the health professionals in English. Japanese, Chinese and Korean respondent were also likely to value being offered information about translation services by the New Zealand health professionals. For decisions around end-of-life, it was found that majority of Japanese, Chinese and Korean respondents thought doctors should disclose information about diagnosis and prognosis of a terminal illness to the patient. However, perspectives differed around disclosing such information to the family members. Japanese respondents were more likely to report that the information should be solely disclosed to the patient alone. When asked about being faced with the perspective of using life-support machines, majority of Japanese, Chinese and Korean respondents thought the decision should be made by either the patient or their families. When asked who they would turn to for advice, Chinese respondents were more likely to value religious leaders higher. The respondents were asked what key factors would be most important for health professionals to know, should the respondents be using palliative or hospice services in New Zealand. Japanese, Chinese and Korean respondents all ranked speaking in their own native languages highly, followed by the health professionals offering information about translation services. Japanese, Chinese and Koreans were all likely to value health professionals respectful of their cultural values. However, Chinese respondents were also more likely to highly value health professionals knowledgeable about Chinese culture. When asked about where they would like to receive end-of-life care if diagnosed with a terminal illness, the views of Japanese, Chinese and Koreans all differed slightly.

Section 5: DISCUSSION

5.1 Introduction

This section discusses the findings presented in the previous section. The background information of the Japanese, Chinese and Korean respondents are discussed first. This is followed by a discussion of the key findings according to the four objectives.

5.2 Background

The Korean respondents were much older in their age groups than Japanese and Chinese respondents. Nearly half of the sample reported being aged 66 years or more. However, this may be due to the fact that majority of the returned questionnaires were from members of the Christchurch Korean social group for the elderly. This group is for those aged 65 years and over. The Korean sample reported residing over 20 different suburbs across Christchurch city (figure 4.1). With health data specifically on older Asian adults particularly lacking (Canterbury District Health Board, 2011, p. 15), it is hoped that results from this study will make a valuable contribution towards better understanding the health needs of this vulnerable group.

The Chinese sample was diverse in their education background and countries of birth (figure 4.7). In particular, it is interesting to note that nearly half of the respondents reported Taiwan as their country of birth. This is a population group that are rarely mentioned across other health studies (Centre for Asian Health Research and Evaluation, 2008). As previously noted (Ho, 2008), the cultural identity of 'being Chinese' has evolved over the years. Rather than being a fixed concept determined by the country of birth, but by shared cultural values and heritage, the Chinese identity has rapidly expanded over the recent years. However, a danger lies in always lumping the views of this diverse population (Scragg, 2010). Therefore, further studies of larger scales are needed to identify for potential similarities and differences of this diverse population.

The large sample size of the Japanese respondent and suggests that in future studies, local ethnic communities and their leaders should be actively encouraged to participate from the earliest stages. This includes both during the planning and the distribution stages. The paradigm of community profiling suggests that local leaders often have information about valuable local networks that may be unfamiliar to an outsider. Active involvement by members of the community can result in collection of

a more extensive data, and also steer the research towards improving the quality of life for the community (Hawtins & Percy-Smith, 2007). By active participation from the Christchurch Japanese Society, this study was able to hear from participants from throughout the wider Canterbury region (figure 4.1).

5.3 Awareness of palliative and hospice services available in New Zealand

All three groups (Japanese, Chinese and Koreans) reported little awareness of the existing palliative and hospice services. In addition, most reported little awareness of the existence of related services. Most reported that they did not know that district nurses can visit people at home. With both the Japanese and the Chinese respondents most likely to select *home* when asked where they would most likely to receive end-of-life services, more information should be made available to the two communities.

In addition, most of the respondents from all three groups reported that they did not think translation services were available at hospices. When the respondents from all three groups were later asked what key factors would be important for them, should they be using palliative and hospice services, being offered information about translation services by the health professionals was listed within the top two factors of importance. Therefore, more information about this service should also be promoted across all three communities.

5.4 Interest in palliative and hospice services

Majority of the respondents from all three groups reported high levels of interest in receiving more information about the existing palliative and hospice services. In particular, nearly all of the Japanese respondents reported they would like further information. With the Koreans, it is interesting to note that nearly all reported that they would like more information. Many of the Korean respondents reported belonging to much older age groups. Approximately half of the respondents reported being aged between 71- 85 years (figure 4.2). With *hospice* being selected as the second most preferred place to receive end-of-life care (figure 4.13), most information should be made available. In particular, this could be done through the Christchurch Korean social group for the elderly.

5.5 End of life decision making

Although Japanese, Chinese and Korean respondents were most likely to agree that diagnosis and prognosis of a terminal illness should be disclosed to the patient, there were slight differences across the three groups regarding the disclosure of such information to family members. The Chinese respondents were most likely to agree that family members should also be told. While further studies are needed to investigate why this may be so, some studies suggest that traditional Chinese culture is such that highly values *filial piety* or a collective, family centred model (Chen, 2001; Liu, Ng, Weatherall, & Loong, 2000; Payne, et al., 2005).

There were also slight differences across the three groups regarding the possibility of using a life-support machine. When asked who they would turn to for advice if faced with such situation, the Japanese and Koreans were likely to rank either family members or doctors highly, but less so for religious leaders. With the Chinese respondents, religious leaders were also ranked higher than the other two groups. When asked what key factors the respondents thought they would like the New Zealand health professionals to know when receiving palliative care, the Chinese respondents were also more likely to rank factors such as knowledge about Chinese culture or traditional religions more highly. While the sample size of this study remains limited, further opportunities for New Zealand health professionals to better understand the diverse cultures of their patients should be made available.

5.6 Place for end-of-life services: Preferences

There were slight differences across the three groups in their preferences, when the respondents were asked where they would like to receive end-of-life care. While the Japanese and Chinese were most likely to select *home* as their first choice, the Koreans did not. Less than one percent of the Korean respondents selected their own home. The Koreans were most likely to select *hospitals*. Further study is needed to understand why this may be so. However, some studies have shown that Korean elderly are often more reluctant to be perceived as “ a burden” for their families (Chung Pang, 1996; Lee, 2007). While attending the social meeting to address potential questions from the Korean elderly group, it was noted that many were residing with their children or grandchildren. With lack of

understanding of palliative or hospice services, including information about financial costs, it may be difficult for this group to access appropriate hospice and palliative services in the near future.

However, further study is needed.

For all three groups, *hospice* was selected as the second place of choice for receiving end-of-life care.

With all three groups suggesting that lack of information may be the key factor currently preventing people of Asian backgrounds from utilising palliative and hospice services, more information should be made available to all three communities.

5.7 Further recommendations

A. Policy levels

- New Zealand currently lacks specific guidelines on how the health professionals may meet the palliative and hospice needs of a growingly diverse population (Ministry of Health, 2009). To prepare for the needs of increasingly diverse populations, multicultural palliative care guidelines have been developed at other western countries (Centre for cultural diversity in ageing, 2010a; Taylor & Box, 1999). Same commitment is also needed from the New Zealand policy makers.
- With lack of guidelines, literature shows that New Zealand health professionals often face cultural and communication challenges in meeting the needs of diverse groups (Hathaway, 2009). While culturally appropriate health models such as Te Whare Tapa Wha, Fonofale and Popao has been developed to assist the health professionals in working with Maori and Pacific clients, such models do not currently exist for any Asian cultural groups. Such models should be developed, after further research and collaboration with leaders of ethnic communities.
- New Zealand currently lacks multilingual palliative care resources. Literature shows that such resources has been made available in other western countries (Centre for cultural diversity in ageing, 2010b). As New Zealand continues to grow as a multicultural nation, stakeholders at national, local and community levels should be further encouraged to collaborate, to promote culturally competent palliative care.

B. Local health organisations

- Future research investigating the health needs of ethnic communities should encourage active participation of the community groups. Community leaders should be encouraged to actively take part from the earliest stages of planning for potential projects.
- Collaboration and communication between different research groups and health organisations should be encouraged to avoid parallel projects.
- Multi-sectoral collaboration and communication participation is an important component of research for local needs (Eyre & Gauld, 2003). As the middle level group of stakeholders in the health system, community health organisations would need to continue to strengthen the

relationship with the policy makers, while also enhancing communication with the local community leaders.

C. Ethnic communities

- Further research is needed to better understand diverse health needs of ethnic communities. No published research has been found in New Zealand that investigates palliative and hospice needs of Asian peoples. However, several grey literatures such as thesis (Hathaway, 2009) could be found. Publications of such resources should be encouraged. Collaboration and discussion between small scale research projects should also be encouraged.
- Other aspects of providing end-of-life care for ethnic communities, such as counselling needs and bereavement support, also needs to be investigated.
- Community leaders have a significant role as the mediator between the New Zealand health organisations and the ethnic communities. Community leaders should continue to engage in active, open communication with the local organisations.

5.8 Limitations and strengths

This study has its limitations. The study was limited to approximately 200 respondents. Further research of longer duration, involving more participants should be encouraged. This study was undertaken as a summer student research project and the timing of this coincided with the Chinese New Year and the Korean Lunar moon New Year. The significance of these events is that it is often considered inappropriate to discuss the topic of death, dying and end-of-life care around these celebrations (Fong, 2000; Janelli & Janelli, 1992; Smith, 2004). However, this study also has several strengths. The respondents were from throughout the wider Christchurch city and beyond. Despite the sensitive nature of the research topic, this research was still carried out with active involvement of local community leaders. This was also the first project to gauge palliative and hospice needs of East Asian peoples living in Christchurch. Several important issues were identified, including high levels of interests from Japanese, Chinese and Korean residents on receiving further information about palliative and hospice services.

5.9 Conclusion

This study identified that East Asian migrants' awareness of palliative and hospice services available in New Zealand may be somewhat limited, but that the migrants have high levels of interests in finding about more about such services. This study also identified research gaps for the following: migrants' perspectives on end-of-life decision making, and preferences about where to receive end-of-life care services.

REFERENCE

- Aitken-Swan, J., & Paterson, R. (1955). The Cancer Patient Delay in Seeking Advice. *British Medical Journal*, 1(4914), 623.
- Baker, M. E. (2002). Economic, political and ethnic influences on end-of-life decision-making: a decade in review. *Journal of Health & Social Policy*, 14(3), 27.
- Blackhall, L. J., Frank, G., Murphy, S. T., Michel, V., Palmer, J. M., & Azen, S. P. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine*, 48(12), 1779-1789.
- Blackhall, L. J., Murphy, S. T., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and attitudes toward patient autonomy. *JAMA: The Journal of the American Medical Association*, 274(10), 820.
- Bosma, H., Apland, L., & Kazanjian, A. (2010). Review: Cultural conceptualizations of hospice palliative care: more similarities than differences. *Palliative Medicine*, 24(5), 510-522.
- Brauer, P. H. (1960). Should the patient be told the truth. *Nursing Outlook*, 8(12), 672-676.
- Bray, Y., & Goodyear-Smith, F. (2007). A migrant family's experience of palliative care. *Journal of Hospice and Palliative Nursing*, 9(2), 92-99.
- Canterbury District Health Board (2011). *District annual plan: 1 July 2010- 30 July 2011*. Christchurch: Canterbury District Health Board.
- Caralis, P., Davis, B., Wright, K., & Marcial, E. (1993). The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *Journal of Clinical Ethics*, 4, 155-165.
- Centre for Asian Health Research and Evaluation (2008). *The third international Asian health and wellbeing conference- Building healthy communities: North&South. Conference proceedings*. Auckland: Centre for Asian Health Research and Evaluation.
- Centre for cultural diversity in ageing (2010a). Palliative care Retrieved 3. February.2012, from <http://www.culturaldiversity.com.au/practice-guides/palliative-care>

- Centre for cultural diversity in ageing (2010b). Supporting cultural diversity in aged care Retrieved 5. February, 2012, from <http://www.culturaldiversity.com.au/about-us>
- Chen, Y. (2001). Chinese values, health and nursing. *Journal of Advanced Nursing*, 36(2), 270-273.
- Chung Pang, K. Y. (1996). Self-care strategy of elderly Korean immigrants in the Washington DC metropolitan area. *Journal of Cross-Cultural Gerontology*, 11(3), 229-254.
- Clark, D. (2007). From margins to centre: a review of the history of palliative care in cancer. *The Lancet Oncology*, 8(5), 430-438.
- Clark, D., & Centeno, C. (2006). Palliative care in Europe: an emerging approach to comparative analysis. *Clinical Medicine, Journal of the Royal College of Physicians*, 6(2), 197-201.
- Cleeland, C. S., Gonin, R., Baez, L., Loehrer, P., & Pandya, K. J. (1997). Pain and treatment of pain in minority patients with cancer: the Eastern Cooperative Oncology Group Minority Outpatient Pain Study. *Annals of Internal Medicine*, 127(9), 813-816.
- Crawley, L. M. (2005). Racial, cultural, and ethnic factors influencing end-of-life care. *Journal of Palliative Medicine*, 8(supplement 1).
- Ethnic communities' council of Victoria Inc (2012). Policy submissions&position papers Retrieved 6. February.2012, from <http://eccv.org.au/policy/submissions/>
- Eyre, R., & Gauld, R. (2003). Community participation in a rural community health trust: the case of Lawrence, New Zealand. . *Health Promotion International*, , 18(3), 189.
- Fallowfield, L. J., Jenkins, V. A., & Beveridge, H. A. (2002). Truth may hurt but deceit hurts more: communication in palliative care. *Palliative Medicine*, 16(4), 297-303.
- Fong, M. (2000). [] Luck Talk'in celebrating the Chinese New Year. *Journal of Pragmatics*, 32(2), 219-237.
- Hathaway, J. (2009). *Over the great wall: a qualitative descriptive study of the experiences and preferences of Chinese immigrant families when receiving hospice service in New Zealand.*, Victoria University of Wellington, Wellington.
- Hawtins, M., & Percy-Smith, J. (2007). *Community profiling* (Second ed.). Berkshire: Open University Press.

- Ho, E. (2008). *Asians in New Zealand: Insights and implications*. Paper presented at the Building healthy communities. Proceedings of the Third International Asian Health and Wellbeing Conference, Auckland.
- Hospice New Zealand (2012a). What is hospice Retrieved 11. November.2011, from <http://www.hospice.org.nz/>
- Hospice New Zealand (2012b). When support is offered, 25. November. 2011, from <http://www.hospice.org.nz/hospice-care>
- Janelli, R. L., & Janelli, D. Y. (1992). *Ancestor worship and Korean society*: Stanford University.
- Krakauer, E. L., Crenner, C., & Fox, K. (2002). Barriers to optimum end-of-life-care for minority patients. *Journal of the American Geriatrics Society*, 50(1), 182-190.
- Lee, Y. (2007). The immigration experience among elderly Korean immigrants. *Journal of Psychiatric and Mental Health Nursing*, 14(4), 403-410.
- Liu, J. H., Ng, S. H., Weatherall, A., & Loong, C. (2000). Filial piety, acculturation, and intergenerational communication among New Zealand Chinese. *Basic and Applied Social Psychology*, 22(3), 213-223.
- Ministry of Health (2001). *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.
- Ministry of Health (2006). *Asian Health Chart Book 2006*. Wellington: Ministry of Health.
- Ministry of Health (2009). *Gap Analysis of Specialist Palliative Care in New Zealand: Providing a national overview of hospice and hospital-based services*. Wellington: Ministry of Health.
- Murray, S. A., Boyd, K., Sheikh, A., Thomas, K., & Higginson, I. J. (2004). Developing primary palliative care. *BMJ*, 329(7474), 1056-1057.
- Palliative Care Australia (2011). Multilingual Care Australia Retrieved 4. February.2012, from <http://www.palliativecare.org.au/Default.aspx?tabid=2116>
- Payne, S., Chapman, A., Holloway, M., Seymour, J., & Chau, R. (2005). Chinese community views: Promoting cultural competence in palliative care. *Journal of Palliative Care*, 21(2), 111-116.
- Queensland Government (2004). Community profiling Retrieved 23. 12. 2011, from <http://www.onlinelearning.qld.gov.au/materials/ce/online/ce/info/learning/guide/t2s5s2.htm>

- Randhawa, G., Owens, A., Fitches, R., & Khan, Z. (2003). Communication in the development of culturally competent palliative care services in the UK: a case study. *International Journal of Palliative Nursing*, 9(1), 24.
- Reid, W. (2009). *Primary health care issues amongst Asian peoples in Christchurch*. Christchurch: Partnership Health Canterbury.
- Reid, W., & Zhang, K. (2009). *Nutritional needs assessment of East Asians living in Christchurch*. Christchurch: Partnership Canterbury.
- Santosh, J., & Crampton, P. (2009). Gender differences in general practice utilisation in New Zealand. *Journal of Primary Health Care*, 1(4).
- Schwass, M. (2005). *Last words: Approaches to death in New Zealand cultures and faiths*: Bridget Williams Books Limited.
- Scragg, R. (2010). *Asian Health in Aotearoa in 2006-2007: trends since 2002-2003*. Auckland: Northern DHB Support Agency.
- Sheehan, D., & Forman, W. (1996). *Hospice and palliative care: Concepts and practice*: Jones & Bartlett Publishers.
- Smith, G. (2004). Asian-American deaths near the harvest moon festival. *Psychosomatic Medicine*, 66(3), 378-381.
- Statistics New Zealand (2009). National Ethnic Population Projections: 2006(base)–2026 update Retrieved 9. February. 2012, from <http://www.stats.govt.nz/searchresults.aspx?q=ethnic%20population>
- Stevens, G., & Cousineau, M. (2007). Health disparities in multicultural populations: an overview. In E. Evans & C. Dellelo (Eds.), *Health promotion in multicultural populations* (Second ed., pp. 102-124). California: SAGE publications.
- Taylor, A., & Box, M. (1999). *Multicultural palliative care guidelines*: Palliative Care Australia.
- Thomas, R., Wilson, D., Justice, C., Birch, S., & Sheps, S. (2008). A Literature Review of Preferences for End-of-Life Care in Developed countries by Individuals With Different Cultural Affiliations and Ethnicity. *Journal of Hospice and Palliative Nursing*, 10(3), 142-162.

- Voltz, R., Akabayashi, A., Reese, C., Ohi, G., & Sass, H. (1999). Attitudes of healthcare professionals toward clinical decisions in palliative care: a cross cultural comparison. *Journal of Clinical Ethics, 10*, 309-315.
- Voltz, R., Akabayashi, A., Reese, C., Ohi, G., & Sass, H. M. (1998). End-of-Life Decisions and Advance Directives in Palliative Care:: A Cross-Cultural Survey of Patients and Health-Care Professionals. *Journal of Pain and Symptom Management, 16*(3), 153-162.
- Werth, J. L., Blevins, D., Toussaint, K. L., & Durham, M. R. (2002). The influence of cultural diversity on end-of-life care and decisions. *American Behavioral Scientist, 46*(2), 204-219.
- Windsor, J., Rossaak, J., Chung, D., Ng, A., Bissett, I., & Johnson, M. (2008). Telling the truth to Asian patients in the hospital setting. *The New Zealand Medical Journal, 121*(1286), 92-99.
- World Health Organization (2012). WHO Definition of Palliative Care Retrieved 22.December.2011, from <http://www.who.int/cancer/palliative/definition/en/>