How do community registered nurses use Advance Care Planning in Japan?

by

Yumi Naito

Supervisors: Dr Yvonne Parry and Dr Katrina Breaden

Thesis
Submitted to Flinders University
for the partial fulfilment of the degree of

Master of Nursing

College of Nursing and Health Sciences

August 2020

CONTENTS

List of tables v
List of figures v
Declaration vi
Glossary vii
Presentations by the researcher viii
Conference viii
Public lectures viii
Acknowledgements ix
Abstract x
CHAPTER 1 INTRODUCTION 1
1.1 An overview 3
1.2 Background of the research 4
1.3 Significance of the research 7
1.4 Aims and questions of the research 10
1.5 Thesis structure 10
CHAPTER 2 LITERATURE REVIEW 11
2.1 Introduction 11
2.1 Article search and selection process 12
2.2 Critical appraisal of selected studies 13
2.3 Thematic analysis 13
2.4 Findings 14
2.5 Discussion 17
2.6 Conclusion 20
CHAPTER 3 METHODS 21
3.1 Introduction 21
3.2 Research design 21
3.3 Research approach 22
3.4 Interpretive description as a methodology 23
3.5 Ethical considerations 23
3.6 Study setting and sample criteria 24
3.7 Data collection 25
3.8 Data analysis 27
Step 1: Becoming familiar with the data 28
Step 2: Generating initial codes 28
Step 3: Searching for themes 30

Step 4: Reviewing the themes 30
Step 5: Defining and naming the themes 30
Step 6: Producing the report 30
3.9 Rigour 30
3.10 Conclusion 31
CHAPTER 4 FINDINGS 32
4.1 Introduction 32
4.2 Participant demographic data 32
4.3 Finding the major themes and sub-themes 33
4.3.1 Family concerns 34
4.3.2 Informed consent and discussion 36
4.3.3 Cultural difference 39
4.3.4 Ageing society and quality of life 40
4.3.5 Responsibility and documentation 42
4.4 Conclusion 43
CHAPTER 5 DISCUSSION 44
5.1 Introduction 44
5.2 Power relations around ACP 44
5.3 Cultural background around ACP 47
5.4 Tools for open conversation and communication 49
5.5 Limitations 52
5.6 Conclusion 52
CHAPTER 6 CONCLUSION 53
6.1 Introduction 53
6.2 Answer to the research question 53
6.3 Suggestions for future research 54
6.4 Implications for policy and practice 55
6.5 Conclusion 56
References 58
Appendices 72
Appendix 1 Inclusion and exclusion criteria table 72
Appendix 2 PRISMA chart (reference for chart?) 73
Appendix 3 Evaluation of qualitative studies included for review (reference for tool used) 74
Appendix 4 Evaluation of quantitative studies included for review 75
Appendix 5 Themes table 76
Appendix 6 Summary table 77
Appendix 7 Letter of introduction 81

Appendix 8 Letter of introduction (Japanese) 83
Appendix 9 Ethics approval 84
Appendix 10 Information sheet 87
Appendix 11 Information sheet (Japanese) 90
Appendix 12 Consent form (Japanese) 91
Appendix 13 Questions 92
Appendix 14 CareSearch blog post 93

LIST OF TABLES

Table 3.1 Inclusion and exclusion criteria 25
Table 3.2 Frequently used words 29
Table 4.1 Demographic data 32
Table 4.2 Themes 33

LIST OF FIGURES

Figure 1.1 The Community-based Integrated Care System (Ministry of National Health, 2017)..... 6
Figure 1.2 Ageing in Japanese society (Japanese Government, 2017) 7

DECLARATION

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed …….

Date …….

GLOSSARY

Advanced Care Planning (ACP)	Advance care planning, a process whereby a person discusses their values and healthcare preferences with family, friends and the healthcare team prior to death or incapacity (Advance Care Planning Australia, 2018). This is a comprehensive process that produces a document to direct care. The ACP provides all the documents for the Advanced Care Directives which should be commenced within 3 weeks of a terminal diagnosis – on average here it is commenced within 10 days of death.
Community registered nurse	A community registered nurse is a registered nurse who works for a community-based facility as well as in private homes; in Japanese, a *houmon-kangoshi* (Takahashi & Fuse, 2012).
Dankai-no-sedai	Japanese for *"*baby boomers", a particularly independent and self-assured generation. In Japan, the baby boomer generation is defined as those born in the years 1947-49 (Nagai et al., 2015). This is different to the global Baby - Boomer definition (Statistics Bureau of Japan, 2015).
Ending note	A Japanese–made English word, meaning a physical notebook used by Japanese people to write their wishes and needs concerning their death and funeral arrangements. It is not including any financial, health and legal components, therefore, it is different to ACP. It has kept as a personal private notebook (Shimizu, 2015; Sumita, 2015)

PRESENTATIONS BY THE RESEARCHER

Conference

Naito, Y. (2019, September 14-15). *The present state of Advance care planning in Australia*. [PowerPoint Presentation]. Presented at the 3rd annual conference of the Japan Society for end-of-life care, Nagoya, Japan. http://plaza.umin.ac.jp/eolcconf2019

Public lectures

Naito, Y. (2019, April 18). *The present state of Advance care planning in Australia.* Presented at the National Nursing School in Saitama, Japan.

Naito, Y. (2019, September 21). *Advance care planning discussion.* Presented at the Public Community Centre, Nagoya, Japan.

Naito, Y. (2019, November 14). *Advance care planning discussion*. Presented at the Public Community Centre, Fukuoka, Japan.

ACKNOWLEDGEMENTS

First of all, I would like to thank all staff at Flinders University including: the administration team, cleaning staff, IT support staff, librarians, lecturers, academic teachers, learning support staff, health team members, security staff, café workers and fellow students. All of them supported me with kindness and encouraged me to keep studying. Without this kind of warm support, I would not have completed this study. Thank you so much. I really enjoyed the environment at Flinders University.

Secondly, I especially thank my supervisors, Dr Yvonne Parry and Dr Katrina Breaden. They gave me consistent, generous help and tender supervision over the two years. They were always available when I needed them and led me on the right path with accurate suggestions. Thank you, Yvonne, and Katrina.

A professional editor, David Alston provided wonderful editing for my first thesis and kind understanding of the cultural contents; his work was in accordance with the standards laid out in the University-endorsed national guidelines. Thank you, David.

I would like to thank my family, my mother Yoshi, my sister Kumi, her husband Fumi and friends in Japan, Australia, and the United States. My father, Rintaro passed away just as I had begun to study in Semester 2, 2018. His end-of-life experience gave me a passion for my topic. They all believed in me and did not doubt my ability to complete.

Finally, my two precious sons, Maha and Louie, strongly believed in me and encouraged and helped me achieve my dream. No words can express my gratitude for all your support.

Thank you from the bottom of my heart, everyone.

Yumi Naito

ABSTRACT

This thesis explores the perceptions of Japanese community registered nurses towards the use of advance care planning (ACP). The Japanese government has introduced new guidelines for end-of-life care which now includes the concept of ACP. However, unlike Australia, Japan does not have a legal framework to support ACP. Advance Care Planning is indeed a new concept in Japan and a controversial topic among medical professionals.

The researcher attended the 7th Advance Care Planning International (ACPI) conference in Rotterdam 2019 to gain knowledge of the various global perspectives on ACP. The 250 participants from 25 countries demonstrated a strong interest and enthusiasm for the benefits of ACP (ACPI, 2019). As a result of attending this conference, it became clear that there is a need for research exploring the various cultural issues involved in the understanding of ACP around the world. From both the researcher's attendance at the conference and her own presentations at public lectures in Japan, it became apparent that ACP is urgently needed as a tool for individual decision-making, and that health professionals should take the lead in talking more openly about ACP. Health professional leadership in this area should support a change in both public opinion and culture in Japan.

This study was informed by the qualitative methodology of interpretive description, which involved interviewing 11 community registered nurses. The results showed that the majority of community registered nurses interviewed ACP to be of high importance; however, they were not sure how to use ACP in their role as community registered nurses. There were also difficulties in adopting ACP arising from differing cultural contexts and backgrounds between the use of ACP in Australia and Japan.

The results from this study emphasised the need for the establishment of governmental policy, clear documentation, further education, and training in assertive communication. Advance Care Planning is the key to improving the quality of the end of life for Japanese people and it will ensure more information about decision-making in the future.

This research may encourage the development of a new policy, establishing both a definition of ACP and standardised documentation.

CHAPTER 1 INTRODUCTION

After observing various death and dying processes as part of the researcher's nursing career in Japan, India and Australia, the researcher was motivated to investigate advance care planning (ACP) in Japan. For the purpose of this research, ACP is defined as a process whereby a person discusses their values and healthcare preferences with family, friends and the healthcare team prior to their death or incapacity (Advance Care Planning Australia, 2018). The goal of ACP is to provide clear, documented preferences concerning a person's future medical and treatment needs.

Advance Care Planning has recently become a controversial topic among medical and health professionals in Japan. This controversy is due to an ageing population, consideration of end-of-life care and consideration for their quality of life. Consequently, the public now pays attention to the ACP issue and to how older Japanese wish to plan their end-of-life care. However, in Japan, ACP often involves complex problems concerning differing cultural values and beliefs. Furthermore, the conversation around ACP has arisen as a new phenomenon, as evidenced by the development of the *ending note*, a Japanese-made English word, meaning a physical notebook used by Japanese people to write their wishes and needs concerning their death and funeral arrangements (Shimizu, 2015). This is a widely used approach to ACP throughout Japan however, the notebook itself is not a legally binding document.

Advance Care Planning has only recently been recognised in Japan. There are now some guidelines on the medical and health decision-making process provided by the Ministry of Health, Labour and Welfare (Shimizu, 2015), but unlike Australia, Japan does not have a legal framework to support ACP, nor has the issue of ACP been researched in a Japanese context. The current ACP practice in Japan has evolved from government guidelines designed for medical and health decision-making discussions through to the end-of-life stages of illness rather than merely for life choices. The government recommends individualised self-determination by patients if the people concerned are competent; however, there is no definitive documentation as yet. This lack of clarity means that both patients and medical and health professionals are struggling to consider the most suitable way to utilise ACP.

The researcher observed these particular cultural differences while working as a registered nurse caring for patients' who were at end-of-life stage in Australia. The researcher's first

encounter with death as a nursing student made her realise how important and fragile life is. Death could occur at any moment, regardless of how healthy an individual might be. This experience made the researcher reflect on the different ways in which life could be spent. This reflection led to the question of whether there are possibilities of a better way of living. The researcher observed that in Australia, nursing practice places emphasis on the patient's opportunity to make choices around their care (even at end stage).

In 2019, the researcher attended the 7th Advance Care Planning International conference in Rotterdam in order to gain knowledge of the various global perspectives on ACP. The 250 participants from 25 countries demonstrated a strong interest in and enthusiasm for the benefits of ACP (ACPI, 2019). As a result of attending this conference, it became clear to the researcher that there are various cultural issues involved. This awareness triggered the researcher to consider the cultural differences around ACP, and how an ACP policy can provide opportunities for patient decision-making preferences.

One of the strengths of this research is that the researcher is a bilingual registered nurse who lives in Australia and is therefore familiar with both the Japanese and Australian context; the researcher thus has a good understanding of the language and context around ACP in both the countries involved (Masujima, 2017). The researcher can thus utilise the knowledge of ACP in Australia, including practical experiences, to deepen her understanding of the practices. Additionally, the researcher can draw on her own experience of working as a community registered nurse in Japan in order to understand their experiences. The researcher's bilingual background also assists in comparing the benefits and differences of ACP in both Australia and Japan. The researcher's own nursing experiences in a Western country has enabled her to combine her understanding of Japanese society with Western concepts (Shiomi et al., 2011).

This study explored ACP from the perspective of the experiences of community registered nurses in Japan. Broadly, this study will introduce the context of community registered nurses and address how registered nurses use ACP in Japan. This first chapter consists of five sections as outlined below:

1.1 An overview

1.2 Background of the research

1.3 Significance of the research

1.4 Aim and questions of the research

1.5 Thesis structure

1.1 An overview

Advance Care Planning consists of a person's preferences regarding future healthcare planning, also contains financial and legal components (Bird, 2014). It has been described as a process whereby a patient, in consultation with healthcare providers, family members, and important others, makes decisions about the patient's health care, should the patient become incapable of participating in medical treatment decisions (Bird, 2014). Advance Care Planning has been found to improve quality of life, increases patient and family satisfaction and is likely to reduce the stresses of decision-making (Nakazawa et al., 2014).

The original idea of visiting or community nurses as a service to the public began in 1880, on a voluntary basis (Nagaya & Dawson, 2014). The visiting nurse service was recognised in 1960, when there was a social problem of increasing numbers of bedridden elderly patients in need of nursing care at home (Asahara et al., 2013). By 1990 community nursing services were widely provided and recognised for their importance in Japanese society (Nagaya & Dawson, 2014).

The community nursing service performs an important role in public health in Japan. (Kashiwagi, Tamiya, & Murata, 2015). For the purpose of this study a community nurse is defined as a home vising registered nurse who works for a community facility as well as in private homes and is called a *houmon-kangoshi* in Japanese. In English this word means home visiting nurse (Takahashi & Fuse, 2012). When a patient is discharged from hospital, the social worker will contact a community general support centre or care manager to do a patient handover to the community registered nurse. The community registered nurse will support the family and provide appropriate nursing care for the patient in their private home.

Community registered nurses have some knowledge of ACP but may not fully understand the concept of ACP, nor its implications (Maeda et al., 2014). Although most Japanese palliative care doctors recognise the importance of ACP, many have failed to implement aspects of patient-directed ACP that they acknowledge as being important, such as recommending completion of legal documentation (Nakazawa et al., 2014). The health

professionals who work in hospital palliative care units are only just beginning to recognise the concept of ACP and its importance (Nakajima et al., 2015).

The Japanese government has presented new guidelines aimed at supporting patients and their families in making informed care decisions (Ministry of Health, Labour and Welfare, 2018). The updated guidelines about the decision-making process of medical care in the last stage of life now include the concept of ACP (Ministry of Health, Labour and Welfare, 2018). These guidelines will impact broadly on the nursing profession as part of the government's guidance for health professionals.

1.2 Background of the research

According to Advance Care Planning Australia (2018), ACP gives a person the opportunity to think about, discuss and record preferences for the type of care preferred and the outcomes that they would consider to be acceptable. The plan helps to ensure that family members and doctors know what a person's health and personal preferences are, and that these preferences are respected.

Ideally, ACP will result in your preferences being documented in a plan known as an advance care directive and the appointment of a substitute decision-maker to help ensure that an individual's preferences are respected (Hunt, 2012).

The priorities for each country are different regarding the varying degrees of progress and development for implementing ACP. Advance Care Planning has been recognised as a concept for nearly 20 years in Western societies, but in Japan, ACP is still a new concept (Sumita, 2015). Unlike Australia, Japan does not have a legal or policy framework to support ACP and very little is known about the present state of ACP in Japan. The recently developed ACP guidelines in Japan provide no clear direction for patients (Shimizu, 2015),

and this lack of clarity means that both patients and health professionals often struggle to find the most suitable way to utilise ACP (Sumita, 2015).

In response to the lack of current guidelines and the growing number of elderly people in Japan (Shimizu, 2015), the Japanese government recently presented new ACP guidelines

to support patients and family to make informed decisions about their end -of-life care[1] (Minister of Health, Labour and Welfare, 2018). The term ACP was borrowed from western documentation; therefore, it does not represent the definition a same process. The Ministry of National Health (2017) has developed guidelines for medical decision-making processes in the terminal stages of an illness and recommends individualised self-determination by patients for as long as they are competent (Shimizu, 2015). The government recommends respect for a patient's self-determination based on a consensus reached by deliberation between patients, family and health professionals (Shimizu, 2015). However, decision-making processes include shared decision-making through the process of communication, whereby the patient and other people share information and seek consensus on the basis of a patient's way of life (Masujima, 2017). According to the guidelines in Japan, ACP is the process of making a care plan for the terminal stage, it is more than ending note. The guideline of ACP in Japan is best understood as based on sharing information and reaching a consensus. The patient's way of living and values must be at the centre of the advance shared care planning (Shimizu, 2015). However, research demonstrates that even when the government guidelines value the patient's self-determination, the reality is that in practice a patient's wishes are often not the priority (Miura et al., 2017).

Despite Japan being a modern country, existing customs and traditions make it difficult to completely adopt the concept and practice of ACP (Hamamura, 2012). Barriers include the customs and traditions of the Japanese cultural context, along with a lack of understanding of individual decision-making. Some ideas common in Western society such as informed consent is not commonly utilised in the same way in Japan (Miura et al., 2017). As such, cultural differences are one of the barriers preventing the adoption of ACP in Japan (Sato, Beppu, Iba, & Sawada, 2012). It is important to investigate how community registered nurses use ACP in Japan as they are most likely to be in the position of supporting dying patients in their home.

This research seeks to address a gap in the research literature by exploring Japanese attitudes towards ACP. It does this by exploring the effectiveness of ACP as a practical tool

[1] In Australia, ACP means more than end of life care, it is comprehensive process that produces a document to direct care earlier in the disease trajectory. The ACP provides all the documents for the advance care directives which include financial, health and legal components. In Japan, ACP means a discussion of terminal care only (Sudone,2017).

for community registered nurses in Japan (Sato et al., 2012). There is a need for both public awareness of ACP and further research exploring ways of improving ACP in the Japanese context (Tanaka, 2018).

Figure 1.1 (below) was created by the Japanese government in 2017 to demonstrate how to care for elderly people in the community. At present, community registered nurses have a large number of patients in a community without ACP. Therefore, community registered nurses face a difficulty in knowing how to care the patients without any specific documentation. Advance care planning is different in Japan, there is no particular document, policy and process. Community registered nurses struggle to provide nursing care for patients without the clarification of ACP, while the government provides the ACP model but not the framework.

Additionally, hospitals have a limited number of beds for the medical care of patients and patients may therefore be discharged to the community for ongoing care and follow up. Discharging means transferring them into the community sector (Miura et al., 2017). Figure 1.1 (below) highlights the different care options for older Japanese people. However, ACP directions and polices are not mentioned. This figure demonstrates the community-based integrated care system model and the populations its serves.

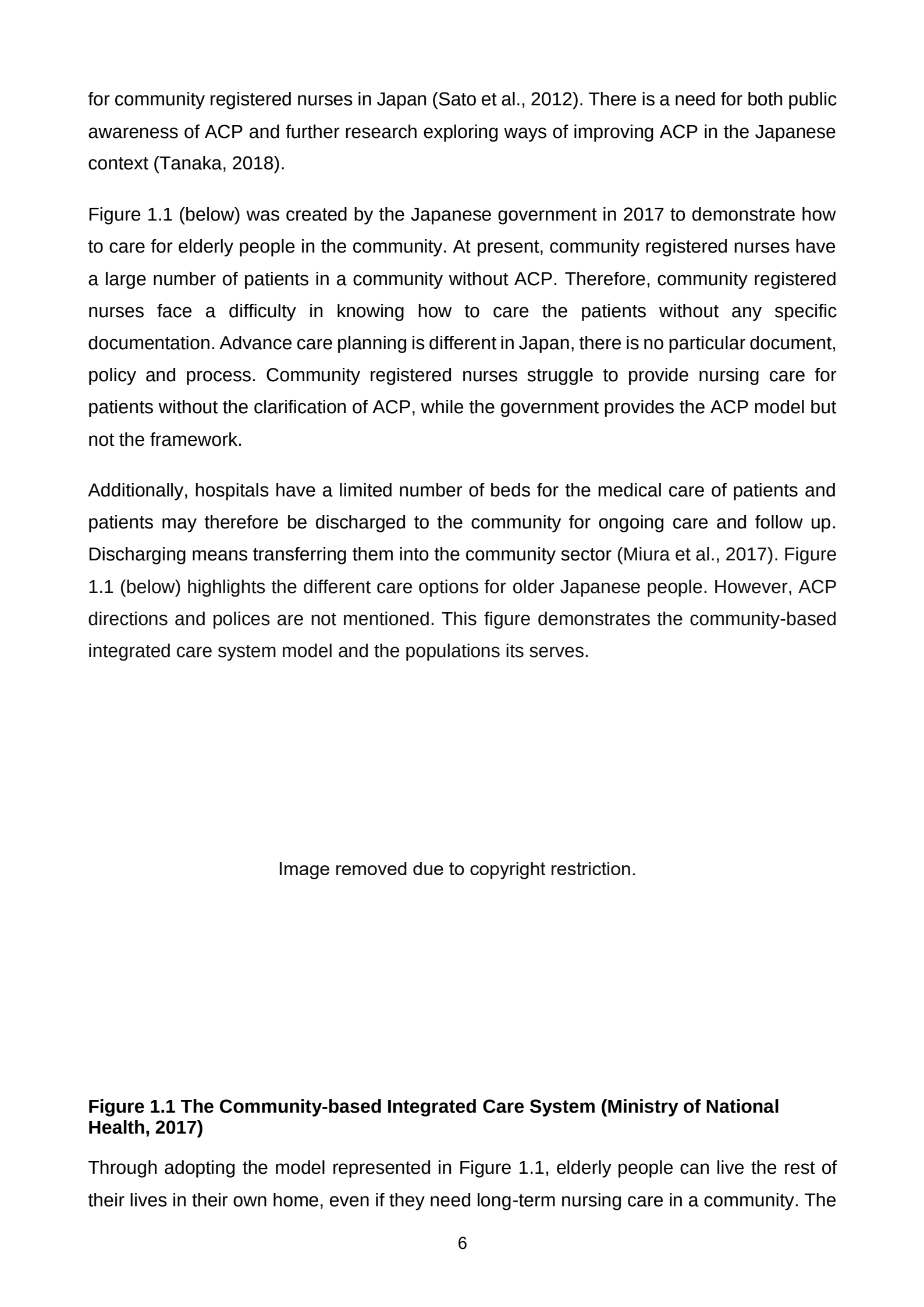


Figure 1.1 The Community-based Integrated Care System (Ministry of National Health, 2017)

Through adopting the model represented in Figure 1.1, elderly people can live the rest of their lives in their own home, even if they need long-term nursing care in a community. The

establishment of the Community-based Integrated Care System is important as it provides care for the elderly patients living in the community (Miura et al., 2017).

The change in population demographics is well documented in Japan (Ministry of National Health, Labour and Welfare, 2018). Figure 1.2 (below) is the diagrammatic representation of the ageing shift in Japanese society (Ministry of National Health, Labour and Welfare, 2018). The Japanese government provided this information because of the need for public awareness regarding supporting the ageing population in the future (Ministry of National Health, 2017). Therefore, Advance Care Planning is needed as a practical concept for medical and health professionals, so that community registered nurses have the capacity for making a choice as to which facility is most suitable for the care needs of their patients.

Image removed due to copyright restriction.

Figure 1.2 Ageing in Japanese society (Japanese Government, 2017)

Figure 1.2 above highlights the total Japanese population of 100 million in 2015, with 15 per cent were people over 75 years of age. However, the entire population is predicted to decrease by 2040, and yet, the 75 years and older category will increase to 20 per cent of the total population (Ministry of Health, Labour and Welfare, 2018). This ratio will be changing rapidly. There is, therefore, an increasing need for health professionals to address the health care needs of older Japanese people.

1.3 Significance of the research

The speed and extent of the ageing of the Japanese population is unmatched anywhere in the world (National Institute of Population and Social Security Research, 2017). Japan is

rapidly ageing, and with this increase in average age there is an increase in the number of elderly people in this country (Ministry of Health, Labour and Welfare, 2018). According to the Ministry of Health (2018), Japan's ageing phenomenon has not yet peaked. The official 2017 forecast predicts that around 40 per cent of Japanese people will be aged 65 or older by 2065 (National Institute of Population and Social Security Research, 2017). This ageing population impacts on every aspect of governance and for ACP, it presents both challenges and opportunities. Advance Care Planning offers an opportunity to address one aspect of the impact of an ageing population (Hirakawa, 2017).

The Japanese Department of Health has been aware for some time of the need for the establishment of a community-based integrated care system (Ministry of National Health, 2017) to support the elderly within the community. However, in Japan, when a patient is transferred from hospital to the community sector, there are problems such as unclear communication, and no specific ACP documentation (Tanaka, 2018). The guidelines provided by the Japanese government are not very clear regarding the patient's self-determination around decision-making of ACP. (Shimizu, 2015). The government recommends respect for patient self-determination based on the consensus reached by deliberations between health professionals and the family (Shimizu, 2015). Without this deliberation, patients cannot have their preferences either known or documented. By 2025, the "Baby Boomer" generation will be aged 75 and above and by then, may have the opportunity to live the rest of their lives in places familiar to them, even if they do become reliant on long-term care (Ministry of National Health, 2017).

The large cities and metropolitan areas in Japan have stable total populations but are rapidly increasing in the percentage of people aged over 75 (Nagaya & Dawson, 2014). As the number of elderly people increases, the establishment of the community-based integrated care system is important to support the community life of elderly people (Ministry of National Health, 2017). Furthermore, while towns and villages have decreased their total population (National Institute of Population and Social Security Research, 2017), there has been a gradual increase in rural areas in people over 75 years of age (Akatsu, 2018). Community registered nurses have an enormous responsibility to respond to this phenomenon (Ono, 2016).

As noted above, there is a movement in Japan to adopt ACP and it is now one of the most controversial topics in the medical and health professionals' field (Bito, Wenger, Ohki, & Fukuhara, 2001). Advance Care Planning is a new concept which is being adopted in a

Japanese way. As a result of health professionals communicating with each other and exchanging information in the field (Nishikawa, Nakashima, Miura, Endo, & Toba, 2011) the ACP grassroots movement is growing and spreading all over Japan (Freeman, 2010). Advance Care Planning should be understood as a communication tool for health professionals and patients (Fahner et al., 2019). The purpose of ACP is to act as a trigger to assist elderly people to speak openly about their feelings and encourage them to plan their dying or end-of-life care (Takezako, Ishikawa, & Kajii, 2013).

In conclusion, several factors need to be addressed when considering ACP and its impact on Japan's ageing population (Ministry of National Health, 2017). There are three main issues identified in the literature regarding ACP:

1. There are challenges for health professionals. Health professionals are concerned about the timing of introducing ACP in Japan (Masaki et al., 2017). There is a conflicting relationship between (a) community registered nurses' responsibilities towards patients in the ACP process, and (b) the responsibilities of health professionals towards the family, who may have wishes different from those of the patient (Sumita, 2015).
2. Barriers such as the customs and traditions of the Japanese cultural background, along with lack of knowledge among the general public; community nurses perceived that patients have many fears about death and illness, which have combined to create a taboo surrounding the subject (Shelley, 2017).
3. Consideration of how to implement ACP is needed. This includes ACP training and education sessions and providing ongoing support (Seymour, Almack, & Kennedy, 2010). Preparing for ageing and ensuring the needs of ageing people are met requires information on the various choices available to a person if they can no longer decide for themselves (Masujima, 2017).

Community registered nurses are often required to provide information to their patients on ACP and to assist them and their families with these decisions (Taguchi, Naruse, Kuwahara, Nagata, & Murashima, 2013). However, there is a significant gap regarding the information provided to people in the community when making their own ACP decisions (Sumita, 2015). It is important to expand registered nurses' knowledge of ACP in Japan as it is a new concept in that country. This research could inform nursing policy and procedures in the area of ACP use in the Japanese community.

1.4 Aims and questions of the research

The overarching question for this research is: “How do community registered nurses use Advance Care Planning in Japan?” There are few research papers relating to those keywords in Japan (Sudore et al., 2017). The gap in this area of research needs investigating and the barriers to the use of ACP by nurse needs to be explored.

This research aims to explore the experiences and perceptions of community registered nurses using ACP in Japan. The objectives are as follows:

1. To explore how community registered nurses utilise ACP in Japan.
2. To explore community registered nurses’ experiences of ACP in Japan.
3. To explore nursing care through an ACP framework in Japan.

These objectives will be met via the answers to questions regarding issues or problems that may arise when discussing ACP with community registered nurses. The researcher explored how community registered nurses could utilise ACP in Japan, and how ACP could assist people with decision making regarding their future medical care. The researcher applied a qualitative method to the research process and the methodology of Interpretive description was used to answer the question. Interpretive description is a qualitative research methodology aligned with a constructivist and naturalistic orientation to inquiry (Thorne, 2016). The aim of interpretive description is to generate knowledge relevant for the clinical context of applied health disciplines such as nursing.

1.5 Thesis structure

This thesis consists of six chapters. Chapter 1 has introduced the background regarding ACP and the current role of ACP in Japan. Chapter 2 presents the literature review, which explores themes around the present state of ACP in Japan. Chapter 3 outlines the research methodology utilised and issues of rigour in researching ACP, including a discussion of the method, recruitment of participants, data collection, ethics and political considerations, and the limitations of this research. Chapter 4 presents the findings of the interviews and discusses the collected data meaning, interpretations, and connections to the previous literature. Chapter 5 presents discussions that describe the findings and recommendations. Finally, the conclusion and suggestions for future research are outlined in Chapter 6.

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction

This chapter considered issues concerning ACP (*advance care planning*) in Japan through a review of previous research on how community registered nurses used ACP in Japan. In Chapter 1, the present situation of ACP involving community registered nurses in Japan was introduced; however, to understand the issues more deeply, this chapter explored and reviewed the literature on this issue. While this thesis focused on registered nurses working in the community setting in Japan, the literature review had also examined the research that has been published within the broader context of ACP. The eight articles included in the review were evaluated using two critical appraisal tools to analyse the quality of each article before highlighting their strengths and limitations: Critical Appraisal Skills Programme (CASP) (2018) applied the evaluation of qualitative studies was using review checklist. In addition, The JBI Critical quantitative study applied an appraisal checklist for the analytical cross-sectional studies (JBI check list,2017). A thematic analysis of the eight articles resulted in the identification of three themes: the perceptions of ACP by Japanese community registered nurses, cultural difference aspects surrounding of ACP in Japan and the legal facts -documentation.

The first theme identified were the perception of ACP by community registered nurses and an understanding of how ACP supported community registered nurses who had have experienced difficulty in taking care of patients due to the rapidly ageing population in Japan. An issue that caused numerous deaths in the community. The second theme was concerning the cultural component of ACP in Japan, to examine the issues surrounding the cultural contexts of the decision-making process. For the final theme the review explored the legal issues, including the uncertain definitions of ACP and documentations. A systematic literature review (SLR) identified, selects and critically appraises research in order to answer a clearly formulated question (Dewey, A. & Drahota, A. 2016). The systematic review followed a clearly defined protocol or plan where the criteria is clearly stated before the review was conducted. It was a comprehensive, transparent search conducted over multiple databases and grey literature that can be replicated and reproduced by the researcher. It involved planning a well thought out search strategy which had a specific focus or answers a defined question. The review identified the type of information searched, critiqued and reported within known timeframes. The search terms, search

strategies (including database names, platforms, dates of search) and limits all need to be included in the review.

The review used “Preferred Reporting Items for Systematic Reviews and Meta-Analysis” (PRISMA) chart to summarise the article selection process and a summary table was used to organise and summarise information about each article (Shamseer,2015).

The review aimed to examine the studies related to the research question regarding the factors that contributed to the utilisation of ACP for health professionals, and to identify the gaps and challenges in this area of study. This review outlines, summarises and critiques the articles relevant to the research question, before ending with an integrated discussion of the research literature. The removal of irrelevant literature provided the perception of other health professionals experiences and particular medical settings.

2.1 Article search and selection process

A comprehensive search was conducted using the electronic databases PubMed, CINAHL, MEDLINE, Scopus and J-STAGE. Initially, searching was limited to primary research articles: an electronic database search was conducted based on research articles published between 2010 and 2020. Studies considered for inclusion in the review were those which used a qualitative methodology, or a mixed methods approach with qualitative results clearly distinguishable. Qualitative and mixed methods peer-reviewed work, in order to have the greatest possible pool of potential appropriate studies. The retrieved articles were restricted to those on ACP published in English and Japanese, and the literature search field setting was in Japan. The literature review exclusion criteria were: 1) not primary research articles; 2) peer-reviewed research included excluded; 3) articles not written in the Japanese or English languages; 4) articles published before 2010; and 5) articles related to emergency departments and sudden death (see Appendix 1). The inclusion criteria for the search included primary research journals using the following keywords and combinations: “nurses” or “community nurses”; “advance care planning” or “advance directives”; “Japan”.

The PRISMA chart represented the flow of the review process, including the initial search, identification, second search, screening, and the final results of the search (see Appendix 2). A search of the Medline database failed to find any articles matching the specified terms. To broaden the scope of the search, the researcher accessed additional works of literature. This involved extending the keywords by removing “community registered nurse” from the inclusion criteria and changing the keyword to “nurse”. Scopus was searched for articles

with the search terms: “ACP”; “advance directives”; “nurses”. The researcher also added the keyword “Japan”, and the subsequent literature search resulted in 142 articles being retrieved; however, 131 of these were excluded as they did not match the specific keywords community registered nurses and by abstract and title. The Scopus database yielded 9 articles. The search of the MEDLINE and PubMed databases resulted in 10 articles. The search of CINAHL resulted in 11 articles. An additional search was conducted through Google Scholar J-STAGE (a Japanese data base) and a further 21 articles were identified; and two duplicate articles were removed. This left 30 full-text articles, of which 22 were discarded as they did not meet the inclusion criteria. Thus, eight full-text articles were included in the review; two were qualitative and six were quantitative in their design.

2.2 Critical appraisal of selected studies

The literature review sought to explore the experiences of community nurses who used ACP in a community setting. The research methods used in the two qualitative studies were a descriptive qualitative approach and a Delphi survey and semi-structured interviews (Takahashi & Fuse, 2012:Tsuruwaka, Omomo, & Sumita, 2016). These were critically appraised using the Critical Appraisal Skills Programme (CASP) tool for qualitative research to explore the rigour of the research (CASP, 2018) (see Appendix 3). Six quantitative studies (Ishikawa, Fukui, & Okamoto, 2018; Nakanishi, Hirooka, Morimoto, & Nishida, 2016; Nishiguchi, Sugaya, Sakamaki. & Mizushima, 2017; Takada et al., 2019; Takahashi et al., 2017; Takezako et al., 2013) were evaluated using the JBI (2017) critical appraisal checklist for analytical cross-sectional studies (see Appendix 4).

The final eight reviewed articles were all primary research articles, with each being carefully appraised to examine the quality of the evidence provided. The articles were evaluated using a relevant appraisal tool, to judge the research evidence and to identify their strengths and weaknesses, in order to assess the validity of their findings.

2.3 Thematic analysis

Thematic analysis of the qualitative and quantitative findings of the relevant studies enabled an understanding of the experiences of the community registered nurses in relation to ACP, through the identification of themes, elements and patterns within the text (Aveyard, 2014). The findings of each study were analysed to allow familiarity with the data. Firstly, reading the articles many times helped the researcher to become immersed in and intimately familiar with the content. After this, the most common terms were labelled, and the findings were the perception of ACP by community registered nurses, cultural differences aspects were

surrounding of ACP and legal facts and documentation grouped according to the recurring themes and concepts which emerged. These themes were described, summarised and presented in tables (see Appendices 5 & 6). The analysis revealed various perceptions of ACP concerning the role of community registered nurses in Japan.

2.4 Findings

Three themes were derived from the qualitative findings of the eight studies that relate to the perceptions of ACP of community registered nurses:

1. The perceptions of ACP by Japanese community registered nurses.
2. Cultural difference aspects surrounding of ACP in Japan.
3. Legal facts-documentation.

Each of the three areas were discussed in more detail below.

The perceptions of ACP by Japanese community registered nurses

Regarding perceptions, there were several barriers to community registered nurses discussing ACP with patients (Masaki, 2017), and these were avoiding talking about death, dependency on others about decision-making regarding treatment, and difficulty talking about nursing care and estranged family relationships (Tsuruwaka,2016: Takahashi,2012). however, there were several positive factors regarding talking about ACP that were identified: it was a way of resolving anxiety by the family; it was a way to support the patient's wishes beyond those of the family; and it was a way for the patient talk about nursing care with all family members.

Cultural difference aspects surrounding of ACP in Japan

Nurses were not often informed of the patient's end-of-life care wishes. In the studies, many patients talked about their ideal way of dying. Some wished for a *pokkuri* death, which means dying immediately without suffering from disease or bothering the family. Others wished for a natural death surrounded by family at home (Ishikawa et al., 2018). In one case, these wishes were not communicated to the family, so when the patient stopped breathing the family called the ambulance and life-sustaining treatment was provided by the medical professionals against patient's wishes (Ishikawa,2018). In this situation, the family were able to keep their "public face" without the patient sudden death by the further prolong medical

treatment. The cultural difference in the decision-making around nursing care included the experience of life-sustaining treatment being requested by the family members. These studies showed how health professionals perceived the importance of knowledge of a patient's ACP for the family.

Japanese society traditionally tended to value non-verbal messages over verbal communication (Takahashi & Fuse, 2012). For example, the emoji had been created by the Japanese to express their feelings in non-verbal ways and displayed what was being experienced or felt without using verbal communication (Nakanishi et al., 2016). This was a customary trait among the Japanese people that had complicated the ethical issues surrounding ACP. In Japanese society, people who knew each other often shared their feelings through non-direct forms of communication. Furthermore, physicians were very indirect in conveying their diagnoses or prognoses to cancer-ridden patients, because the doctor was felt that if the patient were told of their diagnosis, patients lost the will to live and then had chosen to die (Takada, et al., 2019). There were still some physicians in Japan who did not provide enough information, preferred the former strategy to encourage patients to retain hope and had have a better quality of life (Takahashi et al., 2017). Therefore, the community registered nurses were confronted with lack of clarity, information and the direction in supporting patients with the quality of end-of-life care.

Planning and achieving quality of life during terminal nursing care needed to be supported by informed consent (Tsuruwaka, 2018). Nursing was a discipline strongly embedded in cultural and social phenomena. Japanese cultural matters and beliefs and how they were socially transmitted, played a major role in how Japanese nurses felt and how they managed their work with elderly patients. Traditionally, the individual was viewed as being socially embedded and part of the larger group. However, with the generational change, especially amongst the baby -boomers, and the shift to Western individualism, the current generation expressed more clearly their wishes and opinions to the others (Nishiguchi et al., 2017).

The skills of community registered nurses were examined via the qualitative studies. The results revealed community nurses' understanding of the terminal care needs and the wishes of elderly patients (Takahashi & Fuse, 2012). Takahashi (2012) collected data from 12 nurses using semi-structured interviews and the data were analysed using content analysis. The community registered nurses' understanding of their patients' wishes was based on two key factors: status and skill. In this context, status referred to the uncertainty of when the terminal period started for the patient (the patient being unaware that they were

at the terminal stage) and the terminal timeline when the circumstances changed for the patient (Takahashi & Fuse, 2012). Additionally, many patients were unable, unwilling and too uninformed to communicate with doctors and nurses, so most of patients relied on their family to make decisions. The skill of nursing care involved understanding the patients' wishes on how they would like to spend their time, through daily communication and interpreting the patients' wishes. Community registered nurses used these skills to cope with the difficult issue of understanding their patients' wishes. Overall, the articles had only a small study population and while the qualitative results did not appear generalisable.

Legal facts-documentation

The quantitative article (Ishikawa, 2018) was the association between ACP by a visiting nurse and achieving the desired place of death for patients with end-stage cancer, the cross-sectional nationwide 1000 question survey with 374 responses. It showed the interest had risen in ACP in recent times, particularly concerning the patient's right of self-determination and a variety of issues regarding decision-making. Regarding the place of death,65 % of patients wanted die at home, however, 74% of patients died at the hospital and 13% of patients died at home. With these findings, the patients' preferences needed to be protected by the documentation, however, there was no specific documentation with the definition of ACP. Therefore, both patients and health professionals were struggling with the issue and were considering the most suitable way to practise ACP. (Takezako et al., 2013). Takezono (2016) sent a nationwide survey to 913 nursing homes to investigate whether adoption of advance care directives were useful and effective. Takada (2019) developed and validated ACP support tools for patients. This researcher suggested that there was a need to develop ACP, to accumulate information about education, to clarify the definition of ACP, and to establish and improve technical support for ACP in Japan.

There was little evidence and research in the research literature about nurses' experiences of, and perspectives on, ACP. To fill this gap, qualitative research was deemed to be more beneficial than quantitative research for examining people's experiences and perceptions (Kumar, 2014). In relation to the Japanese experience, decision-making processes were already occurring, as evidenced by the phenomenon of the *ending note,* an approach widely used throughout Japan over the last decade (Takahashi et al., 2017). *Ending note* was a Japanese word for which there was no direct English translation, and it meant a notebook, mostly for elderly people who may be facing the end of life, in which someone had written

their wishes and needs concerning their funeral, the grave, and their belongings (Shimizu, 2015). However, the physical notebook, message or memo called *ending note* in Japan was not a legally binding document and remains a personal document that relies on the good will of the family to enact.

2.5 Discussion

The findings of the eight selected articles discussed the implementation of ACP in Japan. The articles emphasised the importance of developing knowledge of ACP among health professionals, patients and families. The literature had provided some insight into the experiences of community registered nurses using ACP.

The article showed the ACP decision-making in Japan show that Japanese people were unwilling to speak out about their preferences and demands because family unknowingly tended to care too much about public appearances (Sullivan, 2017). Therefore, a clear documentation needed for both the greater public awareness and the research on effective ways to gather this information and transform the culture to enhance awareness and practice of ACP.

Japan has had the highest proportion of elderly citizens in the world and is facing the imminent arrival of an era of increasing rates of mortality in this age group. In general, elderly people in Japan did not discuss their nursing care preferences with family members and/or health professionals (Masujima, 2017). In response to this omission, a suite of web-based education tools has been developed to encourage public awareness of ACP. This encouraged adults who had have not previously considered ACP to recognise the importance of end-of-life care decisions and preferences.

With breakthroughs in medical technology, there was an increasing number of situations in which the person could extend their life without improving the quality of life. In such cases, the health professionals and the patient's family were conflict in coming to an understanding of the person's final decision. Introducing ACP introduced the possibility of constructing better experiences during a person's last moments.

According to the literature, the Japanese government had been very much aware of the need to establish a community-based integrated care system (Shimizu, 2015). It was essential to have nationwide common guidelines with legally framed decision-making ACP to protect patients' preferences and avoid unnecessary suffering (Nishioka & Arai, 2016). Dealing with dying patients was stressful work for most nurses and nursing was one of the

key occupations that supported patients and family at this time. Patients in Japan were not always informed of the diagnosis or prognosis of their illness (Takahashi et al., 2017). Without the definitive documentation and policy, it was difficult to talk about future medical treatment and a patient's wishes.

Definitive documentation of ACP could protect patients' preferences and wishes concerning their future medical treatment (Takezako et al., 2013; (Masujima, 2017). For nurses with experience of patient-centred care for patients in a terminal condition, ACP could provide a structure to support nurses provided the quality of end-of-life care and enhance quality of life for the patient (Nishiguchi, Sugaya, Sakamaki, & Mizushima, 2017; Takezako et al., 2013).

The cross-cultural analysis emphasised the concepts of individualism and collectivism (Hamamura, 2012). Generally, in Western countries, individualism and personal effort were highly prized, while in Japan there was more of a collectivistic culture (Hamamura, 2012). The core element of individualism was the valuing of independence, whereas collectivism values the group and mutual task obligations (Hamamura, 2012). The consequences and implications of individualism were the valuing of individual choice, personal freedom and self-actualisation, while collectivism made the group's achievements and interests more of a priority (Masaki et al., 2017). The difference in these concepts showed what was culturally appropriate for ACP in Japan. Commonly, quality of life was associated with an absence of pain and/or suffering at the end of life as well as being surrounding by family and friends. Generally, a peaceful end of life was considered an ideal way to die in Japan (Ogihara, 2017; Doenges, 2014). The literature (Takahashi et al., 2017) discussed how the *ending note* was one of the communication tools among Japanese people, and how it was a unique way of approaching documenting their life story. Also, it provided an important function to initiate a discussion about their choices for future medical preferences. Furthermore, there was no definitive written documentation, resulting in misunderstandings through a lack of communication. Best practice needed to also be supported by policy (Jimenez et al., 2018). The Japanese government accordingly established new guidelines for end-of-life care, which enhanced better communication among health professionals (Sumita, 2015).

In the first ACP guide, called *Advance Care Planning* in Japanese, the Japanese government recently presented new guidelines to support patients and their families in making informed decisions concerning their end-of-life care (National Institute of Population and Social Security Research, 2017). Additionally, there were several practical strategies

such as written forms which can also better support communication and ensure consistency. In response to the lack of current policy about decision-making for the end of life, the Ministry of Health, Labour and Welfare (2017) had developed guidelines to improve medical decision-making processes in the terminal stages of an illness and recommends individualised self-determination by patients as long as people are competent to make decisions (Shimizu, 2015). According to Shimizu (2015), ACP was the process of making a care plan which was best understood as on the process of sharing information and coming to a consensus. The patient's way of living and their values must be the centre of ACP (Shimizu, 2015) in a community. This new policy should contribute to resolving issues of communication breakdown in nursing practice in Japan. Clear documentation and standardised ACP forms encouraged better patient-centred care and provided a framework to improve communication between health professionals (Hancock, Butow, Tattersall, & Currow, 2007).

Therefore, it was important to further explore the issues of ACP and how community registered nurses utilise ACP in their daily nursing care. Although of the studies in this review contain beneficial information, they failed to sufficiently consider the perceptions of community registered nurses regarding ACP.

The provision of optimum care for the ageing population was dependent on the understanding of their views and values on end-of-life issues. A qualitative descriptive study was conducted to describe views of elderly Malaysians on Advanced Care Planning (henceforth ACP) and Advanced Directives (henceforth AD), and explored factors influencing these views. Fifteen elderly subjects with ages ranging from 65 to 83 years, representing different ethnic and religious groups in Malaysia were selected for in-depth were interviews guided by a questionnaire. Five core themes were extracted from the interviews:1) Considering the future 2) Contingency plans for future illnesses 3) Attitudes towards life prolonging treatment procedures 4) Doctor-patient relationships and 5) Influence of religion on decisions related to future illness. Despite the lack of knowledge on ACP and AD, older respondents were very receptive to their concept. Although the majority agreed on the importance of planning for future medical management and having open discussion on end-of-life issues with their doctor, they felt it unnecessary to make a formal written AD. Most felt that the future was best left to fate or God, and none had made any contingency plan for severe future illnesses, citing religion as reason for this view. Cardiopulmonary resuscitation, mechanical ventilation and dialysis were considered by most to be invasive life prolonging treatments.

2.6 Conclusion

The focus of this review had been on an exploration of the issues and the knowledge gaps in the perceptions of the community registered nurses regarding ACP. This review had identified strengths and weaknesses in the research literature. Most of the reviewed literature found similar factors that contribute to or act as barriers to the development of ACP in Japan.

Specifically, there was confusion around issues regarding the use of ACP for community registered nurses. There were no recent qualitative studies of Japanese community registered nurses using ACP and had made explicit experiences related to clinical practice around ACP in Japan. Therefore, the researcher sought out the perceptions and experiences of community registered nurses utilising ACP in a metropolitan area of Japan. In the following chapter, the methodology and methods used to carry out the research will be discussed.

CHAPTER 3 METHODS

3.1 Introduction

The previous chapter introduced the issue of ACP (*advance care planning*) in Japan and critically reviewed the literature on this issue. This chapter discussed the research design, approach, methodology, ethical considerations, the study setting and sample criteria, data collection and analysis procedures.

3.2 Research design

This research applied a qualitative descriptive method, as it aims to examine people's experiences and perceptions (Creswell & Guetterman, 2019; Sandelowski, 2004). In qualitative research, the design is flexible, evolving, and emergent, with the researcher as an instrument for data collection (Creswell, 2018). The methodology of Interpretive description attempts to answer the question and the study are made explicit within the interpretations (Thorne, 2016).

The qualitative research questions addressed the community nurses' knowledge on ACP, the use ACP and nurses' experiences when applying ACP for the patient. The participating community nurses were all registered nurses with more than 10 years' experience working with various patients. This last criterion ensured that the nurses had a deep understanding of patient care through their life span.

This study was informed by the qualitative methodology of interpretive description, which involved interviewing eleven community registered nurses. The research employed qualitative approach applied a qualitative method, as it aims to examine people's experiences and perceptions (Kumar, 2014). In qualitative research the design is flexible, evolving, and emergent, with the researcher as an instrument for data collection (Creswell, 2013). In addition, qualitative research design is appropriate for this research question because a smaller sample size is suitable for understanding and interpreting human perspectives in richness and depth of the data rather than focus on the size (Liamputtong, 2013).

Research design involved first formulating a question to investigate what is important, and then defining this question using the Population Intervention Comparison Outcome (PICO) framework (Riva, Malik, Burnie, Endicott, & Busse, 2012). Various types of questions required a different type of study design depending on the nature of the questions (Creswell,

2013). Consequently, the study questions related to a deeper understanding of the ACP experiences of community registered nurses is necessary in qualitative research (Wenger, 1991). Furthermore, qualitative research was useful in answering how, why and what questions regarding human behaviour, and therefore had been chosen to help answer the how and what questions regarding community registered nurses' behaviour (Creswell.2013). When researching a new area, it was important to explore the experience of those working in or with the phenomenon under investigation (Schneider & Whitehead, 2016). Moreover, as ACP was an unfamiliar concept in Japan, the deeper understanding which comes from qualitative research can help examine this new concept and provided a framework to explore a subject area in which very little is known (Kumar, 2014). Therefore, the researcher had determined the qualitative research approach as most suitable one for answering the research question and most appropriate for the research design.

3.3 Research approach

The term epistemology referred to the nature of knowledge and understanding that can be gained through various types of inquiry, and other methods of investigation (Clark, 1996). Epistemology was a consideration for this research as it concerned the connection between the researcher and their knowledge. Epistemological approaches included several conceptual frameworks: objectivism, subjectivism and constructionism (Crotty, 1995). The conditions of these frameworks had implied truth, belief and justification (Crotty,1995). Subjectivist epistemological theory stated that in the social world, when a human strives to find meaning in something, they may well import meaning from other sources that were quite removed from that something, or even from a world of make-believe (Charon & Ferréol, 2009). This approach also explored the subjective meaning of social action – the relationship between an individual's perceptions, interpretations and actions. Subjectivism depicts the society in which individuals live, even though they could only experience a small part of the overall social and cultural world (Laberge, 2009), and suggested that this was strongly influenced by an individual's experiences. Everyone had gone through a unique socialisation process and social-cultural journey (Charon & Ferréol, 2009). Human culture was the basis of communication and co-operation, which made it possible to pass down that culture from one generation to the next (Charon & Ferréol, 2009). This subjectivist approach, which could be the basis for this research, is concerned with the question of where human action and behaviour came from and developed ideas about how the world operates (Creswell, 2013). The approach defined the interpretive paradigm in terms of a subjectivist epistemology, where inquirer and inquired into were fused into the findings that were created in the process

of the interaction between the two (Polit & Beck, 2016) Epistemology is a consideration for the research and describe different aspects of the research findings. This relationship influenced the research questions and answers.

3.4 Interpretive description as a methodology

Thorne (2016) developed an approach known as interpretive description to facilitate the transfer of the knowledge to the clinical nursing context. Interpretive description studies attempt to answer the practical thematic and integration aspects of a phenomenon, and the study within the interpretations (Thorne, 2016). Moreover, interpretive description as a methodology was more effective at producing results than phenomenological or grounded theory description. Phenomenology was intended to explore a specific phenomenon and grounded theory is used to develop a theory (Sandelowski, 2007). Because interpretive description entered the findings derived from blended approaches, it was more likely to result in the easier establishment of consensus among researchers. The researcher decided this was a significant strength of the methodology to deal with community registered nurses' experiences in how to use ACP in Japan. Interpretive description reflected a significant proportion of the questions filtered through a disciplinary lens (Polit & Beck, 2016). This emphasised the nature of the value of analysing a phenomenon and was adopting it to the context of healthcare practice. It suggested that there was inherent value in the careful and systematic analysis of a phenomenon and an equally pressing needed for putting that analysis back into the context of the practice field, with all of its inherent social, political and ideological complexities (O'Donoghue, 2007). The researcher was able to maintain a coherent logic in the research structure with the selected methodology. The following section discussed ethical considerations, the selection of the sample, the data sources, data analysis and rigour of this study (Thorne, 2016).

3.5 Ethical considerations

Ethical approval was obtained from the Flinders University Social and Behavioural Research Ethics Committee (SBREC) project number 8297, before the commencement of the study (see Appendix 9). Written approval was also obtained from the Kenwa-kai organisation in Japan. This organisation was responsible for research interviews and therefore needed to provide ethics. The researcher presented the information sheet (Appendices 10 & 11) and the introductory letter (Appendices 7 & 8) to those willing to participate, who were expected to sign a consent form (Appendix 12).

Upon approval, it was important for the researcher to minimise the risk of harm. All the participants were treated ethically and had prior knowledge of the research background and purpose to the study. The information sheet carefully briefed the participants. It informed them about participation in the research, and that they could withdraw from the interview at their own direction at any time and without any prejudice. Further information was given to participants to enable them to contact a free counselling service, if needed. Subsequently, the researcher contacted each participant by telephone to schedule the interview at a time and in a private place that was suitable for the participant.

Regarding confidentiality and anonymity, the participants were treated in strict confidence, and were encouraged to uphold their rights in the interview through the explanation of the consent forms and the reiteration of best practice research protocols. Their real names were never revealed, nor did the actual names emerge through the interview process, and the names were changed to pseudonyms for the interviewing process. The interviews were conducted using a personal digital audio recorder and the data was stored securely in Flinders University's OneDrive system.

3.6 Study setting and sample criteria

The participants were recruited from a community setting in a metropolitan area in Japan. They worked in a community-based facility which has been established for more than 10 years, and the community nurses were well known among local people. The facility was well connected to the local people and had a high reputation for providing quality primary health nursing care.

The participating community nurses had a registered nurse qualification and more than 10 years' experience working with various patients, criteria that ensure they have a deep understanding of patient care. Potential participants who were excluded were community nurses who were working in hospitals or clinic facilities, company nurses and school nurses. Table 3.1 (below) presented the inclusion and exclusion criteria for potential participants.

Table 3.1 Inclusion and exclusion criteria

Inclusion	Exclusion
Located in a metropolitan area of Japan	Not in metropolitan Japan
Community registered nurses	Enrolled nurses, hospital registered nurses
Community-based facility	Hospital, clinic, school, company or nursing home facility
Over 10 years' work experience as registered nurses in Japan	Less than 10 years' work experience as registered nurses; not working in a community.
Japanese	Non-Japanese

The final sample consisted of 11 community nurses from community-based facilities in a metropolitan area in Japan. Each participant worked at a different facility, so the researcher could encounter several different approaches to ACP and community registered nurses' opinions of ACP. A large number of participants were not considered necessary as for qualitative research richness of data is more important than the number of participants. For this kind of study, 11 participants were not a small number.

3.7 Data collection

Eleven community nurses were individually interviewed. The participants had an average of 26 years' experience working as registered nurses. The minimum length of experience was 20 years, and the maximum, 35 years. The average time of community nursing experience was seven years, with a range from five to 14 years. The length of time indicated a broad range of interviewees' experiences in nursing and community care. Within this sample, 9 of the 11 nurses interviewed were familiar with ACP, and one had attended a seminar on the topic.

All participants were recruited by the poster at the permitted nursing station in three metropolitan areas in Japan. They were in a community-based facility which has been established for more than 10 years, and the community nurses were well known among local people. The facility was well connected to the local people and had a high reputation for primary health nursing care.

In-depth individual unstructured interviews were used to collect qualitative data. Interviews were recorded via audio-voice recordings, which were transcribed in Japanese. On the same day, the Japanese transcriptions were translated into English by the bilingual

researcher. At the time of transcription and translation, the researcher took care to respect the participant's right to privacy and confidentiality (Borbasi, 2015). The participants were interviewed individually face to face to explore the more intimate and personal aspects of their caring experiences. Unstructured interviews allowed participants to tell their stories with little interruption and provided an opportunity for in-depth, data collection.

The individual interviews were used to collect qualitative data. The participants were interviewed individually face to face to explore the more intimate and personal aspects of their caring experiences. Unstructured interviews were used as these allowed participants to tell their stories with little interruption and provided an opportunity for in-depth, data collection. The semi-structured interview technique was not suitable because of the possibility of over representing the researcher's views, and due to the lower flexibility of that interview technique and consequently lower capacity to collect participants' views, attitudes, behaviours and experiences.

Interviews were audio-voice recorded and transcribed in Japanese. Interviews ranged from 30minutes to 60 minutes in length. On the same day, the Japanese transcriptions were translated into English by the bilingual researcher. At the time of transcription and translation, the researcher took care to respect the participant's right to privacy and confidentiality (Borbasi, 2015).

There are several issues with implications for the interpretation of the research results (Polit & Beck, 2016) This issue here is the translation from Japanese to English and from English to Japanese. The researcher is in this case one of the research instruments determining the results; the researcher is bilingual but there is always a risk of compromising the reliability of the results (Polit & Beck, 2016). Following Braun and Clarke (2006) 6-step framework of thematic analysis, the researcher made an extensive reading the transcripts noting down the initial ideas. Then the researcher manually coded every piece of text that seemed to specifically address the research question. The researcher did this by hand initially, working through hard copies of the transcript. The themes and potential subthemes were then categorised, analysed, reviewed, and named. Validity checked by supervisors and supported by the triangulation of data sources.

3.8 Data analysis

Collected data only became meaningful when it has been analysed (Polit & Beck, 2016). The qualitative researcher was described as the research instrument insofar as her ability to understand, describe and interpret experiences and perceptions was the key to uncovering meaning in particular circumstances and contexts.

Thematic Analysis, according to Braun and Clarke (2006), were conducted inductively or theoretically. Inductive analysis codified the data without taking into account the researcher's preconceptions. In this kind of analysis, the review of prior literature may restrict the researcher's engagement with the data, so it was advised to first browse through the data carefully. In theoretical analysis, on the other hand, the codification process was theory-driven, hence good understanding of available and accessible literature was more helpful in this study.

One of the strengths of Thematic Analysis was that it could draw themes both from motivation, experiences and simple meanings (that reside in the data) which referred to the essentialist point of view and socio-cultural contexts which referred to the constructionist approach. There can, however, be an amalgamation of both that may be suitable for a more rigorous analysis. The data analysis in this study was conducted following Braun and Clark's (2006) Six-step guidelines: When the transcripts were completed, data were grouped and coded to identify their meaning.

Step 1: Become familiar with the data

Step 2: Generate initial codes

Step 3: Search for themes

Step 4: Review the themes

Step 5: Define and name themes

Step 6: Produce the report

The initial lists of codes were generated by the data. Maguire (2017) states that the process of coding is part of the analysis and can be undertaken either manually or by using a software program. In this study, the manual approach to analysing the data was applied.

Step 1: Becoming familiar with the data

The verbal data were transcribed and then pseudonyms were given to the 11 interview participants – Mayumi, Naomi, Saki, Takako, Yoko, Keiko, Yoshi, Asami, Hisako, Chisato and Denko. The 11 transcripts were read and re-read many times, as Braun and Clarke (2006) emphasised the importance of immersion in the data. 'Repeated reading' helped the researcher to find meanings in the participants' responses and to establish patterns in the data.

Braun and Clarke (2006) stated that it was useful to first make notes and jot down early impressions. This record allowed the researcher to reflect on the interviews and obtain deeper insights. The notes below quoted from the research diary outline the researcher's thoughts and impressions, along with points of reflection following several interviews. This diary entry occurred on the second day of the interviews:

> *16th April 2019*
>
> *The researcher found it was not easy to talk about ACP, the community registered nurse had various thoughts for the ACP assessment process, including patient preferences with family discussions, the researcher felt it could be complicated. The nurse seemed confused about the concept of ACP in practice in Japan. The definition of ACP was different in each facilities that the researcher attended. There were cultural reasons and barriers behind to utilise of ACP as well. The community registered nurses could not have a hope to change to discuss ACP directly with the patient (R1).*

The use of name codes and pseudonyms throughout the thesis maintained anonymity and confidentiality. The code name R1 referred to the researcher.

Step 2: Generating initial codes

Following Braun and Clarke (2006), this step was where the researcher started to organise the data in a meaningful and systematic way. The process of coding reduced data into small portions of meaning and enabled the researcher to become embedded in the deeper nuances of the data.

An initial list of ideas was generated about what the data contained, and this step involved the production of initial codes from data. The researcher manually coded every piece of text, then developed and modified the codes as she worked through the process. The researcher worked through each transcript, coding every segment of text that seemed to specifically address the research question. The researcher did this by hand initially, working through

hard copies of the transcript with pens and highlighters. The themes were then categorised and analysed. Table 3.2 (below) shows the most commonly used words.. The themes and potential sub-themes were then categorised, analysed, reviewed and named. Validity was checked by supervisors and supported by the triangulation of data sources.

Table 3.2 Frequently used words

Participant Pseudonym	**Words**				
Mayumi	Super ageing society	Family thought	Treatment for prolonging life	End-of-life care	Decision-making support
Naomi	Decision-making support	Treatment for prolonging the life	Family thought	Informed consent	Home care responsibility
Saki	Communication	Treatment for prolonging the life	Documentation	Decision-making support	Family thought
Takako	Home care	Decision-making	Quality of life	Family support	End-of-life care
Yoko	Family support	Decision-making	Responsibility	End-of-life care	Documentation
Keiko	Advance directives	Home care support	Decision-making tool	Definition	Family support
Yoshi	End-of-life care	Family support	Decision-making	Quality of life	Documentation
Asami	Treatment for prolonging the life	Decision-making	Documentation	Family support	*Ending note*
Hisako	Advance directives	Decision-making	Family thought	Home care	End-of-life care
Chisato	Decision-making	Family support	End-of-life care	Definition	Advance directives
Denko	Responsibility	Family	Decision-making	End-of-life care	Ageing

Step 3: Searching for themes

The listed codes were searched to develop the research themes. The five chosen themes were: 1) family concerns; 2) informed consent and discussion; 3) cultural differences; 4) an ageing society with prolonged life; and 5) responsibility and documentation.

Step 4: Reviewing the themes

The five major themes were refined, after which some were collapsed into themes. The five themes were then identified as: 1) Family concerns, including sub-themes of family power and guilt; 2) Informed consent and discussions, including sub-themes of unclear information and “no one talks about it”; 3) Cultural differences, including sub-themes of the traditional ways of thinking and not talking about death; 4) An ageing society and quality of life; and 5) Responsibility and documentation.

Step 5: Defining and naming the themes

This step involved the final refinement of the themes. Formal names were given to the themes to give a sense of what each theme was about. The relationships between the themes and the collected data were continuously reviewed to ensure compatibility and inclusiveness.

Step 6: Producing the report

Five themes were identified, which will be presented in depth in the following chapter – Chapter 4 Findings.

3.9 Rigour

Methodological rigour of qualitative research involved four main concepts: credibility, transferability, dependability and confirmability (Sandelowski, 2007).

Credibility was a measure of how well the researcher understands and interprets the views presented by participants (Leeman & Sandelowski, 2012). To ensure credibility, all participants’ interviews were recorded accurately, and the audio-recorded data were transcribed verbatim and stored in a secure location.

Transferability referred to the generalisability of the inquiry (Melny, 2015). In this context, it meant to what extent the community registered nurses’ perspectives on ACP could be generalised more broadly to the Japanese health professionals’ context.

Dependability referred to the responsibility of the researcher to ensure the process was transparent, logical and traceable, with clear documentation (Liamputtong, 2013). All the procedures for data collection and interpretation were clearly organised and well-documented to enhance dependability.

Confirmability was concerned with interpretations of data. The researcher provided the research findings via data from interviews and ensured that the research findings were derived from the data, not the perspective of the researcher (Borbasi, 2015). The collected interview data were audio-recording, played many times for listening and noted, accurately transcribed, interpreted and translated into English from Japanese by the researcher with supervised by supervisors.

When evaluating the rigour of research, common criticisms of the study's qualitative approach were considered. These considerations included lack of reducibility, lack of generalisability, and researcher bias. These considerations were taken into account in the design of this qualitative study to ensure that the research results were trustworthy. The methodological rigour of the study minimised any potential bias.

3.10 Conclusion

This chapter had provided an overview of the methodological approach taken to answer the research question. The criteria for the selection of the sample were explained in detail (Polit & Beck, 2016). The chapter also described the strategies used to recruit the participants, collect data and analyse the data, as well as considering the ethical issues for the study. Finally, a discussion of the rigour of this study described strategies used to enhance the trustworthiness of the findings. The next chapter will present the study's findings.

CHAPTER 4 FINDINGS

4.1 Introduction

This chapter described study findings. Data were collected by interviewing community registered nurses in Japanese. The interviews were transcribed into Japanese then translated into English and then interpretive descripted analysed. The chapter consists of two parts: the demographic data of the participants; and the major themes and sub-themes from the thematic analysis of the interview data.

4.2 Participant demographic data

There were 11 participants in this research study. All were Japanese women who were working as community registered nurses in a metropolitan area of Japan. Table 4.1 (below) presented the demographic data of the participants (anonymised with pseudonyms) who were interviewed.

Table 4.1 Demographic data

Pseudo Name	Years working as a registered nurse	Years working as a community nurse	Knowledge of ACP	Attendance of an ACP seminar
Mayumi	28	5	no	no
Naomi	21	10	yes	yes
Saki	27	8	yes	no
Takako	35	5	yes	no
Yoko	22	5	yes	no
Keiko	34	14	yes	no
Yoshi	20	5	yes	no
Asami	21	5	yes	no
Hisako	30	6	yes	no
Chisato	24	8	yes	no
Denko	28	5	no	no

Participants had an average of 26 years' experience working as registered nurses. The minimum length of experience was 20 years, with the most experienced registered nurse having 35 years' experience. The average time of working in the community was 7 years,

ranging from 5 to 14 years. The length of time indicated a broad range of experiences in nursing. Within this sample, 9 of the 11 nurses interviewed had heard of ACP (Advance Care Planning), and just one had attended a seminar.

4.3 Finding the major themes and sub-themes

The data analysis in this study was informed by Braun and Clarke's (2006) Six-step guidelines, which emphasised the importance of being immersed in the data (Braun & Clarke, 2006). In accordance with Step 1, was becoming familiar with the data, the 11 transcripts were read many times. This "repeated reading" helped the researcher to find meanings in the participants' responses and to establish patterns in the data.

Five major themes were defined and named (Step 5). The themes that were identified:

1) Family concerns

2) Informed consent and discussion

3) Cultural difference

4) Ageing society with quality of life

5) Responsibility and documentation.

These themes were presented in Table 4.2 (below). As well as the five major themes, six sub-themes were identified. The last stage of the process, Step 6, focuses on producing a report on these themes, which will be presented in the remainder of this chapter.

Table 4.2 Themes

Major theme	**Sub-theme**
Family concerns	Family power Family guilt
Informed consent and discussion	Unclear information No one talks about it
Cultural difference	The traditional ways of thinking Not talking about death
Ageing society and quality of life	
Responsibility and documentation	

4.3.1 Family concerns

The patient's family was the key to the patient care and decision-making in ACP. All participants mentioned interventions of family members, who had their concerns, and the imbalance of power. One issue was the patient's feeling that they had no say in the matter as the family have already made the decision on their (the patient's) behalf. The participants emphasised the dependent relationship between the patient and the family. In most cases, families were the decision-makers with the power and authority, and with this there often came a sense of guilt. This theme was divided into two sub-themes: Family power (4.3.1.1) and Family guilt (4.3.1.2).

4.3.1.1 Family power

All the participants illustrated how family power could control ACP. Even when the patient made a final decision regarding preferences, their preferences were often discounted as a result of being overruled by the family. Therefore, the preference regarding ACP often had more to do with the family intervening and their preferences rather than those of the patient. The family, relatives or close friends often have had a high degree of authority over ACP decisions. This was a common theme expressed by many participants, as demonstrated by these quotations:

> *In Japan, we cannot ignore the family's decision even when the decision they make for the patient is different from what the patient's preference is. We need to support the family's feeling towards the patient because the family has more power than the patient. It is very common in Japan, the family always comes in the first position (Saki).*

> *When the patient said, "I want to die", the family kept continuing medical treatment (Hisako).*

> *The patient's intention is not reflected most of the time when the family has a different opinion about medical treatment (Takako).*

The Japanese community registered nurses in this study identified how a family influences the opportunity of the patient, especially if the family already knew information about the diagnosis and prognosis before the patient. Most patients relied on the family for decisions based on the information were given to them. Even though the community nurses often heard the direct voice of the patient daily, the wishes of the family often contradicted the wishes of the patient. This difference of opinion often leaded to conflict as the family often had difficulty accepting the dying process or the death of a loved one.

Participants emphasised the importance of the patient's longer life was important for the family. When assessed information about the patient's quality of life and found the difference made frustrating and confusing for the family. in fact, the first contact was always for the family for any decision-making, before even the patient. Participants stressed the importance of timely patient involvement:

> *There is no discussion when the patients stop breathing, the family call the ambulance immediately even when the patient does not want to be sent to the hospital (Takako).*
>
> *The decision is made by the family without any question; the patient always follows their opinion (Asami).*
>
> *At the community home-based facility, we are supposed to provide a good death at home, however often we cannot choose a good death because the family calls the ambulance to transfer the patient to the hospital (Naomi).*

These quotations illustrated how the power of the family and their involvement in making decisions could not be avoided. When engaging in ACP, the nursing care efforts needed to focus on balancing the patient's wishes with family wishes.

4.3.1.2 Family guilt

The nurses interviewed explained that many families carried the burden of responsibility and guilt in Japan. In traditional Japanese culture, the family should look after each other, especially in relation to the patient's death and the dying process. Sometimes the family's care was clouded by concerns about how the family appeared to public. The family members felt ashamed about how the public might judge the family if the patient died at home without any medical treatment. This feeling of guilt was best illustrated by participants Mayumi and Yoshi:

> *The family does not want to regret the death of the patient, so they ask the doctor for life-extending treatment. It does not matter how much the patient suffers or does not want it (Mayumi).*
>
> *The family's satisfaction is important to medical professionals because they are at the centre of deciding for the patient (Yoshi).*

The participants stated that even when the patient wanted to die, the family would often disagreed, explored instead the possibility of extending life at all costs. Consequently, when extending life treatment was against the patient's wishes, then the family felt guilty:

The family said that they wish I could do a better way. It was so sudden I was not prepared. So I was confused and panicked. I don't know the best way to choose (Yoko).

Regrets and concerns always manifest around someone's death. With many cases, there is no perfect death (Hisako).

The family feel guilty about the patient's wishes (Takako).

When, with an elderly patient, a final dying situation occurs, often the family must make the decisions quickly, without much time for deeper thoughts. This urgency meant the family often felt a great deal of doubt and guilt about the decisions the family made. One community registered nurse thought that she could alleviate the family's guilt through appropriate nursing care following the patient's wishes, which relieved the family of guilt and gave them some satisfaction:

I often felt I had done well when I had attended the funeral, through the family's attitude and behaviour. They thank me. I can only reflect on the response to my nursing care for the patient through family expressions of how the patient had a good life with the community-based care (Keiko).

This guilt was more likely to appeared when the family was taking sole responsibility for making decisions.

4.3.2 Informed consent and discussion

Disclosure of diagnosis was an important aspect of informed consent for ACP (Sullivan, 2017). However, there were cultural differences involved in discussions around disclosure of diagnosis. In North America, for example, there was a focus on upholding the principle of patient autonomy, while in Japan the focus was more on prioritising family dynamics over an individual patient's needs and wishes (Sullivan, 2017). Thus, in these two cultures, the process of informed consent differs significantly.

For the nurses interviewed in this study, *informed consent* means the treatment of a patient by a doctor without the agreement of the patient, a concept slightly different from what the English words imply. Information was not always giving to the patient when the doctor talked about the diagnosis or the treatment and often there was no direct discussion with the patient. This theme was divided into two sub-themes: Unclear information and No one talks about it.

4.3.2.1 Unclear information

This sub-theme referred to unclear or vague information given to the patient or family, and even between health professionals. The community registered nurses in this study

expressed frustration about the doctor not giving enough information to the patient and the family or the nurses. In Japan, it was common for doctors to prioritise the family as the first person or persons to talked about the patient's medical condition. Therefore, the patient did not know the full diagnosis or prognosis. This quotation illustrated the problem:

> *Part of the problem with informed consent is that it's not always directly delivered to the patient. The patient doesn't know what's going on; the family have to make a decision instead of the patient and this is huge stress (Naomi).*

The participants also recognised that disclosure was stressful for the doctor as well as the patient and family. Individual doctors had the choice to tell the patient or the family, depending on their relationship with them.

> *Informed consent is not always delivered to the patients directly; instead, it is delivered to the family first. The patient does not know the diagnosis and the prognosis until the end-of-life stage. The family are concerned and think it is better to hide the information because of concerns and worry that the patient will find it impossible to cope (Yoshi).*

When a sudden situation occurs, such as when the patient stopped breathing, the family was forced to make immediate decisions. The family had difficulty clarifying the situation or making decisions around care because they were hesitant to ask doctors for more information, even if they did not understand what's happening. Another issue was that the nurses often have not had appropriate handover information from doctors and other health professionals. This meant the whole process becomes unclear. It did not matter whether the information was provided at the beginning, middle or end of the process, but often the information was not given to the patient at all. Instead, it was given to the family, regardless of the patient's mental capacity.

4.3.2.2 No one talks about it

The participants emphasised the lack of communication between health professionals, the patient and their family. Communication was a very important element of nursing care, but in an end-of-life situation few people talked about the prognosis.

One participant stated that often the doctor did not explain the patient's prognosis to the nurses and the patient's family and recommend the best treatment options available to extend life, even in situations where it was clear the patient was dying. In many cases, community registered nurses were faced with pressing concerns that needed to be communicated to the patient and the family while doctors were absent:

Doctors never talk clearly about someone's prognosis; some of them consider patients as not ready to listen to bad news. They are afraid of the family's reaction as well. Time goes by, and there is not much opportunity to face reality for the time being. They lose the chance to talk about it. On reflection, there are consequences when people are fearful of taking responsibility. I felt I was blamed for this. (Saki).

One nurse stated that sometimes health professionals omitted bad news instead of providing all information to the patient so doctors could make their own decisions in a timely way. Participants expressed frustration at situations where it was unclear how much information the patient had when they made decisions. Many suggested that additional communication training would be helpful and argued that more support was needed to promote good communication skills:

There is no opportunity to discuss with a doctor and a patient; no one talks about it. The doctor doesn't initiate the conversation, and because of that, patients stay suffering and their pain is not managed at all (Naomi).

With any treatment, the positives and negatives for the future should be clearly explained to the patient (Hisako).

Doctors need to explain the treatment in more detail to the family (Mayumi).

In Japan, it was common for patients and families to hesitated when expressed opinions to the doctor. Doctors tried to keep opportunities to talk to a minimum even though it was their job to give medical information to the patient. Often, patients were unsure as to whether they had the full truth of their diagnosis and were likely to just accepted what health professionals told the patient to do without asking further questions.

In Japan, the main priority for health professionals was to extend life, regardless of an individual patient's situation or age. It was common for doctors to explain the purpose of the treatment in terms of reducing symptoms, but doctors rarely talked about the negative aspects of the procedure:

The Medical Doctors Association has a positive attitude to ACP in Japan. They say it's important to discuss patients' preferences at an early stage; however, the guidelines are unclear and vague. ACP can be a good way to trigger clear conversation (Chisato).

Participants recognised ACP as an important topic in the health profession and thought it could be useful as a way to address the barriers of disclosure and unclear information.

4.3.3 Cultural differences

Participants were aware of cultural differences when introducing ACP and described how ACP had been accepted in Japan. While the concept of ACP was imported from Western culture, when translated into Japanese the concept was unclear and did not have any legal imperative. The difference in translation of ACP between the West and Japan will be further elaborated on in the next chapter.

It seems that some health professionals were against the Western concept of ACP and were unwilling to accept it. Some cultural differences, including professional responsibility, indirect communication, and the role of the family, had been used to explain the different approach to disclosing medical information in Japan. Also, Japan was often described as having a "shame culture" (Hamamura, 2012), which explained a family's concerns about how their behaviour perceived in public. Shame was commonly linked to hesitation and was associated with negative feelings. There was a word commonly used in Japan, *sekentei*, which translated as 'appearance'. This concept of *sekentei* meat that appeared well to others was highly valued and preferable and was peculiar to Japanese culture.

This theme was divided into two sub-themes: Traditional ways of thinking, and not talking about death. These were discussed in more detail below.

4.3.3.1 Traditional ways of thinking

Traditional ways of thinking affected the delivery of care to patients in the community. Even experienced nurses who have worked as community nurses for more than five years found that the traditional Japanese way of thinking influenced their professional practice in various situations; displaying feelings, for example, was rare in Japanese society. The expectation was that people should hide feelings. Publicly showed emotions was practiced not widely accepted in Japan:

> *The problem is we don't talk much about anything verbally; maybe it's the culture of the Japanese. We expect understanding of one's feelings without talking, and underneath we are seeking acceptance (Yoshi).*

Some participants argued that the Japanese way of thinking will never go away and expressed strong opinions opposing the name of "Advance Care Planning (ACP)".

The Japanese government initiated a project for ACP but renamed it *Jinseikaigi* (Ministry of National Health, 2019). This term translated as "meeting about the meaning of life and

medical care". This project led to professionals were having a conversation and talking openly, which was the key to implementing ACP.

The participants thought that change in Japanese society was unlikely to happen quickly in the future:

> *If this situation was looked at 20 years later, the reality would be ACP won't change and it's wasting time discussing individual ways of thinking (Denko).*

The participanrs hoped, though, that public awareness would change the way of thinking, even if the cultural background and traditional Japanese values did not change.

4.3.3.2 Not talking about death

The participants talked about how the provision of care to their patients were greatly influenced by the Japanese taboo concerning conversations about death. The lack of understanding of cultural practices around death and dying greatly affected the delivery of nursing care to patients and in meeting family expectations. Not talking about death was noted as a significant barrier. The Japanese taboos around talking about dying make ACP very difficult:

> *It is a taboo to talk about someone's death in Japan, so it's difficult starting to talk about what to do if anything happens to you … (Chisato).*

> *Historically, over many years in Japan, we have a taboo on talking about dying and death (Denko).*

In Japan, there were particular words about death that it was preferable not to say openly. As the participants mentioned, it was difficult to bring up a conversation about ACP. It required both courage and good communication skills.

4.3.4 Ageing society and quality of life

This theme referred to the current ageing problem in Japan and the extended of life with medical treatment Where prolonging someone's life did not necessarily mean improving a person's quality of life. In addition, community registered nurses felt they had a responsibility and a role to played in understanding the differences between prolonging lives and improving the quality of those lives. Their viewpoints on this issue provided valuable insights into nursing care in Japan.

The quality of a person's life was important however, due to demanding timeframes, in everyday life practical care was a high priority. Therefore, quality of life was not usually the

main focus of the medicine in Japan. Longer life is more important, as evidenced by the family making use of advanced medical technology:

> *The patient is alive just breathing, unconscious without any quality of life, the treatment is for prolonging life … I cannot see it. So many bedridden patients. It is wasting money, no one gets any benefit (Mayumi).*

This participant stated strongly that there was no quality of life for this particular elderly patient. This was a valid cause for concerned given the large proportion of people over 75 years old, a rapidly growing sector in Japan resulted in a high prevalence of death, and little consideration for the quality of a person's life.

> *Patients over 80 years old usually do not express their intentions for their treatment and documentation. They rely on doctors or the family's plan. The patient may have no chance to talk about it. Nobody asks them (Mayumi).*

The quotation above illustrated nobody asks elderly about their preferences. The elderly did not share their opinions with family or health professionals because they worry about being a burden. Instead, it was assumed the patient followed either the doctor's decision or the family's decision regarding end of life decisions.

> *I know the word ACP, but the question is what and how elderly people express their opinion? When? (Saki).*

The participants were disappointed that the worked in hospitals prioritised routine medical care over individualised planning or consideration gave to the quality of a person's life. However, the registered nurse who worked in the community, experienced the similar priorities routine medical care in the community as well.

The participants clearly stated that open conversation was beneficial in terms of identifying the quality of a person's life. In Japan, people tended to be busy in their daily life so did not take a great deal of time to become aware of or think deeply about quality of life in general. Most simply thought that a longer life is better. In contrast to the desire for a longer life, one participant talked about a patient's desire for quality rather than quantity of a life:

> *One of my patients had terminal cancer at 56 years old. He wanted to know about the prognosis: how much longer he could be himself and the treatment's effects on him. He*

was prepared to have a good end to his life. He had a beautiful birthday party with his partner and he spent valuable time with his children (Hisako).

This example made the participant believe that the patient's quality of life should be protected and respected. This participant strongly supported ACP practice.

The researcher was particularly moved by one interview with a nurse who had been previously diagnosed with cancer and revealed her insights about death. During her interview she cried and was very emotional, but she was expressed how she felt about ACP. She noted how important it was to talk about death and the dying:

I never thought it would happen in my life, that there would be illness leading to the end. Then I noticed I had never really understood patients' feelings at all, I had a very superficial idea of caring for someone. I became a patient. I wanted to have the treatment, but the family was against me. I was scared and confused (Yoshi).

The participant described experiences that indicated to her the fragility of life and an awareness that it could end at any moment, regardless of the health of the individual. Moreover, this nurse realised when she was reflecting on her previous nursing experience that she had not treated her patients with sincerity during her care for them.

4.3.5 Responsibility and documentation

Many participants indicated the importance of documentation outlining nursing responsibilities in the community setting, where most community registered nurses worked one-to-one with the patient at home. The implementation of ACP with documentation (that is, forms) is needed and the documentation is essential to both health professionals and patients. One of the issues participants talked about was their struggle to find consistent documentation:

There are no forms, no definition and no framework about ACP, so at each facility, implementations are varied among health professionals (Saki).

ACP has been introduced (in 2017); however, we already provided patients with care anyway; it was the government who suddenly recommended the use of ACP. However, there is no documentation for the guidelines and framework of ACP and therefore legal forms do not exist (Keiko).

Since I recognised ACP as important, I like to try and practise ACP, but I don't know how to use it. It is difficult to know each patient's intention without documentation (Yoko).

Participants were positive about using ACP but had difficulty finding the appropriate documents to used. Similarly, many of the participants indicated that they did not have any agreed concept of ACP, as there was no legal ACP documentation in Japan, and so each facility had its own idea of the ACP concept. In some cases, people thought ACP was just a discussion process.

4.4 Conclusion

Five themes were identified in the present study which were family concerns, informed consent and discussion, cultural differences, ageing society and quality of life, and responsibility and documentation. These themes were explained using the quotations from the participants and the diary entries from the researcher. There were various barriers to community registered nurses utilising ACP. Overall, all these themes are connected and overlap with aspects of law, ethics, sociology, culture and politics. These findings represented a different cultural view to ACP, which discussed in more depth in the final chapter (Chapter 6) along with recommendations and suggestions for future research. The next chapter discusses these findings in more detail as well as the implications for practice and policy of ACP in Japan.

CHAPTER 5 DISCUSSION

5.1 Introduction

This chapter aims to interpret and discuss the findings presented in Chapter 4. The main purpose of this study is to explore the perceptions of ACP (advance care planning) held by Japanese community registered nurses and how they engage with it. The findings highlighted a range in participants' perceptions of ACP, their knowledge and understanding of the role of community registered nurses and flagged the lack of a specific definition of ACP in Japan. One strong finding which emerged was the influence of the patient's family's power, including cultural traditions/expectations, which significantly shaped the decisions after the patient's diagnosis with regards to treatments and any other aspect of medical and health care. It became apparent throughout this research that Japanese family structures and roles are different from those of the Western family; and because of this the implementation of ACP is not easy (kumagai, 2010). There are communication barriers and power relationships and conflicts between patients, families and doctors which must be considered. There are also legal boundaries and professional ethics, including the nature of hierarchy concerning informed consent and discussion; cultural differences are also powerful factors that influence all aspects of ACP decision-making.

Some of the participants stated that there is no quality of life for the patients who are bedridden, with the level of unconsciousness, in a hospital for a long time. When patient choices regarding end-of-life quality nursing care are non-existent, questions arise about quality of life or quantity of life care, and which is more important. The final aspect to be discussed is the issue of professionalism with responsibilities and documentations. Throughout this chapter, these findings will be discussed within the context of existing literature. The limitations of the study and implications of the findings for nursing practice and recommendations for further research are also discussed.

5.2 Power relations around ACP

The power of the family and their involvement in making decisions cannot be avoided, so decisions will often lead to feelings of guilt. This guilt was more likely to appear when the family were taking sole responsibility for making decisions. If there was a specific document designed to respect the patient's wishes stated as an ACP, including advance directives, the burden of the family's responsibility might be reduced. Also, with patient-centred care, the health professionals involved could gain more satisfaction.

ACP discussions have begun to take place in Japan but have not been widely implemented yet. The real issue of the implementation of ACP in Japan is that there is no clear definition of ACP, including advance directives. Also, the establishment of ACP without information regarding diagnosis and prognosis from medical professionals to patients is the most difficult aspect of discussing ACP (Bito et al., 2001). Without clarity around the concept of informed consent, it will be difficult for the patient to make decisions. There are encouraging suggestions that Japanese health professionals could provide adequate medical information to both the patient and the family. However, the Japanese health system is different from that of Australia in that Japan does not have a GP system. This lack creates complex issues when the nurses approach patients, example for, the community nurses have not received enough information about how much doctors informed for the patient about the prognosis (Hamano, Oishi, Morita, & Kizawa, 2020).

While ACP is an appropriate tool to support decisions, the community registered nurses in this study used a non-approved tool that has the same purpose as patient-centred care through conversations with patients and family during daily nursing work. The tool has supported decision-making, but as the patient's death approaches, their wishes are likely to be thwarted. The impediment referred to here is, “Patients originally had a strong desire to stay at home”, but as their care needs increased, they were admitted to hospitals (Ishikawa,2018). Furthermore, although the community registered nurses had been practising patient-centred care for a long time, they did not have a word to describe ACP and did not have nursing documents named as ACP documents; however, they have written their own nursing notes regarding the patients’ wishes. The participants assisted as best they could the patients and their families in the provision of end-of-life care. However, the individual ability and skills vary for each nurse, and so there is a need to establish a manual for documentation training.

In November 2019, the Health Ministry (part of the Japanese government) attempted to promote the idea of ACP (Miki, Becker, Ide, & Kawakami, 2018) by using comedy. This consisted of posters picturing a well-known comedian, with the intent to encourage people to discuss care options with their families in advance. This tactic fell flat with the public and was criticised by medical professionals and other people in Japan as being in poor taste, thus prompting its withdrawal (*The Japan Times*, 2020) (*The Japan Times* is one of the major English language newspapers published in Japan and is considered a reliable newspaper.) The poster attempted to promote a government-led initiative on ACP dubbed *Jinseikaigi* (“life meeting”). The researcher identified the critical miscommunication in this

example, emphasising the slightly different meanings of the definition of ACP in Japanese and English. In September 2019, the researcher delivered a presentation on the current state of ACP in Australia at the Japan Society for End-of-Life care conference in Nagoya, Japan. At this event, a new form of ACP decision-making process was introduced. One presentation which stood out emphasised the ideas of choice, responsibility and autonomy (Inoue, Hanari, Gallagher, & Tamiya, 2018). Through talking with nurses, doctors, other health professionals and patients at this conference, the researcher observed several misunderstandings between different stakeholders. Perhaps this indicates that the meaning of ACP has not been clearly defined for each health profession (Sumita, 2015) and when ACP is translated from an English concept it may lose meaning. When directly translated to the Japanese word *jizenshiji* (advance directives), the translation infers a different meaning and a different goal (Sullivan, 2017).

In Japan, a clear documentation and standard ACP forms guiding the healthcare professions will encourage both patient-centred care and discussions about quality-of-life (Hancock et al., 2007). From this research and the findings, it is evident that there is a need to improve public awareness of ACP law and policy in Japan. An enlightened Japanese society needs the power of positive ACP stories in media. In line with the globalisation trend currently popular in Japan, television and social media remain influential tools able to reach a wide audience (Horie, 2002). Advance care planning is a comprehensive process that produces a document to direct care. The ACP provides all the documents for the Advance Directives. Therefore, the ACP is different to the Japanese *ending note*.

Improving public awareness of the decision-making process is key to facilitating better understanding of ACP in Japan, and it should include advance directives, called *jizenshiji* in Japanese *which translates to mean* the document itself. This will provide a clearer definition than ACP and will be easier for the public to understand. Clear *jizenshijisho* documentation and terminology will have impact on the daily practice of medical professionals and reduces the emotional decision-making and will hopefully reduce the feelings of guilt families and health professionals may feel for someone’s death. It will also enable nurses to spend quality time on decision-making processes in their nursing care plans (Bradley, 2015). Clarifying the definition and implementing ACP in Japan would enhance patient-centred care, reduce conflicts with family and improve satisfaction for patients, family, and health professionals.

5.3 Cultural background around ACP

There are various barriers to implementing high-quality ACP, including issues with Japanese customs and traditions (Sumita, 2015). Examples include aspects of Japanese culture, such as indirect communication and the reliance on others or younger family members to make decisions (Sullivan, 2017). These factors influence and shape a different definition of ACP in Japan. In Japanese society, elderly people are often viewed as not being capable of making their own decisions, and thus an elderly person's autonomy is often overridden in favour of decisions made by family members or others (Takeuchi & Karasawa, 2008).

Ageing and ACP is a complex issue, which must consider both the negative and positive aspects of culture and tradition. It is important to mention here that culture and tradition are not always negative concepts (De Mente, 2005). There are positive aspects to Japanese society which include the values around caring for, loving and respecting elderly people (De Mente, 2005). In Japanese society, it is typical for the family to care for their elders and protect them by assuming a dominant standpoint (Sullivan, 2017). As a result, families often make decisions without telling the elder members, because the family believes the elderly cannot face the emotional trauma of the situation and it would cause undue distress. On the other hand, the negative aspects that elderly people cannot express their honest feelings and leave their wishes.

In Japan, there is a greater reliance on others to assume decision-making roles for lifestyle and health care. A common understanding among Japanese people is that *omakase-shimasu* is a preferable tradition. *Omakase-shimasu* means a heavy reliance on others to assume the decision-making role when it comes to health care, medical treatment and end-of-life care for the elderly (Miyanaga & Poudyal, 2019). This over-reliance means that some patients want to leave decisions to their family and doctors, a traditional Japanese approach to medical decision-making (Sullivan, 2017). However, this tradition encourages a lack of early consultation between patients, family, surrogate decision-makers and health professionals and an over-reliance on others to assume the decision-making role, thereby complicating decisions for people (Miyanaga & Poudyal, 2019). Additionally, this over-reliance on others to assume the decision-making role may lead to poor quality healthcare practices that do not align with the patient's wishes. A similar disconnect exists between people and surrogate decision-makers, who are also not seeking to find out the wishes of patients (Butler, 2009). Japan needs to address what is best for the patient and respect every individual's choice. This new approach to care requires a cultural shift that might take several generations.

Another factor influencing cultural differences is the traditional communication style of Japanese people – it is rare to speak directly to a person face to face. Instead, non-verbal and indirect communication styles have traditionally been highly encouraged society (Došen, 2017). Japanese people are often expected to be intuitive as to what the other person's needs are, and much communication or unspoken understanding is implicit. This is a unique Japanese characteristic that may be hard for Western (or non-Japanese) people, who tend to be direct, especially in professional contexts, to understand (Fetters, 1995).

In Japan, the term *aun no kokyu* refers to the so-called Japanese sixth sense of being able to attune to others' minds (De Mente, 2005). This stems from the historical traditional view of a homogenous Japanese society with "one nation, one civilisation, one language, one culture and one race" (De Mente, 2005). Also, the hierarchical nature of the healthcare environment presents a key risk factor for effective inter-professional communication in Japan (Omura, Stone, & Levett-Jones, 2018). The inherent cultural and social norms discourage assertive communication. These cultural views and understandings pose obvious barriers for implementing ACP. The preceding sections highlight several issues for elderly people, including reliance on surrogate decision-makers, different styles of communicating and cultural traditions.

Another key concern lies in the importance of "shame culture" in Japanese society. Japan is often described as a shame culture, which may explain Japanese people's behaviour (De Mente, 2005), as discussed above (section 4.3.3). Shame is also related to fear of evaluation and blame. Hence, these cultural beliefs lead to negative views about behaviour in public (Hamamura, 2012). The concept of *sekentei* (appearance), as discussed above (section 4.3.3) is of key concern to Japanese people, and it often leads to the belief that old people should live as long as possible even if this means living in a hospital and being taken care of by nursing staff. It means presenting a good appearance in public and being socially valued and accepted (Hossein, 2010). This concern makes it difficult to talk about concepts such as quality of life versus quantity of life. It is important, therefore, to develop a legal framework of the definition of ACP with advance directive *(jizenshiji*) documentation.

Japan needs to learn induvial preferences for the patient and respect every individual's choice. Part of improving end-of-life care for the elderly may include establishing a new policy encouraging ACP both as a legal entity and as documentation requirement. Health professionals and family have a role to play in discussing ACP with patients, however legislation would be beneficial in making sure the patient's wishes are respected and are

not subsequently changed by the wishes of the family and health professionals. It is also important that the elderly have the opportunity to start preparing the documentation early while they are healthy enough to make decisions. With clear instructions, this will enable elderly people to choose their own options for their future health care.

5.4 Tools for open conversation and communication

The term *ending note* is a unique concept which was originally introduced in Japan in 1991. It has become a popular activity among the Japanese population since around 2011, out of necessity for preparation for the end of life. The concept was obviously needed, as Japanese people desire to control their lives and express their wishes in writing without being a burden to their family. However, an *ending note* does not include decision-making for future health care or medical preferences; it is a personal note and is kept private, although it does show a serious attempt on a person's part at expressing end of life wishes. The note can also be a trigger to open conversations and discussions around the subject. There is also a card game called *mosibana* imported from the United States ("Go Wish", from coda alliance.co), which is a useful tool for stimulating ACP discussion around preferences at the end of life.

Baby boomers (*dankai-no-sedai* in Japanese) are a particularly independent and self-assured generation (Statistics Bureau of Japan, 2015). In Japan, the baby boomer generation is defined as those born in the years between 1947–49 (Nagai et al., 2015). This generation has strongly steered Japan's economy and has become a major leader in society (Shimada et al., 2015). Members of the baby boomer and younger generations often like to say, "let me decide", and their decisions must be protected by policy (Bradley, 2015). Also, according to the TED Talk by Dr Peter Saul and Advance Care Planning Australia, the concept of the decision-making process came from intensive care situations, where family and health professionals started to question the quality of life of each patient (Saul, 2011). This controversial topic has been discussed in recent years in Japan and there is a movement towards implementing ACP. Further research is needed to investigate the generational difference, and how this affects attitudes towards decision-making.

Advance care Planning must be legalised to protect patients' wishes, however, there are various barriers to the implementation of such legislation. It is important to note, however, that ACP is the document is for those who wish to use ACP, this is one of the options in the decision-making process for end-of-life care. During the interview process, one participant

stated that they had been practising patient-centred care for a long time before ACP appeared. They tried to do their best for the patient and the family and to talk openly about end of life care. However, from the government in 2015, a guideline called ACP appeared, a specific name was given to use existing concepts of end-of-life discussion. The researcher observed that community registered nurses practised better nursing care when individual patient care with the family was taken into consideration, in accordance with Japanese culture. The concept of ACP will be merged into future decision-making discussion guidelines, however, for now Japan needs a guideline regarding communication with patients. In addition, research is needed on how best to implement ACP, and how to effectively communicate this process to the patient.

The impact of Japanese culture on the communication process is complex. These complexities include *wa* or maintaining harmony, collectivism, implicit communication and *nemawashi* or groundwork (Fetters, 1995). *Nemawashi* is key to organisational relationships in Japan and refers to laying the groundwork for consensus building in preparation for speaking before meetings (Fetters, 1995). These deep-rooted cultural values are embedded in nurses working in Japan, so it is difficult for them to speak up assertively, especially to those in positions of authority (Fetters, 1995; Omura, Stone, & Levett-Jones, 2018). However, it will be possible to improve communication (California, 2017) and the *nemawashi* method is an ideal tool to implement ACP smoothly in the Japanese way. The following sections will discuss possible strategies to support changes in the culture or practices connected to policy and education.

A person's way of thinking is influenced by individual factors such as gender, education history, geographical location, environment and the culmination of life events (Kato & Sleeboom-Faulkner, 2011). Each individual experiences the communication process and perceives cultural background in different ways (Uchinuma, 1992). Often inappropriate verbal communications will come from an individual without their awareness, because of his or her cultural background. Culture is often perceived by the family structures as static; however, it is also dynamic and changeable (Ogihara, 2018). Cultures only change gradually (Morton, 2003) as a result of time and education, bringing changes to social patterns and family structures. Education is the key to better practice and better choices (Ogihara, 2018). Therefore, for ACP implementation a culturally appropriate, assertive communication training program would be beneficial (Omura, Maguire, Levett-Jones, & Stone, 2017).

Communication and appropriate education are extremely important (Ban & Fetters, 2011), Interventions to improve assertive communication are reported to be effective for nurses (Omura et al., 2017). There are several important communication skills to be learned, that may involve discussions and roleplay, support from leaders, teamwork skills training and communication technique programmes (Omura et al., 2017). The assertive communication approaches have identified methods for optimising the effectiveness of assertiveness communication training programmes (Omura, Stone, Maguire, & Levett-Jones, 2018). Nurses felt that assertive communication could save their time and protect patients' safety. Assertive communication is intended to be a clear, succinct, and a direct exchange, and not a vague and winding series of conversations (Omura, Stone, & Levett-Jones, 2018). There are various social pressures in nursing to provide better practice, and nurses in this study felt pressured to conform rather than speak out to senior nurses and doctors. Within cultural norms there exists, hierarchical structures and power dynamics in the healthcare environment (Fetters, 1995). Because of this, assertive communication training may not be enough to trigger a change in this area: the training needs to be supported by health regulations and government policy (Jimenez et al., 2018). In response to the lack of current policy about decision-making for end-of-life care in Japan (Shimizu, 2015), the Japanese government established a new guideline for end-of-life care.

At a policy level there is also the need to establish a new policy with a legal form, called *jizenshiji* (advance directives) in the Japanese language. As discussed previously, establishing a new policy is challenging due to cultural factors and traditions. The policy should include understanding of the value of decision-making, and the ideas of choice relating to anyone over 18 years old (not just the elderly). Individuals must be asked in advance how they would like to choose their end-of-life care when the time comes. This controversial topic has been discussed in recent years in Japan and there is a movement towards having ACP with *jizenshiji*. To be useful, this new policy must be clearly defined, and legislation will be necessary.

In Japan it is crucial to have ACP for providing the increasing large number of ageing population. At present, there are no legally enforceable guidelines around ACP and progress in integrating national policies has been slow. This research project explored the interest around ACP in Japan to ensure that future policies introduced are both in accordance with public interest and have the potential to be accepted. The research will continue to

investigate Japanese people's need for ACP for decision-making and must consider the influence of culture and generational change on medical decision-making.

5.5 Limitations

This study has several limitations. Firstly, interpretive description in this study, as a qualitative research methodology, was justified by the richness of the data produced, in the details of the data, and the depth of analysis of community registered nurses' experiences. However, interpretive description is limited, by subjective bias and interpretation. In terms of the study sample, participants were limited to who those were interested in talking about their experiences of ACP. Additionally, most community registered nurses have varied experiences in a community, so inclusion criteria were limited. In this study, the amount and detail of the qualitative data generated, and the depth of the data has given insight into community nursing practice. However, as the sample size was small the findings cannot be generalised. Finally, the initial data were transcribed and translated; as the researcher was the interpretive instrument, though, this process may contain some bias (Thorne, 2016).

5.6 Conclusion

This research sought to explore the perceptions, experiences and framework of ACP by community registered nurses in Japan. The findings revealed the power relations regarding the decision-making, cultural background and communication processes around ACP. The researcher critically discussed the importance of specific documentation and of having the definition of ACP supported by a legal framework. The thesis also discussed the language used in Japan needed to provide a clearer understanding among Japanese people. Furthermore, assertive communication education and a manual supporting ACP documentation are essential for health professionals. ACP is not just for the elderly; it is an option for everyone over 18 years old who wants to express their preferences for future medical and health care.

CHAPTER 6 CONCLUSION

6.1 Introduction

The previous chapter expanded on the meaning of the ACP experiences of community registered nurses. This final chapter concludes the study and highlights its most important outcomes, such as the importance of choice in the decision-making process, and the fact that patients' preferences should be protected by policy. The results emphasised the need for a Japanese government policy, clear documentation, future education and training in assertive communication among health professionals. The research explored various aspects of implementation of ACP, and the researcher gained knowledge of the current state of ACP in Japan and other countries. The following recommendations from this research and suggestions for future research will be useful, not only for Japanese people; but they will also be informative for neighbouring Asian countries who have a similar culture and traditions.

6.2 Answer to the research question

The main aim of this study was to explore the perceptions of community registered nurses about ACP in Japan. The ageing population of Japan is rapidly increasing which places demands on the role of community registered nurses who have an enormous responsibility to respond to ACP. There are also challenges for health professionals introducing ACP in Japan given the conflicting relationships and differing priorities between the community registered nurses, the family and the patient. There are barriers such as the customs and traditions of Japanese culture, along with the lack of knowledge of ACP among both the general public and health professionals. Further research is needed with consideration of cultural norms and their effect on implementing ACP. The implementation of ACP needs to include professional development in assertive communication and provision of ongoing support to health professionals. It is important to invest in expanding community registered nurses' knowledge of ACP given it is such a new concept in Japan. This research could possibly inform the nursing policy and procedures in the field of ACP in the community in Japan.

The findings of the interview data revealed that community registered nurses were positive about using ACP processes, policies or documents. But there is no specific ACP they could access. This documentation is important to develop as it protects patient preferences. Without specific documentation, ACP is just a verbal discussion, and it will not fully protect

the patient's preferences. The participants especially emphasised the dependent relationship between the patient and the family as one that was problematic. In most cases, the families were the decision-makers with power and authority. The family's power tended to control ACP even when the patient had already made a final decision regarding their preferences. Instead, the patient's preferences were often discounted as a result of family overruling. The family's decisions could provoke a sense of guilt when it conflicts with traditional Japanese cultural norms where the family should look after each other, especially regarding the death and dying process. There was also a strong feeling of shame about how the public might judge them if the patient died at home without any medical support. Another barrier relates to the disclosure of diagnosis and the nature of informed consent in Japan. It is common for doctors in Japan to prioritise the family as the first to talk with about the patient's medical condition. Therefore, the participants were aware of cultural differences when introducing ACP and described how ACP had been accepted into Japan from Western culture. Overall, all these themes are connected and overlap with aspects of culture, law, ethics, sociology and politics.

Moreover, this research is timely given that there is significant public interest in ACP with the growing popularity of the *ending note*. This study advocates the importance of utilising ACP with clear documentation, along with assertive communication training for all health professionals. The researcher intends to use this study's results as a steppingstone for future research, and to promote a decision-making policy in Japan with specific documentation and a clear definition of ACP.

6.3 Suggestions for future research

There are several areas for further research which have become clear through the course of this Master's research, and through meeting people at public lectures and attending conferences to openly discuss ACP and the decision-making in Japan. The researcher learned a great deal when attending the conferences, especially about the problems of decision-making among the Baby Boomer generation.

Given the small nature of this study (with a total of 11 participants), further studies are needed with a larger cohort of participants. Ideally, this research could investigate the impact of the choices involved in decision-making. Furthermore, the sample should include not only community nurses, but also general medical professionals and nurses in emergency settings and inpatient palliative care settings. Exploring public attitudes to, and perceptions of, ACP

is important, and conducting additional quantitative research using surveys would be beneficial, as would comparing the attitudes of different age groups in Japan.

There is an urgent need to help the ageing population to understand ACP. At present, there are no legally enforceable guidelines around ACP in Japan and progress in integrating national policies has been slow. A larger research project could be undertaken in the future to explore the public interest surrounding ACP in Japan which may be useful in informing policy makers and ensuring that any legislation introduced is aligned with the public interest. The research could investigate Japanese people and their need for ACP for decision-making. Further research is also needed to survey people living in Japan about their attitudes towards ACP comparing different age groups, cultural identities and personal experiences and collect longitudinal data to better understand the process of learning about decision-making and ACP over time.

6.4 Implications for policy and practice

For change to happen and for ACP to change people's lives for the better, it is important to also consider practical implications. This research has highlighted the need for an education and support system which includes legal policy. In the past, against the background of Japanese culture, paternalist values ensured that many Japanese patients and their families revered their doctors' orders. Therefore, a patient and his/her family tended to leave everything in the doctors' hands. However, this culture has changed somewhat in contemporary Japan, along with Japanese attitudes towards death and dying since the idea of patient-centred care was introduced.

Hence, at a practical level when ACP is integrated into registered nursing education, it requires consideration of cultural traditions and the promotion of individual choice. This approach may enhance and support those who are challenged in identifying and initiating conversations and practices on ACP in the clinical settings. The establishment of a Nursing practice framework is perhaps the key for implementation of ACP in Japan. According to the research, even though Japanese culture around dying and death has changed, it is crucial for nurses to remember that the majority of Japanese people still adhere to traditional cultural norms and struggle to make decisions. Thus, nurses must examine various aspects of the decision-making process and support the patient and their family. The researcher strongly believes that community registered nurses have already reached their limit of delivering optimum decision-making support for a growing population of elderly people. Hence, training in assertive communication for health professionals may improve the

effectiveness of decision-making, along with a clear communication structure and a clear understanding between people by ACP documentation.

Encouraging public awareness will hopefully lead to establishing a new ACP policy. People in Japan are now ready to have an individual choice, and ACP will be potentially widely accepted in future Japanese society. It has already introduced the concept of *ending note*, which has become popular among Japanese people. Medical professionals may support the provision of information to both the patient and their family. Most people have not experienced end-of-life care situations, so they need detailed information and clear explanations from health professionals. Proactively talking about death and terminal care is important for the preparations for ACP.

6.5 Conclusion

This research aimed to explore the perceptions of community registered nurses using ACP in Japan. The importance of the community-based registered nurse experiences have remained central to this research by the use of interpretive analysis. The objectives have been met via answers to questions regarding issues that were raised when discussing ACP with community registered nurses. Even though the majority of participants of community registered nurses had heard of ACP, they could not utilise ACP in Japan effectively because of the difference of the definition of ACP along with the cultural background components compared to Western concepts. The term of ACP was borrowed from Western documents; therefore it does not represent the definition of a comprehensive process in Japan as it does not include legal policy. Therefore, community registered nurses tended to show frustration and hesitation in using ACP as the process of the decision-making in Japan.

There is no specific ACP framework for nursing care in Japan, and without the legal documentation it is difficult to improve patient-centred care. *Ending note* is widely used and is popular among Japanese people, however, it does not contain any healthcare processes or legal authority; it remains a personal document. International globalisation and a rapidly ageing society have greatly increased awareness of ACP among both the general public and health professionals, which substantiates the significance of this research. Previous research in the area had its limitations, such as the majority were quantitative in design, and a lack of focus on community registered nurses' attitudes and experiences of ACP. This qualitative research explored the experience of community registered nurses, who most need to adopt and utilise ACP amongst the ageing population in Japan. The qualitative

interviews conducted within the current study have identified important factors in experiences and perceptions of ACP in Japan.

In the process of using ACP, the participants found cultural barriers and difficulty in the immediate utilisation of ACP. Registered Nurses need to be comfortable with the conversation and informed by policy and processes to initiate conversations with those in their care. There is no definition of ACP among health professionals in Japan, due to the misunderstanding of the English translation to Japanese and the lack of clarity in written documents. There are also existing cultural barriers, such as indirect communication and family power relations; establishing formal documentation and a specific definition of ACP in Japan is urgently required.

Whilst this research provides only a small contribution to knowledge, it does highlight a range of areas that need further attention including, future policy establishment and practices that motivate people to choose ACP documentation, rather than, for example, the less formalised *ending note*. Advance Care Planning is an essential tool and the choices and decisions people make are vitally important. It may empower older Japanese people to initiate their own care decisions.

REFERENCES

Advance Care Planning Australia. (2018). *Advance Care Planning Australia*. Retrieved April 11, 2018, www.advancecareplanning.org.au

Akatsu, Y. (2018). The conciousness survey and effect of educational intervention of advance care planning. *Nippon Ronen Igakkai Zasshi, 55*(3), 358–366. doi:10.3143/geriatrics.55.358

Asahara, K., Ono, W., Kobayashi, M., Omori, J., Momose, Y., Todome, H., & Konishi, E. (2013). Ethical issues in practice: A survey of home-visiting nurses in Japan. *Japan Journal of Nursing Science, 10*(1), 98–108. doi:10.1111/j.1742-7924.2012.00216.x

Aveyard, H. (2014). *Doing a literature review in health and social care: A practical guide* (3rd ed.). Maidenhead: McGraw-Hill Education.

Ban, N., & Fetters, M.D. (2011). Education for health professionals in Japan—time to change. *The Lancet, 378*(9798), 1206–1207. doi:10.1016/S0140-6736(11)61189-6

Bird, S. (2014). Advance care planning. *Australian Family Physician, 43*(8), 526–528. https://search.proquest.com/docview/1554442416?accountid=10910

Bito, S., Wenger, N.S., Ohki, M., & Fukuhara, S. (2001). Japanese attitudes toward advance care planning for end-of-life decisions. *General Medicine, 2*(1), 3–10. doi:10.14442/general2000.2.3

Borbasi, S. (2015). *Navigating the maze of research: Enhancing nursing and midwifery practice* (4th ed.). Chatswood, NSW: Elsevier Australia.

Bradley, S. (2015). *Advance directives in an e-health environment: South Australian preferences and baby boomer choices* (Doctoral dissertation). Retrieved from https://theses.flinders.edu.au

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. doi:10.1191/1478088706qp063oa

Butler, R.N. (2009). Combating ageism. *Internatinal Psychogeriatric Association, 21*(2), 211. doi:10.1017/S104161020800731.x

Charon, J. & Ferréol, G. (2009). Symbolic interactionism. An introduction, an interpretation, an integration. *Recherches sociologiques et anthropologiques*, *40*(2), 150–151. https://search.proquest.com/docview/761030080?accountid=10910

Clark, A. (1996). Nursing research: Principles and methods. *American Journal Nursing, 96*, G16. doi: 10.1097/00000446-199611000-00024

Creswell, J.W. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, California: Sage Publications, Inc.

Critical appraisal skills programme [CASP] (2018). CASP Checklist. Retrieved from https://casp-uk.net/casp-tools-checklists/

Crotty, M. (1995). *Phenomenology and nursing research*. Melbourne: Churchill Livingstone.

De Mente, B. L. (2006). *Japan unmasked: The character & culture of the Japanese*. Rutland, Vermont: Tuttle Publishing.

Doenges, M. (2014). *Nursing care plans: Guidelines for individualizing client care across the life span* (9th ed.). Philadelphia, Pennsylvania: F.A. Davis Company.

Došen, A. (2017). Silent bodies: Japanese taciturnity and image thinking. *Etnoantropološki Problemi, 12*(1). doi:10.21301/eap.v12i1.5

Fahner, J.C., Beunders, A. J. M., Van Der Heide, A., Rietjens, J. A. C., Vanderschuren, M. M., Van Delden, J. J. M., & Kars, M. C. (2019). Interventions guiding advance care planning conversations: A systematic review (report). *Journal of the American Medical Directors Association, 20*(3), 227. doi:10.1016/j.jamda.2018.09.014

Fetters, M.D. (1995). Nemawashi essential for conducting research in Japan. *Social Science & Medicine, 41*(3), 375–381. doi:10.1016/0277-9536(95)00090-T

Freeman, J.M. (2010). Rights, respect for dignity and end-of-life care: Time for a change in the concept of informed consent. *Journal of Medical Ethics, 36*(1), 61. doi:10.1136/jme.2009.031773

Hamamura, T. (2012). Are cultures becoming individualistic? A cross-temporal comparison of individualism-collectivism in the United States and Japan. *Personality and Social Society Psychology Review, 16*(1), 3–24. doi:10.1177/1088868311411587

Hamano, J., Oishi, A., Morita, T., & Kizawa, Y. (2020). Frequency of discussing and documenting advance care planning in primary care: Secondary analysis of a multicenter cross-sectional observational study. *BMC Palliative Care, 19*(1), 1–8. doi:10.1186/s12904-020-00543-y

Hancock, K., Butow, P., Tattersall, M., & Currow, D. (2007). Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Medical Journal of Australia, 186*(12), S77-108. doi:10.1089/thy.2007.0183

Hirakawa, Y. (2017). A qualitative study on barriers to achieving high-quality, community-based integrated dementia care. *Journal of Rural Medicine, 12*(1), 28–32. doi:10.2185/jrm.2927

Horie, M. (2002). The internationalization of higher education in Japan in the 1990s: A reconsideration. *The International Journal of Higher Education and Educational Planning, 43*(1), 65–84. doi:10.1023/A:1012920215615

Hossein, M. (2010). Psychoanalysis in a ‘shame culture’: Japanese psychoanalytic insights. *The International Journal of Psychoanalysis, 91*(5), 1242–1245. doi:10.1111/j.1745-8315.2010.00316.x

Hunt, R. (2012). The development of statutory law in South Australia to support advance care planning. *BMJ Supportive & Palliative Care, 2*(2), 177. doi:10.1136/bmjspcare-2012-000250.26

Inoue, M., Hanari, K., Gallagher, J., & Tamiya, N. (2018). Current practice of advance care planning among doctors and nurses: Results from a national survey in Japan. *Journal of Pain and Symptom Management, 56*(6), e146–e146. doi:10.1016/j.jpainsymman.2018.10.460

Ishikawa, T., Fukui, S., & Okamoto, Y. (2018). Advance care planning and home death in patients with advanced cancer: a structured interview analysis. *International Journal of Palliative Nursing, 24*(9), 418-426. doi:10.12968/ijpn.2018.24.9.418

Ishikawa, Y., Nishiuchi, H., Hayashi, H., & Viswanath, K. (2012). Socioeconomic status and health communication inequalities in Japan: A nationwide cross-sectional survey. *PLoS One, 7*(7). doi:10.1371/journal.pone.0040664

JBI critical appraisal checklist (2017). *Checklist for analytical cross sectional studies.* Retrieved from

https://joannabriggs.org/sites/default/files/2019-05/JBI_Critical_Appraisal-Checklist_for_Analytical_Cross_Sectional_Studies2017_0.pdf

Jimenez, G., Tan, W.S., Virk, A.K., Low, C.K., Car, J., & Ho, A.H.Y. (2018). Overview of systematic reviews of advance care planning: Summary of evidence and global lessons. *Journal of Pain and Symptom Management, 56*(3), 436–459.e425. doi:10.1016/j.jpainsymman.2018.05.016

Kashiwagi, M., Tamiya, N., & Murata, M. (2015). Characteristics of visiting nurse agencies with high home death rates: A prefecture-wide study in Japan. *Geriatrics & Gerontology International, 15*(8), 936–943. doi:10.1111/ggi.12372

Kato, M., & Sleeboom-Faulkner, M. (2011). Dichotomies of collectivism and individualism in bioethics: Selective abortion debates and issues of self-determination in Japan and 'the West'. *Social Science & Medicine, 73*(4), 507–514. doi:10.1016/j.socscimed.2011.05.053

Kumagai, F. (2010). Forty years of family change in Japan: A society experiencing population aging and declining fertility. *Journal of Comparative Family Studies, 41*(4), 581-610. https://search.proquest.com/docview/756461300?rfr_id=info%3Axri%2Fsid%3Aprimo

Kumar, R. (2014). *Research methodology: A step-by-step guide for beginners* (4th ed.). Los Angeles: SAGE.

Laberge, Y. (2009). *Symbolic interactionism: An introduction, an interpretation, an integration* (8th ed.). Sociological and anthropological research, 40-2 | 2009, 151-156. https://journals.openedition.org/rsa/180?lang=fr

Leeman, J., & Sandelowski, M. (2012). Practice-based evidence and qualitative inquiry. *Journal of Nursing Scholarship, 44*(2), 171–179. doi:10.1111/j.1547-5069.2012.01449.x

Liamputtong, P. (2013). *Qualitative research methods* (4th ed.). South Melbourne, VIC: Oxford University Press.

Maeda, I., Tsuneto, S., Miyashita, M., Morita, T., Umeda, M., Motoyama, M., . . . Eguchi, K. (2014). Progressive development and enhancement of palliative care services in Japan: Nationwide surveys of designated cancer care hospitals for three consecutive years. *Journal of Pain and Symptom Management, 48*(3), 364–373. doi:10.1016/j.jpainsymman.2013.09.017

Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *The All Ireland Journal of Teaching and Learning in Higher Education, 9*(3), 3351–33514. Retrieved from http://ojs.aishe.org/index.php/aishe-j/article/view/335

Masaki, H., Kawai, N., Matsumoto, K., Kuwata, M., Yoshioka, S., Nishiyamari, . . . Endo, K. (2017). Consensus development of quality indicators for end-of-life care for elders in Japan. *International Journal of Nursing Practice, 23*(S1). doi:10.1111/ijn.12562

Masujima, M. (2017). Development of the nursing practice based on advance care planning to support the person in the end-of-life period to live a fulfilling life. *Journal of Japan Society of Physiological Anthropology, 22*(4), 203–208. doi:10.20718/jjpa.22.4_203

Melny, R. (2015). *Evidence-based practice in nursing and healthcare: A guide to best practice* (3rd ed.). Philadelphia: Wolters Kluwer Health.

Miki, R., Becker, C.B., Ide, K., & Kawakami, K. (2018). Timing and facilitation of advanced directives in Japan. *Archives of Gerontology and Geriatrics, (79)*, 83–87. doi:10.1016/j.archger.2018.08.003

Ministry of Health, Labour and Welfare. (2018). *Vital statistics of Japan final data natality, 2017 Volume 1: Trends in live births, live birth rates (per 1,000 population), Total fertility rates and sex ratio of live births*. Retrieved from https://www.e-stat.go.jp/en/stat-search/file-download?statInfId=000031743384&fileKind=

Ministry of National Health Japan. (2017). *The community-based integrated care system model*. Retrieved from https://www.mhlw.go.jp/english/.../care-welfare/care-welfare.../establish_e.pdf

Miura, H., Kizawa, Y., Bito, S., Onozawa, S., Shimizu, T., Higuchi, N., . . . Toba, K. (2017). Benefits of the Japanese version of the advance care planning facilitators education program. *Geriatrics & Gerontology International, 17*(2), 350–352. doi:10.1111/ggi.12814

Miyanaga, R., & Poudyal, H. (2019). Participation of nurses and care workers in the decision-making process for people with dementia in Japan: Discussion paper. *International Journal of Nursing Studies, 96*, 91–98. doi:10.1016/j.ijnurstu.2019.02.011

Morton, L. (2003). *Modern Japanese culture: The insider view*. South Melbourne, VIC: Oxford University Press.

Nagai, M., Ohta, A., Nishina, M., Shimada, N., Nakao, S., & Kurokawa, M. (2015). Sex, age and other epidemiological characteristics of aplastic anemia patients in Japan. *International Journal of Epidemiology, 44*(suppl1), i170–i170. doi:10.1093/ije/dyv096.236

Nagaya, Y., & Dawson, A. (2014). Community-based care of the elderly in rural Japan: A review of nurse-led interventions and experiences. *The Publication for Health Promotion and Disease Prevention, 39*(5), 1020–1028. doi:10.1007/s10900-014-9847-5

Naito, Y. (2019). *The present state of advance care planning in Australia*. Paper presented to 3rd Annual Conference of the Japan Society for End of Life Care, Nagoya, Japan.14-15, September. Retrieved from http://plaza.umin.ac.jp/eolcconf2019

Naito, Y. (2019). *The present state of advance care planning in Australia.* Lecture, The National Nursing School in Saitama, Japan.

Naito, Y. (2019). *Advance care planning discussion.* Lecture, The Public Community Centre, Nagoya, Japan.

Naito, Y. (2019). *Advance care planning discussion*. Lecture, The Public Community Centre, Fukuoka, Japan.

Nakajima, K., Iwamitsu, Y., Matsubara, M., Oba, A., Hirai, K., Morita, T., & Kizawa, Y. (2015). Psychologists involved in cancer palliative care in Japan: A nationwide survey. *Palliative and Supportive Care, 13*(2), 327–334. doi:10.1017/S1478951514000029

Nakanishi, M., Hirooka, K., Morimoto, Y., & Nishida, A. (2016). Quality of care for people with dementia and professional caregivers' perspectives regarding palliative care in Japanese community care settings. *International Journal of Geriatric Psychiatry 32*(12) 1342–1351

Nakazawa, K., Kizawa, Y., Maeno, T., Takayashiki, A., Abe, Y., Hamano, J., & Maeno, T. (2014). Palliative care physicians' practices and attitudes regarding advance care planning in palliative care units in Japan: A nationwide survey. *American Journal of Hospice and Palliative Medicine, 31*(7), 699–709. doi:10.1177/1049909113507328

National Institute of Population and Social Security Research. (2017). Population projections for Japan 2017: 2016 to 2065. Retrieved from http://www.ipss.go.jp/pp-zenkoku/e/zenkoku_e2017/pp29_summary.pdf

Nishiguchi, S., Sugaya, N., Sakamaki, K., & Mizushima, S. (2017). End-of-life care bonus promoting end-of-life care in nursing homes: An 11-year retrospective longitudinal prefecture-wide study in Japan. *BioScience Trends, 11*(1), 54–61. doi:10.5582/bst.2016.01183

Nishikawa, M., Nakashima, K., Miura, H., Endo, H., & Toba, K. (2011). Advance care planning in Japanese nursing homes. *BMJ Supportive & Palliative Care, 1*(1), 95. doi:10.1136/bmjspcare-2011-000053.100

Nishioka, H., & Arai, H. (2016). The attitude of Japanese individuals toward end-of-life care. *Japanese Journal of Geriatrics, 53*(4), 374–378. doi:10.3143/geriatrics.53.374

O'Donoghue, T. A. (2007). *Planning your qualitative research project: An introduction to interpretive research in education*. London: Routledge.

Ogihara, Y. (2018). The rise in individualism in Japan: Temporal changes in family structure, 1947–2015. *Journal of Cross-Cultural Psychology, 49*(8), 1219–1226. doi:10.1177/0022022118781504

Omura, M., Maguire, J., Levett-Jones, T., & Stone, T. (2017). The effectiveness of assertiveness communication training programs for healthcare professionals and students: A systematic review. *International Journal of Nursing Studies, 76*, 120-128. doi: 10.1016/j.ijnurstu.2017.09.001

Omura, M., Stone, T.E., & Levett−Jones, T. (2018). Cultural factors influencing Japanese nurses' assertive communication. Part 1: Collectivism. *Nursing & Health Sciences, 20*(3), 283–288. doi:10.1111/nhs.12411

Omura, M., Stone, T. E., Maguire, J., & Levett-Jones, T. (2018). Exploring Japanese nurses' perceptions of the relevance and use of assertive communication in healthcare: A qualitative study informed by the theory of planned behaviour. *Nurse Education Today, 67*, 100–107. doi:10.1016/j.nedt.2018.05.004

Ono, W. (2016). Development of grief care education program for visiting nurses in Japan. *Journal of Hospice and Palliative Nursing, 18*(3), 233–241. doi:10.1097/NJH.0000000000000238

Patton, M., & Westby, C. (1992). Ethnography and research: A qualitative view. *Topics in Language Disorders, 12*(3), 1–14. doi:10.1097/00011363-199205000-00003

Polit, D.F., & Beck, C.T. (2016). *Nursing research: Generating and assessing evidence for nursing practice* (10th ed.). Philadelphia: Wolters Kluwer Health.

Prisma. (2009). *Prisma 2009 Flow Diagram*. Retrieved from http://www.prisma-statement.org/documents/PRISMA%202009%20flow%20diagram.doc

Riva, J. J., Malik, K. M. P., Burnie, S. J., Endicott, A. R., & Busse, J. W. (2012). What is your research question? An introduction to the PICOT format for clinicians. *The Journal of the Canadian Chiropractic Association, 56*(3), 167-171. Retrieved from https://search.proquest.com/docview/1069208371?accountid=10910

Sandelowski, M. (2007). *Handbook for synthesizing qualitative research*. New York: Springer.

Sato, R. S., Beppu, H., Iba, N., & Sawada, A. (2012). The meaning of life prognosis disclosure for Japanese cancer patients: A qualitative study of patients' narratives. *Chronic Illness, 8*(3), 225-236. doi:10.1177/1742395312448940

Saul, P. (2011). *Let's talk about dying*. (TED Talk). Retrieved from https://www.ted.com/talks/peter_saul_let_s_talk_about_dying?language=en

Schneider, Z., & Whitehead, D. (2016). *Nursing and midwifery research: Methods and appraisal for evidence-based practice* (5th ed.). Chatswood, NSW: Elsevier Australia, a division of Reed International Books Australia Pty Ltd.

Seymour, J., Almack, K., & Kennedy, S. (2010). Implementing advance care planning: A qualitative study of community nurses' views and experiences. *BMC Palliative Care, 9*(4). Retrieved from http://dx.doi.org/10.1186/1472-684X-9-4.

Shamseer, L., Moher, D., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., . . . PRISMA-P Group. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: Elaboration and explanation. *BMJ (Clinical Research Ed.), 350*(1). doi:http://dx.doi.org/10.1136/bmj.g7647

Shelley, M.R. (2017). Talking about the taboo topic of death: State and federal initiatives to reach informed consent at the end of life through advance care planning. *Drake Law Review, 65*(2), 583–614. Retrieved from https://lawreviewdrake.files.wordpress.com/2015/01/shelley-final.pdf

Shimada, C., Nakazato, K., Arai, K., Aita, K., Shimizu, T., Tsuruwaka, M., . . . Takahashi, R. (2015). Communication with important others regarding their preferences for end-of-life care. *Japanese Journal of Geriatrics/Nihon Ronen Igakkai Zasshi, 52*(1), 79–85. doi:10.3143/geriatrics.52.79

Shimizu, T. (2015). Supporting patients and their families to make informed decisions. *Medical Society/Iryo To Shakai, 25*(1), 35–48. doi:10.4091/iken.25.35

Shiomi, A., Ito, M., Saito, N., Ohue, M., Hirai, T., Kubo, Y., & Moriya, Y. (2011). Diverting stoma in rectal cancer surgery. A retrospective study of 329 patients from Japanese cancer centers. *International Journal of Colorectal Disease, 26*(1), 79. doi:10.1007/s00384-010-1036-0

Statistics Bureau of Japan. (2015). *Dankai-no-sedai in Japan,* (No. 114). Retrieved from www.stat.go.jp/info/today/114.html

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., . . . Heyland, D. K. (2017). Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management, 53*(5), 821–832.e821. https://doi.org/10.1016/j.jpainsymman.2016.12.331

Sullivan, L. (2017). Dynamic axes of informed consent in Japan. *Social Science & Medicine, 174*, 159-168. doi:02779536

Sumita, M. (2015). The present state of advance care planning in Japan. *Journal of the Japan Association for Bioethics, 25*(1), 57–68. doi:10.20593/jabedit.25.1_57

Taguchi, A., Naruse, T., Kuwahara, Y., Nagata, S., & Murashima, S. (2013). Home visiting nurse agencies for community dwelling elderly at nighttime in Japan. *Home Health Care Management & Practice, 25*(6), 256–263. doi:10.1177/1084822313494086

Takada, Y., Hamatani, Y., Kawano, Y., Anchi, Y., Nakai, M., Izumi, C. … Fukumoto, Y. (2019). Development and validation of support tools for ACP in patients with chronic heart failure. *International Journal of Palliative Nursing. 25*(10):494–502. doi: 10.12968/ijpn.2019.25.10.494.

Takahashi, M., & Fuse, J. (2012). Visiting nurses skills for understanding of home resident elderly patients' will with regard to terminal care. *Journal of Japanese Nursing 35*(1), 99–105. doi:10.15065/jjsnr.20111220005

Takahashi, M., Sugaya, S., Suzuki, Y., Ishizu, M., Fuse, J., & Takahashi, K. (2017). Development of the Japanese version of values history using the delphi method with visiting nurses. *Journal of Japan Society of Nursing, 40*(5), 5_771–5_782. doi:10.15065/jjsnr.20170506011

Takeuchi, M., & Karasawa, K. (2008). Ageism and traditional values in Japan. *Gerontologist, 48*, 69–69.

Takezako, Y., Ishikawa, S., & Kajii, E. (2013). Advance directives in Japanese nursing homes. *Journal of Pain and Symptom Management, 45*(1), 63–70.e7. Retrieved from https://doi.org/10.1016/j.jpainsymman.2011.12.287

Tanaka, T. (2018). The current state and problems of "the practice guidelines for process of decision making regarding treatment in the end of life care". *Life and Environmental Science at Tsu City College, (1*),39-43.

Thorne, S. E. (2016). *Interpretive description: Qualitative search for applied practice* (2nd ed.). New York, NY: Routledge.

Tsuruwaka, M., Omomo, M., & Sumita, M. (2016). Advance care planning processes and specific assistance: Through analysis of the timing of the confirmation of the intentions of care recipients by visiting nurses. *Japan Association for Bioethics, 26*(1), 90–99.-doi:10.20593/jabedit.26.1_90

Tsuruwaka, M. (2018). Barriers to promoting advance care planning for residents living in a sanatorium for hansen's disease: A qualitative study of residents and staff in Japan. *Asian Bioethics Review*, *10*(3),199-217. doi:10.1007/s41649-018-0059-7

Uchinuma, Y. (1992). The concepts of shame and guilt in the light of Japanese culture. *International Journal of Psychology, 27*(3-4), 542.

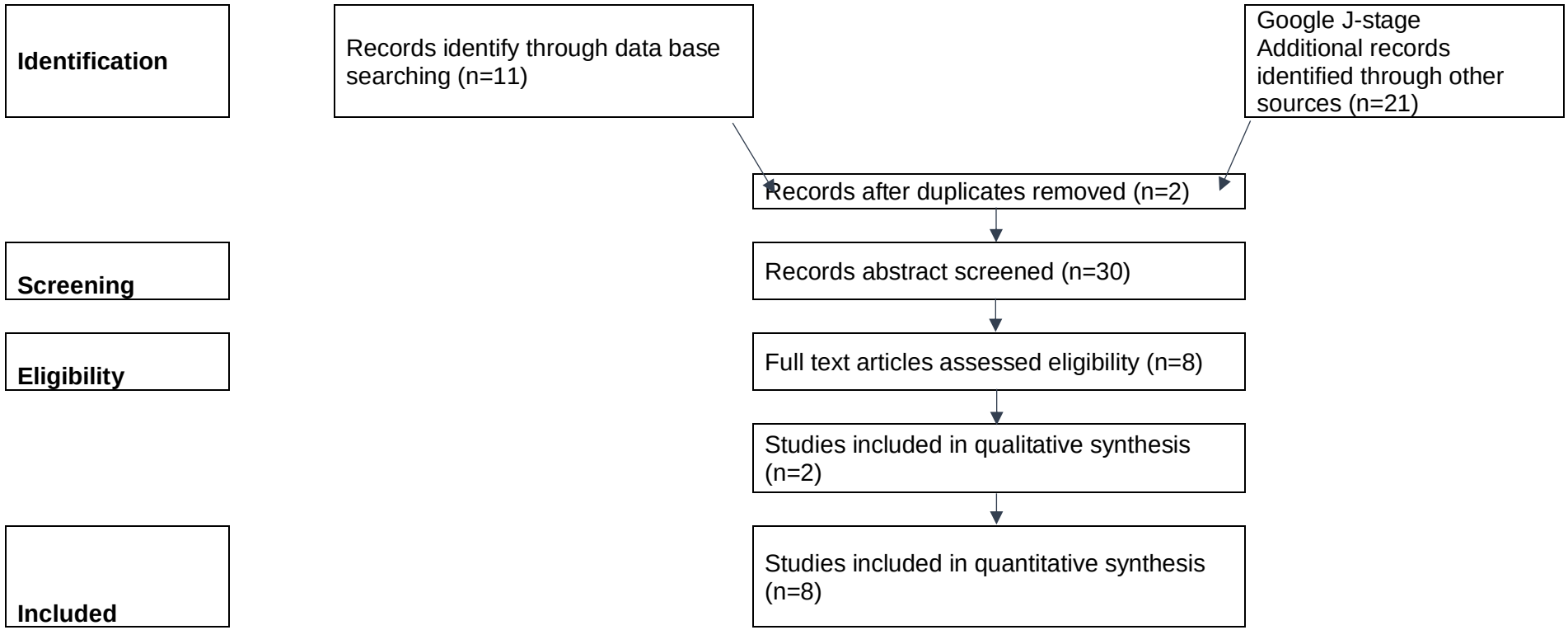
Wenger, A. (1991). Qualitative evaluation and research methods, 2nd edition-patton,MQ. *Nursing Research, 40*(5), 281–281. doi:10.1097/00006199-199109000-000006

APPENDICES

Appendix 1 Inclusion and exclusion criteria table

Inclusion	Exclusion
Setting in Japan	Out of Japan
Community registered nurses	Community nurses, enrolled nurses, hospital registered nurses
Community based facility	Hospitals, clinics, school nurses, company, nursing homes
Primary research	Secondary research
Japanese and English	Except Japanese and English
2010-20 published year	Before 2010

Appendix 2 PRISMA chart (PRISMA Flow Diagram, 2009)



Appendix 3 Evaluation of qualitative studies included for review (CASP,2018)

Author and date	Q1 Clear research aims	Q2 Qualitative approach appropriate	Q3 Research design appropriate	Q4 Recruitment strategy appropriate	Q5 Data collection method appropriate	Q6 Researcher bias recognized	Q7 Ethical issue considered	Q8 Data analysis rigours	Q9 Findings clearly stated	Q10 Research is valuable
Tsuruwaka (2016)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Takahashi (2012)	Y	Y	Y	Y	Y	Y	Y	N	Y	Y

Appendix 4 Evaluation of quantitative studies included for review

JBI Critical Appraisal checklist for Analytical Cross Sectional Studies (2017)

Cross sectional studies	1	3	4	5	7	8
1. Were the criteria for inclusion in the sample clearly defined?	Y	Y	Y	Y	Y	Y
2. Were the study subjects and the setting described in detail?	Y	Y	Y	Y	Y	Y
3. Was the exposure measured in a valid and reliable way?	Y	Y	Y	Y	Y	Y
4. Were objective, standard criteria used for measurement of the condition?	Y	Y	Y	Y	Y	Y
5. Were confounding factors identified?	Y	Y	Y	Y	Y	Y
6. Were strategies to deal with confounding factors stated?	Y	Y	Y	Y	Y	Y
7. Were the outcomes measured in a valid and reliable way?	Y	Y	Y	Y	Y	Y
8. Was appropriate statistical analysis used?	Y	Y	Y	Y	Y	Y

Appendix 5 Themes table

Themes	Sub-themes	Description	Paper number
The perception of ACP by community nurses	Ageing society	ACP is a new concept, difficult to adopt quickly	1,2,3,4,6,8
Cultural aspects surrounding of ACP	Family Communication skills Decision-making process	There are certain barriers with patients, nurses and family	2,3,4,6,7
Legal facts	Documentation Informed consent	Japan does not have a legal-framework. Guideline is uncertain	1,2,3,5,8

Appendix 6 Summary table

No.	Authors/Title/Year	Study aims /purpose	Study design /methodology	Setting and sample	Main findings	Strengths and limitations
1	Ishikawa (2018), Japan Association between ACP by a visiting nurse and achieving the desired place of death for patients with end-stage cancer	To examine the association between ACP by a visiting nurse and achieving the desired place of death	A cross-sectional nationwide questionary survey	1000 randomly selected home care agencies by visiting nurses	A total of 374 responses were analysed. Regarding the place of death, 65.0 % of patients died at home and 73.8% died at their chosen place. The rate of an explanation of the prognosis, including problems likely to occur in daily life was low (27.8-31.8) of ACP. These results suggest that patients are more likely to die in their desired place if visiting nurse confirm the chosen place of death repeatedly with updated information.	Strengths: ACP process examined confirmations of the chosen place of death by visiting nurses. Limitations: responses were collected by nurses who particular interested in ACP, cannot be generalised. The patient stayed home over 3weks with cancer for terminal illness.
2	Tsuruwaka (2016), Japan ACP processes and specific assistance: through analysis of the timing of the confirmation of the intension of care recipients by visiting nurses	To consider appropriate ACP processes and specific assistance by analysing the timing of the confirmation by visiting nurse	Semi-structured interviews	23 visiting nurses with over 3 year's experiences. 34 non-cancer patients aged over 65 years old with living with family members.	The timing of the confirmation of the intensions of care recipients and subsequent dialogue between care recipients, their family members, and medical teams are part of the ACP process. The duties of nurses assisting of ACP is to provide insight based on the prioritisation of daily care and assessments underpinned by sufficient medical knowledge and communication skills to build trust and allow care recipients and their family members to express their true wishes.	Strength: ACP process examined confirmations of the timing of intension of care. Limitations: limited as case study of non-cancer patients.

No.	Authors/Title/Year	Study aims /purpose	Study design /methodology	Setting and sample	Main findings	Strengths and limitations
3	Nakanishi (2016), Japan Quality of care for people with dementia and professional caregiver 'perspectives regarding palliative care in Japanese community care settings	To examine the association between care quality for patients with dementia and caregivers	A cross-sectional, paper-based questionnaires	2116 care givers from 329 home based communities in Tokyo metropolitan area	Professional caregiver's knowledge and attitude regarding palliative care were positively associated with quality of life in patient with dementia. Physical restraint and antipsychotic medication were used regardless of professional caregiver's knowledge and attitudes. A national strategy for advocacy and the protection of adult is required to integrate several lows and guidelines for preventing use for chemical restraint.	Strength: the first study to demonstrate a positive association between dementia care quality and patients and perspectives from home based care givers. Limitations: the design could not provide a causal model of caregiver's view and dementia quality. The response rate was low, and sampling bias have occurred. Staff rating for quality of life could differ from those of patients.
4	Nishiguchi (2017), Japan End-of-life care bonus promoting end-of-life care in nursing home: an 11 years retrospective longitudinal prefecture-wide study in Japan	To clarity the effects of the EOL bonus in promoting EOL care in Nursing homes	A pilot survey with questionnaires	378 nursing homes Kanagawa	EOL care bonus has the potential to increase the number of residents receiving EOL care in nursing home over several years. The government financial incentive may contribute to effective EOL care among nursing homes residents. EOL care bonus contributes to reducing undesired transfers to hospitals and a wide spread framework of quality preservation for EOL care including ACP.	Strength: the results of the linear mixed method model was useful by a national government. Limitations: a longitudinal study occurred a considerable amount of missing data. There may have been bias in which facilities consented to participants. Limited location, one prefecture only

No.	Authors/Title/Year	Study aims /purpose	Study design /methodology	Setting and sample	Main findings	Strengths and limitations
5	Takada (2019), Japan Development and validation of support tools for ACP in patients with chronic heart failure	To develop and validate ACP support tools for patients with heart failure	Systematic approach survey questionnaires	21 patients Medical staff intervention group	The health professionals involved in this study found the ACP tools useful and 90% of patients considered the support tool useful.	Strength: developed ACP process for patients with heart failure. Limitations: small sampling. The authors did not randomise and control the patient in this study.
6	Takahashi (2012), Japan Visiting nurse's skills for understanding of home resident elderly patient's will and regard to terminal care	To examine the skill by visiting nurses understand the will of their elderly home resident with EOL	Semi-structure interview Interpretive description Qualitative	12 visiting nurses	The visiting nurses 'understanding of patient's decision-making was on 2 key factors: states and skill. It is uncertain when the terminal period starts, the patient is unaware at the terminal stage, the circumstances change, and many patients unable to communicate. Skill comprised understanding the patient's will from how the patients would like to spend their time, day to day communication through nursing care, interpreting the patient's will from their life style. Coping with difficult issue.	Strength: This study provided the first step Qualitative research by community nurses. Limitations: discussion and analysis were not deep enough. Definition was not very clear.

No.	Authors/Title/Year	Study aims /purpose	Study design /methodology	Setting and sample	Main findings	Strengths and limitations
7	Takahashi (2017), Japan Development of the Japanese version of values history using the Delphi method with visiting nurses	To develop the Japanese version of values history To assist reflecting on value to justify patient's decision-making for EOL	Quantitative description research for using the Delphi method	363 visiting nurses	35 items such as, how to confront health issues, information provided by doctors about health issuers, how you feel about the rest of your life and the reasons, characteristics of your decision-making, characteristics of your communication with people. Patients are not always informed of their diagnosis or prognosis of their illness as well as the characteristic of decision-making of Japanese people who care about situations of other people around and the atmosphere of the place.	Strength: Develop to the process ACP through Values history Limitations: limited populations.
8	Takezako (2013), Japan Advance Directives in Japanese nursing	To investigate the adoption of advance directives by Japanese Nursing homes	A nationwide questionary survey Descriptive analysis	913 nursing homes	Advance directives were used in 58.4% of nursing homes. Instructional directives used, directives providing an explanation and informed consent for EOL care in the nursing home.	Strength: nationwide survey Limitations: Out of date

Appendix 7 Letter of introduction

Flinders University
College of Nursing and Health Silences
GPO Box 2100
Adelaide SA 5001
Tel: +61 8 201 3354
Yvonne Parry
Yvonne.parry@flinders.edu.au
CRICOS Provider No. 00114A

Dear Sir/Madam

This letter is to introduce Ms Yumi Naito who is a Master student in the College of Nursing and Health Sciences at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis or other publications on the subject of "How do community registered nurses use Advance Care Planning in Japan?" She would like to invite you to assist with this project by granting an interview which covers certain aspects of this topic. No more than one hour on one occasion will be required.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make a digital recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed and that the confidentiality of the material will be respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 8201 3354 or e-mail yvonneparry@flinders.edu.au Thank you for your attention and assistance.

Yours sincerely

Dr Yvonne Parry

Senior Lecturer

College of Nursing and Health Sciences.

This research project has been approved by the Flinders University Social and Behavioural Research

Ethics Committee in South Australia (Project number PROJECT No. 8297).

For queries regarding the ethics approval of this proje
complaints, please contact the Executive Officer of th
3116 or email human.researchethics@flinders.edu.au

ABN 65 524 596 200 CRICOS Provider No. 00114A

inspiring achievement

Appendix 8 Letter of introduction (Japanese)

紹介状

修士論文における紹介

この書は、現在　南オーストラリア州　フリンダーズ大学　大学院修士課程に在学している

内藤由美をしょうかいするものです。

この度、訪問看護領域で　いまだまだ新しい　アドバンスケアプランニングを研究しています。

日本が急速に高齢化を迎え、地域においてどの様に　終末期看護を充実したものにできるか。

患者様の看取りを行う中で日頃感じていること、経験されたことを 1 時間ほどの個人インタビューを、参加者のご希望の場所にて行いたいと思います。

インタビューで得た情報は厳密に扱われ、参加してくださった方の身元、また貴院の名前が明かされることはありません。

ボランティアでこの研究に参加していただける方は、研究の紹介の手紙と研究に参加していただく際の承諾書を対象の方々に送付します。

どうかこの研究に承諾していただけるようお願い申し上げます。

この研究は、本大学の研究における倫理委員会の審査、許可をうけております。

もし、何か質問などございましたら下記まで連絡下されば幸いです。

Dr Yvonne Parry, email　yvonne.parry@flinders.edu.au

今回の貴殿への研究への参加、誠に感謝申し上げます。

Dr　Yvonne Parry

ドクター、イボンヌ　パリー

フリンダーズ大学教官 スーパーバイザー

Appendix 9 Ethics approval

Dear Yumi,

Your ethics application was reviewed by the Social and Behavioural Research Ethics Committee (SBREC) Low Risk Sub-Committee at Flinders University and was **approved.** The ethics approval notice can be found below.

APPROVAL NOTICE

Project No.:	**8297**		
Project Title:	How do community registered nurses use Advance Care Planning in Japan?		
Principal Researcher:	Ms Yumi Naito		
Email:	nait0001@flinders.edu.au		
Approval Date:	22 March 2019	Ethics Approval Expiry Date:	**30 December 2020**

The above proposed project has been **approved** on the basis of the information contained in the application and its attachments with the addition of the following comment:

Additional comments:

Governance Consideration:

Data Transmission Protocols (item F10a)

Please confirm that secure transmission of research data to other members of the research team and/or supervisor will be via secure email, One Drive etc.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**
   Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:
   - All participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.

- The Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the 22nd March (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on 22nd March 2020 or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);

- extensions of time.

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Rae

Ms Andrea Mather (formerly Fiegert) **and Ms Rae Tyler**
Ethics Officers and Executive Officers, Social and Behavioural Research Ethics Committee

Ms Andrea Mather | Monday - Friday	T: +61 8201-3116 | E: human.researchethics@flinders.edu.au
Ms Rae Tyler | Monday, Wednesday and Friday mornings	T: +61 8201-7938 | E: human.researchethics@flinders.edu.au
A/Prof David Hunter | SBREC Chairperson	T: +61 7221-8477 | E: david.hunter@flinders.edu.au
Dr Deb Agnew | SBREC Deputy Chairperson	T: +61 8201-3456 E: deb.agnew@flinders.edu.au
SBREC Website	Social and Behavioural Research Ethics Committee (SBREC)

Research Development and Support |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

CRICOS Registered Provider: The Flinders University of South Australia | CRICOS Provider Number 00114A
This email and attachments may be confidential. If you are not the intended recipient, please inform the sender by reply email and delete all copies of this message.

Appendix 10 Information sheet

INFORMATION SHEET

Interviews- community registered nurses

Title: How do community registered nurses use Advance Care Planning in Japan?

Researcher

Ms. Yumi Naito, Master of nursing student

College of Nursing and Health Sciences

Flinders University

Tel: 08095472215 (Japan)

Supervisor(s)

Doctor Yvonne Parry, Senior lecturer

College of Nursing and Health Sciences

Flinders University

Tel 82013354

Doctor Katrina Breaden, lecturer

College of Nursing and Health Sciences

Flinders University

Tel 82013466

Description of the study

Advance Care Planning is a new concept in Japan, this study is part of the project titled “How do community nurses use Advance Care Planning in Japan? “ It will investigate how community registered nurses experience about ACP nursing care. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study

This project aims to explore how community registered nurses care utilise the framework of Advance Care Planning in Japan.

What will I be asked to do?

You are invited to attend a one-on-one interview with Yumi Naito who will ask you a few questions regarding your role as a community registered nurse in dealing Advance Care Planning. Participation is entirely voluntary. The interview will take about 60 minutes, at a location on convenient to participant. The interview will be audio recorded using a digital voice recorder to help the research to understanding your roles and experiences. Once recorded, you will be given the opportunity to review the interview will be transcribed (typed-up) and stored as a computer file.

What benefit will I gain from being involved in this study?

The sharing of your experiences helping for other community registered nurses and expand our understanding of Advance Care Planning. The knowledge gained about end of life care and Advance Care Planning. Roles of community registered nurses will provide information for future policy and procedures.

Will I be identifiable by being involved in this study?

We do not need your name. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be confidential and will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants may experience some emotional discomfort. If any emotional discomfort is experienced please contact for support / counselling at the government community service (3 5321 1111; Tel) that accessed free of charge by all participants. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?

Participation is voluntary. You may answer 'no comment' or refuse to answer any questions, and you are free to withdraw from the interview at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and send it back to me in person. Please ring me directly and I will arrange a time to meet with you and collect your signed consent.

How will I receive feedback?

On project completion, outcomes of the project will be given to participants by email.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project No. 8297). For queries regarding the ethics approval of this project, or to discuss any concerns or complaints, please contact the Executive Officer of the committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix 11 Information sheet (Japanese)

修士論文における概要書

訪問看護師による看護領域において、アドバンスケアプランニングにおいての研究です。

私は、現在　南オーストラリア州　フリンダーズ大学　大学院修士課程に在学しています。

この度、訪問看護領域で　いまだまだ新しい　アドバンスケアプランニングを研究しています。

日本が急速に高齢化を迎え、地域においてどの様に看護を充実したものにできるか。

患者様の看取りを行う中で日頃感じていること、経験されたことを 1 時間ほどの個人インタビューを、参加者のご希望の場所にて行いたいと思います。

インタビューで得た情報は厳密に扱われ、参加してくださった方の身元、また貴院の名前が明かされることはありません。

ボランティアでこの研究に参加していただける方は、研究の紹介の手紙と研究に参加していただく際の承諾書を対象の方々に送付します。

どうかこの研究に承諾していただけるようお願い申し上げます。

この研究は、本大学の研究における倫理委員会の審査、許可をうけております。

もし、何か質問などございましたら下記まで連絡下されば幸いです。ボランティアとしての参加を心待ちしています。よろしくお願いいたします。

内藤由美

Tel：080 9547 2215

nait0001@flinders.edu.au

Appendix 12 Consent form (Japanese)

研究に参加していただく際の承諾書

私、　　は、18 歳以上であり

訪問看護師として、アドバンスケアプランニングと看取りに関する研究のインタビューに参加します。

1. 私は、この与えられた情報を読みました。

2. 手順やリスクは十分に説明を受けました。

3. 私は自分の情報をテープレコーダーに録音することに同意します。

4. 私は、インフォメーション用紙や今後の参考のために保存します。

5. 私は、以下のことに同意します。

　この研究に参加することで直接的な利益を受けない。

　この研究からはいつ中止しても、取りやめてもまた特定の質問に答えることを拒否できる。

　この研究が公表されても、個人的な情報は明かされない。

　この研究によって、勤務が脅かされない。

　この研究に参加すか否かで、現在　あるいは未来の仕事に関係しない。

6. 私には、この研究に参加するかどうか、家族や友人と話し合う機会が認められます。

参加者署名　　日付

私は、確かに参加者が求められていることが理解できるように、参加は自由であることが理解できるように、参加してくださる方に説明しました。

研究者署名　　日付

私、下記に署名したものは、私自身のインタビューを読み、それを研究者が説明されたように

使用されたように同意します。

参加者署名

日付

Appendix 13 Questions

School of Nursing and Health Science

GPO Box 2100

Adelaide SA 5001

Tel: 0412293211

nait0001@finders.edu.au

CRICOS Provider No. 00114A

1 How long have you been a community registered nurse?

2 Tell what you know about Advance Care Planning?

3 What framework or Advance Care Planning model do you use? If you do not use ACP is there another model framework that you use?

4 Tell me of a time when you used Advance Care Planning? What was that like?

5 Have any issues or problems arise when discussing Advance Care Planning with your clients/patients?

Appendix 14 CareSearch blog post

https://www.caresearch.com.au/caresearch/tabid/3781/ArtMID/6000/ArticleID/1058/Default.aspx

CareSearch Blog: Palliative Perspectives

The views and opinions expressed in our blog series are those of the authors and are not necessarily supported by CareSearch, Flinders University and/or the Australian Government Department of Health.

How do we use advance care planning in Japan?

A guest blog post by Yumi Naito, Registered Nurse and Masters Student, Flinders University

- 5 November 2019
- Author: Guest
- Number of views: 933
- 2 Comments

Image removed due to copyright restriction.

Observing various death and dying process in different places throughout my nursing career, has motivated me to investigate advance care planning (ACP) in Japan. I have worked and lived in Japan, India, the United States of America and Australia. I experienced a particular difference when I was working as a registered nurse and witnessed the patient dying process in Australia. The difference in patient care in Australia related to the patient having the opportunity of choices. The choice around what happened at the end of life could be made by the patient. This difference prompted me to become involved in ACP, because ACP policies support a good death by valuing the patient's preferences.

Advance care planning is a new concept in Japan. There is some guidance on medical decision making at the end of life developed by the Ministry of Health, Labour and Welfare (Shimizu, 2015). However, unlike Australia, Japan does not have a legal framework to support ACP.

Advance care planning in Japan has followed from these government guidelines for medical decision making discussion processes in the terminal stages of an illness. They recommend individualised self-determination by patients as long as people are competent, but there is no legal documentation yet. The

impact of this lack of clarity means patients and health professionals struggle to consider the most suitable way to utilise ACP.

Like other countries, Japan is rapidly ageing. However, the speed and extent of the ageing in Japanese society is unmatched anywhere in the world (National Institute of Population and Social Security Research, 2017). This increase in ageing is accompanied by an increase in the number of deaths in this country as our older people reach the end of their life.

Despite Japan being a modern country, existing customs and traditions make it difficult to adopt the concept and practice of ACP. Barriers include the customs and traditions in the Japanese cultural background along with a lack of understanding of individual decision making. Most patients rely on the family or the doctors to make decisions about care and treatments. This is a common understanding among Japanese people. “Omakase” is the Japanese tradition of letting a chef choose your order. The word means "I will leave it to you." This is also the traditional Japanese approach to medical decision making (Sullivan, 2017). It implies that some patients want to leave decisions to their family and doctors.

I recently presented at the End of Life Care conference in Japan. My presentation was about the choices of life: the driver licence, marriage certificate, and decision making and advance care planning. The presentation was a huge success and had a big impact. Health professionals and media and public were interested in ACP in Australia. They had active questions and discussions.

As a researcher, I will go back to Japan again to talk in public about advance care planning in Australia to build community support for this issue. I believe this will contribute positively to the ageing issue as well. This work highlights that globalisation is having an influence on laws and policy. I will continue work with health professionals and assist public awareness with people in Japan.

References

1. Shimizu T. Supporting Patients and their Families to Make Informed Decisions. Iryo To Shakai. 2015 May;25(1):35-48. doi:10.4091/iken.25.35
2. National Institute of Population and Social Security Research. Population Projections for Japan (2017): 2016 to 2065 (1.79MB pdf). Tokyo: National Institute of Population and Social Security Research; 2017.
3. Specker Sullivan L. Dynamic axes of informed consent in Japan. Soc Sci Med. 2017 Feb;174:159-168. doi: 10.1016/j.socscimed.2016.12.031. Epub 2016 Dec 23.

Yumi Naito, Registered Nurse and Master’s Student, Flinders University