Ethical Perspectives of End-of-Life Dementia Care in South Korea

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Contents

Declaration

I, Jungmin Kim 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 reference is made in the text.

Signed:

Date: 08/02/2024

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This thesis could not have been completed without the support and encouragement of many people. At the final stage of the long journey, I wish to acknowledge and thank all these people for their contributions.

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List of Abbreviations

ACP: Advanced Care Planning

ADE: Advance Directives for Euthanasia

ALE: Average Life Expectancy

ANH: Artificial Nutrition and Hydration

CASP: Critical Appraisal Skills Programme

CDS: Continuous Deep Sedation

CPR: Cardiopulmonary Resuscitation

GP: General Practitioner

IPA: Interpretive Phenomenological Analysis

LED: Lived Experience Description

MAID: Medical Assistance In Dying

NHMRC: National Health and Medical Research Council

OECD: Organisation for Economic Co-operation and Development

PTOs: Physician Treatment Orders

QOC: Quality Of Care

SBREC: Social and Behavioural Research Ethics Committee

TA: Template Analysis

WHO: World Health Organization

Abstract

Background

South Korea was the first East Asian country to implement hospice and palliative care, introduced by a group of Catholic nuns from Australia in 1963. Hospice and palliative care in South Korea have been primarily targeted at terminal cancer patients as part of the Cancer Control Act of 2004. However, according to government statistics on cause of death in 2019, dementia ranked 7th in South Korea, up from 13th a decade previously. As the role of home for dementia care is decreasing due to the falling fertility rate and the increase in the elderly population in South Korea, the government has announced a policy to relieve the burden on families of the elderly with chronic illnesses such as dementia. Hence, there is an increasing need for end-of-life care for people with advanced dementia, while at the same time, the provision of care is increasingly being provided by healthcare professionals and family members. Therefore, it is necessary to explore the experiences of family members and healthcare professionals in their provision of hospice and palliative care for people with advanced dementia.

Aim

The purpose of this study is to explore the ethical dilemmas of family members, nurses, and doctors involved in making decisions for people with advanced dementia in South Korea.

Methodology

A qualitative research project designed to explore family members' and healthcare professionals' experiences of decision-making, the barriers they faced in their decision-making, and supports for their decision-making, was undertaken using Hermeneutic Phenomenology as the research methodology. A total of 18 participants were recruited and interviewed for the project. Template Analysis (TA) was conducted to determine the significant issues in the data from the perspective of family members, nurses, and doctors with experience in caring for patients with advanced dementia.

Findings

Four themes were identified from the data collected from nurses who take care of patients with advanced dementia: communication barriers, lack of education, care for people with advanced dementia, and stressful ethical dilemmas. The nurses were actively involved in caregiving activities for patients with advanced dementia, but they felt that education on dementia care was insufficient. Their active expressions of intentions were often hindered when communicating with doctors, and they experienced ethical dilemmas when they disagreed with other healthcare professionals. Four themes from the doctors' experiences were derived: difficulties managing patients with advanced dementia, financial difficulties of patients with advanced dementia, the effects of decision-making, and healthcare professionals' lack of knowledge about dementia. The doctors experienced limitations in their scope of treatment because it was difficult to ensure patient cooperation due to the nature of dementia. Under some circumstances, there were cases where the doctors had to make decisions for patients with advanced dementia, while mental health specialists felt that other

healthcare professionals lacked knowledge of these patients' condition. Finally, four themes were identified in the data from family members of people with advanced dementia: care for people with advanced dementia, experiencing conflict, decision-making for people with advanced dementia, and poor quality of life. The family members in this study made a considerable contribution to caring for their relatives with advanced dementia, but they also experienced conflict with them, other family members, and healthcare professionals, particularly in relation to treatments for people with advanced dementia. As the next of kin, family members are often involved in making decisions for relatives with advanced dementia.

Conclusion

Understanding the experiences of family members, nurses, and doctors in caring for people with advanced dementia in South Korea assists with the identification of their ethical dilemmas. By highlighting what is and what is not known about the decision-making of family members and healthcare professionals for people with advanced dementia in South Korea, a range of educational support and policy development needs were identified. A number of suggestions are made at the end of the thesis for future research as well as for family members and healthcare professionals engaged in dementia care.

Key words: advanced dementia, decision-making, end-of-life care, ethical dilemma, doctors, family members, nurses, palliative care, South Korea

Chapter 1: Introduction

This study explored the ethical dilemmas faced by healthcare professionals and family members of people with advanced dementia when they make decisions for end-of-life care for the people with advanced dementia in South Korea. This chapter presents a background of demographic and social change, end-of-life care, and decision-making culture in South Korea. This is followed by a brief overview of the research questions, the aims, goals, and significance of the study, the implications of the research findings, and the potential contributions of the study. An overview of the remaining chapters and the major findings of the study will also be presented to complete the introductory chapter.

Background to the study

Dementia is general term for cognitive decline in aspects of memory, thinking, language, problem-solving abilities that are severe enough to interfere with social or occupational function (Chertkow et al., 2013). A loss of independence has a significant impact on the person, their caregivers, and communities as well as the national healthcare system (Matthews et al., 2019). Due to the ageing of the global population, the current number of people with dementia worldwide is approximately 55 million, which is expected to reach around 78 million by 2030, and 139 million by 2050 (WHO, 2021). The burden of dementia care has become a significant issue as support and care for people with dementia has a wide impact on families, medical systems, and society as a whole (Jia et al., 2020; Aranda et al., 2021).

Previous studies on the incidence and prevalence of dementia in Western countries showed that the incidence and prevalence of dementia are stable or decreasing (Wu et al., 2017). Especially, in Western Europe countries, the prevalence of dementia has decreased by up to 25% in recent decades, indicating that the number of people with dementia in the regions have stabilised despite the presence of ageing populations (Wu et al., 2016). On the other hand, the incidence and prevalence of dementia are increasing in East Asian countries such as Hong Kong, Taiwan, China, Japan, and South Korea (Wu et al., 2015; Wang et al., 2023). Some of these differences between Western and Eastern countries can be attributed to differences in research populations, research design, economic status, and/or cultural and social contexts (Wu et al., 2017). The reason for the increase in the prevalence rate in South Korea is that the diagnosis dementia rate may have increased due to changes in social and educational conditions, and because of modern national insurance systems and national education about dementia (Jang et al., 2021). In addition, when the diagnosis is more sensitive and accurate, the prevalence and incidence may increase (Livingston et al., 2020).

The increase in prevalence and incidence in Eastern countries in recent years, where medical development has occurred rapidly, may reflect an improvement in diagnostic sensitivity and accuracy rather than an increase in the number of people with dementia. South Korea has an ageing society, and modern people have high levels of knowledge and interest in dementia and advanced medical technologies. Therefore, the prevalence and incidence of dementia are most likely to increase, and an increased number of elderly people will die as a result.

In the following section, demographic and social changes, end-of-life care, and decision-making in South Korea will be explored. As these factors are related to the decision-making of family members and healthcare professionals who care for people with dementia, they will be explained in detail along with traditional values related to caring for the elderly in South Korea.

Demographic and social change in South Korea

The growth rate of the ageing population in South Korea is very rapid compared to most other countries (OECD, 2021). The Average Life Expectancy (ALE) of the South Korean population has increased from 74.2 years in 1996 to 83.3 years in 2019, while the number of people aged 65 or older per 100 working-age people (20-64 years old) is expected to exceed 78 in 2060 (OECD, 2021). The number of people aged 65 and over per every 100 working age people in the population is old-age dependency ratio. The old-age support ratios are related to the number of people who can support the number of elderly people can rely on other people's support.

The prevalence of dementia among the elderly aged 65 or older in South Korea increased from 5.9% in 2015 to 7.3% in 2019, and the number of people with dementia in South Korea was about 588,000 in 2019 (Shon & Yoon, 2021). Hence, it has been predicted that over one million people in South Korea will have dementia by the year 2024, and this number will reach over two million people by 2041 (Statistics Korea, 2021).

End-of-life in South Korea

Among the East Asian countries, South Korea was the first country to introduce hospice and palliative care. Australian nuns introduced this particular types of care to South Korea in 1963. Hospice and palliative care in South Korea provides care to only terminal cancer patients under the Cancer Control Act of 2004 (Kim & Hong, 2016). There are two famous cases that have strongly influenced the right-to-die law in South Korea, the Boramae hospital case and the Severance hospital case (refer to Table 1).

Table 1: Cases that have influenced the Hospice Life Prolonging Medical Care Act

	Boramae Hospital, 1997	Severance Hospital, 2008
Patient History	Patient with sub-arachnoid haemorrhage	76-year-old patient in permanent vegetative state
Issues	Next of kin requested terminal discharge. After discharge, the patient died 36 hours later	Next of kin requested withdrawal of life-sustaining treatment. However, it was rejected by the hospital
Results	The indictment of two doctors for aiding and abetting the homicide	Court decision to withdraw life-sustaining treatment

Source: Lee, 2007; Park, 2009; Yu, 2015

In the Boramae Hospital case, the court admitted that the doctors were suspected of aiding and abetting murder, and as a result, the hospital refused to request the discharge of patients who were not likely to be resuscitated (Lee, 2007; Park, 2009). This can be seen in the decisions made by doctors at Severance Hospital in 2008. Due to the influence of the results of these cases, and the limitations of the Cancer Control Act, the Hospice Life Prolonging Medical Care Act was enacted in 2016, allowing terminally-ill individuals aged 19 years and older to request withdrawal of life-sustaining treatments (Kim & Hong, 2016). This Act came into force in February 2018. Life-sustaining treatment is legally defined as cardiopulmonary resuscitation (CPR), cancer medication, haemodialysis, and ventilators. This Act does not apply to artificial nutrition and hydration (ANH), active palliative care or oxygen masks (respiration without reliance on a machine).

Signatures of the patients, two professional doctors, and a witness are required to approve the patients’ wishes (Kim & Hong, 2016). Based on the patients’ presumed wishes and personality, this law may also be stipulated when patients are unable to express themselves or make decisions if more than family members agree to hospice care (Kim & Hong, 2016). In case this is not possible, hospice care can be initiated if all family members agree (Kim & Hong, 2016). As people with advanced dementia are very unlikely to present their opinions, they have no choice but to decide whether to proceed with life-sustaining treatment based on the judgement of the family members and healthcare professionals who participate in the decision-making.

Roles in decision-making

By the end stage of dementia, family members with power of attorney can become emotionally exhausted (O'Dwyer et al., 2013). This is because dementia is a disease that has serious medical, social, and economic consequences not only for the individuals involved, but also for the wider family and society (Fetherstonhaugh et al., 2017). Dementia can lead to a lingering journey to death by living for an average of 3 to 10 years post-diagnosis, even though physical function decreases and cognitive loss increases after the diagnosis (WHO, 2021). When people with dementia reach the end of their lives, their needs are often ignored, as they are unable to verbally communicate (Brorson et al., 2014). As the dementia progresses, people lose cognitive function and are often unable to understand the trajectory of their disease, as their family members or healthcare professionals often make decisions on their behalf (Fetherstonhaugh et al., 2017). Several studies have shown that there are hierarchical patterns that emerge when elderly people need to choose who will make decisions on their behalf if they are too unwell to do so (Fetherstonhaugh et al., 2017; Martin et al., 2019; Fried et al., 2021). The pattern of choice is generally in the following order: spouse, adult children, siblings, and then other family members (Fetherstonhaugh et al., 2017). If there is not a family member or friend available, healthcare professionals make the decisions in relation to medical treatment for patients who are no longer cognitively competent (DeMartino et al., 2017).

Therefore, healthcare professionals play an important role in making decisions on behalf of their patients and are required to juggle the burdens versus the benefits of particular treatments (Grönlund et al., 2016). When there are more than two options for solving an ethical issue which, in turn, can create conflict by choosing one or the other, the issue can be ethically problematic. A definition of an ethical dilemma is a situation in which none of the options provide the best solution for an ethical issue (West et al., 2017), such as those that occur in palliative care (Rushton et al., 2013).

Justification for the study

There may be differences between the assumed beliefs (by family members) of people with dementia and their actual beliefs, as well as between the opinions of healthcare professionals about end-of-life care and the patients’ own beliefs. Therefore, when family members or healthcare professionals make decisions on behalf of people with advanced dementia, they may experience ethical dilemmas. Ethics is a term referring to the norms or standards that explain how human beings ought to act in various situations in which people find themselves as parents, children, friends, neighbours, healthcare professionals, and so on (Varkey, 2021).

There is a demand for research on the ethical dilemmas faced by family members and healthcare professionals in contemporary South Korean society, where the number of dementia patients is increasing along with the rapid ageing of the population.

Significance of the study

South Korea remains a Confucian nation, like some other Eastern countries, including China (Śleziak, 2013). Although bioethics in the Confucian way of life are family-oriented, family decisions cannot be free from Confucian belief. In fact, social reactions can be severe if terminally-ill elderly patients are allowed to die or are denied life-sustaining intervention. The children may be blamed by third parties for violating the principles of filial piety, while advocates may be criticised for being anti-humanitarian or violating the principle of saving the dying (Li, 2013). It has been suggested that it would be difficult for adult children to give up life-sustaining treatment for their parents with advanced dementia due to the Confucian values of filial piety. Filial piety encourages children to 'rescue with all their strength' and to save their parents at any cost (Li, 2013). It has also been suggested that the need of rescue at all costs potentially creates conflict for doctors, who might believe that limitations in treatment can benefit the patient, but fear that discussions with the family would create a situation of dissonance. These are the values that doctors have traditionally upheld (Varkey, 2021).

This study will focus on healthcare professionals and family members of people with advanced dementia, especially those who are actively and inactively involved in end-of-life care for people with advanced dementia and in making decisions for them. This is because family members often take full responsibility for caring for relatives with illness(es) in Asian countries (Ho et al., 2003; Zarzycki et al., 2023). South Koreans particularly value family harmony (Kim et al., 2015), and it is natural for adult children to be guardians of their sick parents (Yang, 2012). In Confucian societies, people also tend to avoid discussing death (Lei et al., 2022), not to mention giving instructions in advance to reject the end-of-life treatments.

In addition, there has been a growing interest in the elderly population, their caregivers, and illnesses of ageing such as dementia in South Korea. However, there are no known studies about the ethics and ethical dilemmas faced by caregivers who make decisions for people with dementia in South Korea. Therefore, this study explores the ethical dilemmas faced by family members and healthcare professionals when they make decisions for their relatives with advanced dementia.

Statement of the problem

There are several concerns about the increasing number of people with dementia in South Korea. The ethical issues and dilemmas faced by family members of people with dementia and healthcare professionals due to their cultural background are a major concern. In Western countries, there are studies regarding ethical issues in decision-making for people with dementia (West et al., 2017); however, studies conducted in South Korea often include only caregivers' difficulties when they provide care for people with dementia. Therefore, there is a lack of evidence for the ethical dilemmas faced by family members and healthcare professionals who provide end-of-life care to people with advanced dementia in South Korea.

There have been a number of studies about caregivers for people with dementia; however, research on the dilemmas they face when making decisions for people with advanced dementia is non-existent. Therefore, this study will explore the dilemmas faced by family members and healthcare professionals as caregivers of people with advanced dementia which, in turn, will illuminate if there are any ethical concerns on the end-of-life care for people with advanced dementia and the hidden burdens of family members and healthcare professionals who provide end-of-life care for people with advanced dementia.

Research question

What ethical dilemmas are experienced by family members and healthcare professionals when they provide end-of-life care for people with advanced dementia in South Korea?

Research objectives

- To explore the ethical dilemmas faced by family members when making decisions about end-of-life care for their relatives with advanced dementia
- To explore the ethical dilemmas faced by nurses when making decisions about end-of-life care for their patients with advanced dementia
- To explore the ethical dilemmas faced by doctors when making decisions about end-of-life care for their patients with advanced dementia

Methodology

The study originated from a need to explore the lived experiences of healthcare professionals and family members who play a role in making decisions for people with advanced dementia. The inclusion criteria for participants included doctors, nurses, and family members who have had experience in decision-making to provide end-of-life care for people with advanced dementia. van Manen's phenomenological approach (1990) was used to obtain a deep understanding of the phenomenon. Data was collected through semi-structured interviews and analysed using King's (1998) template analysis (TA).

Thesis structure

This thesis comprises seven chapters. Chapter 1 has introduced the context of, and the background to, the study; a justification for, and significance of, the study; a statement of the problem; and the research questions, objectives, and methodology.

Chapter 2 presents a review and critique of a number of studies on decision-making for people with advanced dementia. The literature review findings are categorised into the following four major points: 1) Scope of end-of-life care for people with advanced dementia; 2) Needs of pre-decision communication for people with advanced dementia care; 3) Differences in the depth of understanding of end-of-life care; and 4) Ethical dilemmas. The distinction between treatment considered necessary and unnecessary for people with advanced dementia differed from individual to individual. In the selected studies, two values of conflict and dilemma can be found: treatment to maintain human dignity, and not prolonging the time of suffering. As family members and healthcare professionals operate under different circumstances and have different experiences, their depth of knowledge of end-of-life care that can be provided to people with dementia are also different. Therefore, in order to determine the appropriate level of treatment that can provide comfort to people with dementia without over-treatment, healthcare professionals and family members may require sufficient communication.

Chapter 3 discusses theories of ethics contributing to the conceptual framework for the study. Ethics theories represent the viewpoints of individuals when they make decisions. Major ethics theories, including utilitarianism, Kantian deontology, Kohlberg’s ethics theory, Gilligan’s care ethic, and Noddings’ care ethic, will be explained. They each highlight different aspects of ethical dilemmas and derive the most ethically correct solutions according to the guidelines within the theory of ethics itself. As Noddings’ approach to ethics prioritises an interest in relationships, Noddings' care ethics was chosen for this study to explore the dilemmas in relationships between patients and healthcare professionals or between patients and their family members.

Chapter 4 discusses the methodology and methods used in this study. It describes the method known as Hermeneutic Phenomenology (van Manen, 1990), and justifies why it was used as the research design and methodology for the study. The chapter also explains the recruitment of participants, the conduct of in-depth interviews to collect the data, and the concurrent data collection and analysis process. Ethics considerations, including the maintenance of confidentiality, and anonymity, are explained, and the processes employed to ensure the rigour of the study are also outlined.

Chapter 5 presents the study findings though four themes from each group of nurses, doctors, and family members identified through the qualitative analysis. The themes for the nurses were categorised into: (1) Communication barriers, (2) Lack of education, (3) Care for people with advanced dementia, and (4) Stressful ethical dilemmas. And the themes for the doctors were categorised into: (1) Difficulties managing patients with advanced dementia, (2) Financial difficulties of patients with advanced dementia, (3) The effects of decision-making, and (4) Healthcare professionals' lack of knowledge about dementia. Finally, the themes for the family members were categorised into: (1) Care for people with advanced dementia, (2) Experiencing conflict, (3) Decision-making for people with advanced dementia, and (4) Poor quality of life.

Chapter 6 discusses the major findings identified in this study in a Korean and an international context. These findings are compared to those from a number of relevant studies through their similarities and differences between the healthcare professionals and family members of people with dementia. Reiterating the issues evaluated in Chapter 5, the focus of the discussion is on the experiences of each group of participants.

Chapter 7 summarises the key research findings and highlights the main discussion points of the thesis. The chapter draws conclusions from the major findings and specifies a number of implications for decision-making for people with advanced dementia who are at the end of their life. The chapter also discusses the limitations of the study and makes several recommendations for each stakeholder group, education institutions, family members of people with advanced dementia, healthcare professionals, and policy departments. Finally, suggestions are made for future research in this field of study.

The following chapter presents a comprehensive literature review that sets a context for the study by analysing the current literature about ethical dilemmas that are commonly experienced by family members and healthcare professionals when they provide end-of-life care for people with advanced dementia. The chapter highlights what is and what is not known about the decision-making of family members and healthcare professionals for a person with advanced dementia in many countries, including South Korea.

Chapter 2 Literature Review

Chapter 1 introduced the issues associated with end-of-life care for people with advanced dementia. This chapter presents a critical analysis of the literature related to the research question. It describes the framework used to critique the articles, the literature search process, and analyses the major findings. The purpose of the literature review is to explore the research on the ethical issues associated with end-of-life care for people with advanced dementia. The results indicate what is and is not known about the experiences of family members and healthcare professionals who care for people with advanced dementia in relation to the ethical dilemmas they face in their decision-making.

In addition, the religious and cultural backgrounds of people with dementia and their relatives profoundly influence their preferences and their needs in relation to decision-making, death, and the discussion of unpleasant news in general (Manalo et al., 2013). Hence, the cultural backgrounds of the people involved may need to be considered in decisions regarding end-of-life care.

Framework and search method

An integrative review framework was selected to synthesise the literature related to the experiences of healthcare professionals and family members of people with advanced dementia. Torraco (2016) defined an integrative research review as a synthesis of separate findings into a coherent whole. Cronin and George (2023) described investigators who undertake such reviews as being interested in generalising the substantive issues of a range of studies. Therefore, the integrative review allows the use of evidence from previous studies to investigate equivalent issues. This method generates knowledge that can be applied to the healthcare environment, making it possible to solve problems and carry out further research (de Souza et al., 2010; Oermann & Knafl, 2021).

To guide data reduction, presentation, comparison, conclusion, and verification, the methodological strategies proposed by de Souza, Silva, and Carvalho (2010) were used. These strategies provided direction on the methodological rigour of the integrative literature review. The use of appropriate methods for a literature review reduces the possibility of error, which can include incorrect or incomplete data extraction and interpretation (Salvador-Oliván, 2019). Although several integrative literature review models have been introduced (Cooper, 1982; Torraco, 2005; Whittemore & Knafl, 2005; de Souza et al., 2010), the methodology used by de Souza et al provides a synthesis of knowledge and the application of significant findings to practice. The six suggested stages by de Souza et al. (2010) are listed in Table 2. The approach will infer generalisations regarding the ethical dilemmas faced by family members and healthcare professionals when they make decisions for people with advanced dementia.

Table 2 Process for analysis and synthesis

1. Preparing the guiding question
2. Searching or sampling the literature
3. Data collection
4. Critical analysis of the studies included
5. Discussion of results
6. Presentation of the integrative review

Source: de Souza et al., 2010, p. 104-105

Defining the guiding questions is the most essential phase of the review, as they determine the studies to be included. The guiding question for this integrative review is: 'What are the decision-making challenges experienced by family members and healthcare professionals for people with advanced dementia?'.

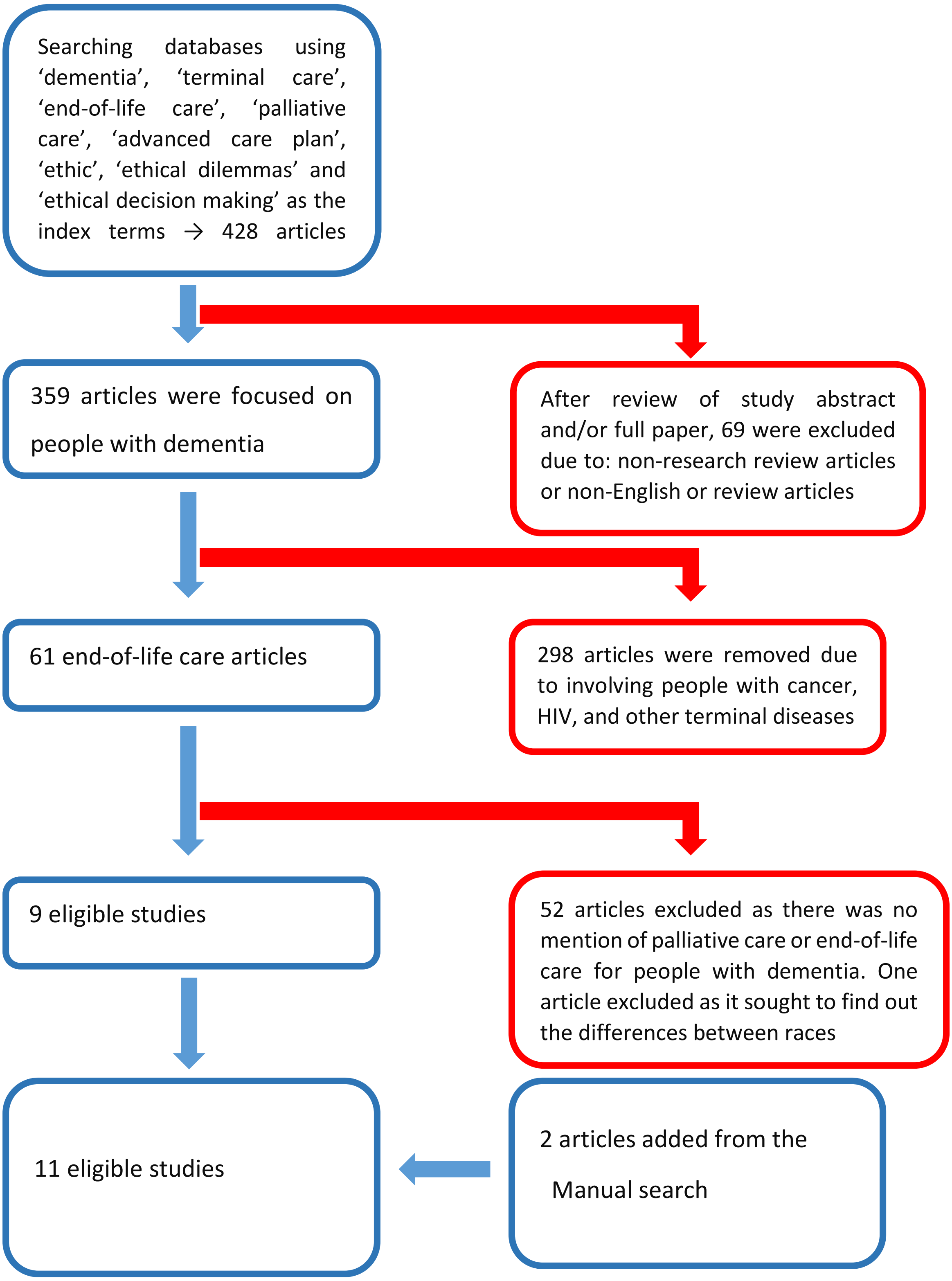
A search strategy guided by the PRISMA statement was conducted in the AMED, CINAHL, Medline, MIDIRS, PsycINFO, Scopus, The British Nursing Index, and The Cochrane Library databases (see Figure 1). 'Dementia', 'terminal care', 'end-of-life care', 'palliative care', 'advanced care plan', 'ethic', 'ethical dilemmas', and 'ethical decision-making' were used as the index terms. The initial search was performed across the time range of 2018 to 2023; however, due to the limited number of results found, the time range was extended from 2013 to 2023. According to de Souza et al. (2010), the most important aspect of this step is to set the inclusion and exclusion criteria. The inclusion criteria used were: studies carried out in the last 10 years; texts written in English; and articles discussing ethical issues in caring for people with advanced dementia across the globe. The exclusion criteria used were: review articles and reports of personal experiences; articles published more than 10 years ago; and articles that did not correspond to the inclusion criteria (refer to Table 3).

Table 3 Inclusion/exclusion criteria for articles search and selection

Inclusion criteria	Exclusion criteria
Published in peer-reviewed journal articles	Non-journal articles
Original studies	Review articles
Primary research articles	Secondary articles
Published in the English language	Published in non-English languages
End-of-life care for people with dementia	End-of-life care for people with other terminal illnesses

The initial phase of the literature search yielded 428 articles. After screening the titles and abstracts, however, 69 studies were excluded as they were not written in English or not research articles. A number of articles were continuously excluded after a review of the full articles as some articles referred to end-of-life care for people with other terminal diseases or studied about dementia but no end-of-life care. From this process, 9 articles were selected for the review. Two additional papers were identified through a manual search of the reference lists of the key articles, for a total of 11 articles included in the review (refer to Figure 1).

Figure 1 PRISMA (Process of selection)

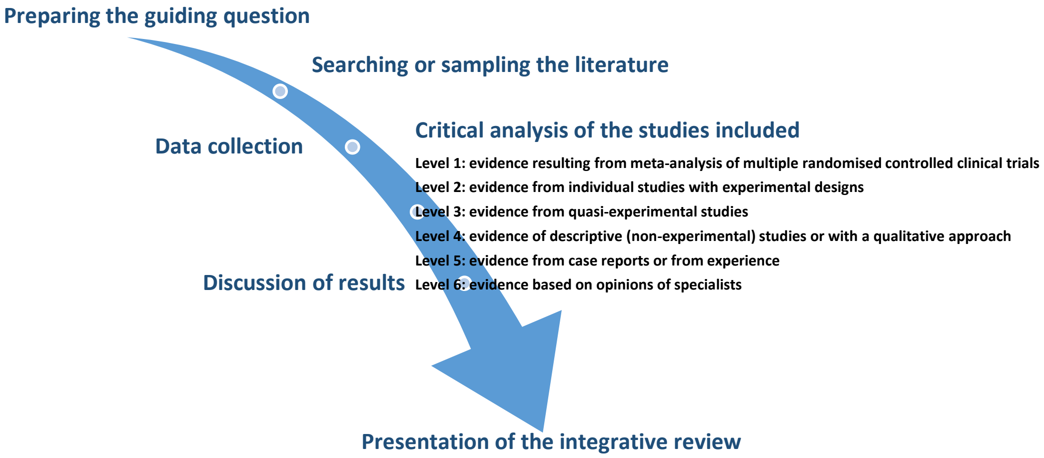


It is necessary to use a previously prepared instrument that helps the researcher to ensure the collection of all relevant data. The final 11 eligible articles were summarised and presented in Appendix 1. The appendix table includes a definition of the subjects, the methodology, sample size, measurement of variables, and method(s) of analysis.

The articles included in the review have been critically evaluated. Salvador-Oliván (2019) argued that the clinical experience of the researchers contributes to the checking of the validity of each study. Thus, this phase of the review requires an organised approach to assessing the rigour and characteristics of each study. The Critical Appraisal Skills Programme (CASP) tools were used to evaluate the quantitative (CASP, 2023a; 2023b) and qualitative studies (CASP, 2023c), with these tools providing 10-12 questions to appraise the selected articles. The results of these assessments are presented in Appendices 2, 3 and 4 respectively.

As de Souza et al. (2010) included a hierarchy of evidence to analyse the articles, the levels of the selected articles within this hierarchy are noted in Appendix 1. Figure 2 below shows the six levels of the hierarchy in detail.

Figure 2 Process for analysis and synthesis



Source: de Souza et al., 2010, p. 105

The selected articles were heterogeneous in terms of their design and methodology. In order to review the intervention methods for the selected studies, a grading system by the National Health and Medical Research Council (NHMRC) was used (NHMRC, 2023). Six studies were quantitative and five were qualitative. According to the hierarchical critical analysis, level 4 evidence methods were used for the five quantitative studies, and one quantitative study was conducted using a level 1 research method. Three studies were cross-sectional survey studies (Bravo et al., 2021), one prospective longitudinal observational study (van der Steen et al., 2018), and one retrospective study (Konttila et al., 2020). According to the NHMRC (2023) definition, level 4 methods are defined as a body of evidence that is weak, and recommendation(s) must be applied with caution. There was one study by Loizeau et al.

(2019) which used a randomised controlled trial, which resulted in strong evidence for the results. Although the research designs and methods used were appropriate for each study, all the researchers failed to justify why they had chosen their research design and methods. However, the quantitative studies had clear research questions which helped the reader to understand which matters the authors were addressing.

The other five studies were undertaken through a qualitative approach, which is Level 4 on the hierarchy. One study used a case study method (Anquinet et al., 2013), while the other four employed in-depth interviews (Smith et al., 2016; Karger, 2018; Midtbust et al., 2018). There was no clear explanation of the methodology underpinning the studies. However, the selection of the sample group and recruiting processes were clearly justified, and the analysis methods were explained.

Selected studies were conducted on healthcare professionals such as doctors and nurses, and people directly related to the care of people with advanced dementia such as family members. The countries where the research studies were conducted were diverse, ranging from the United States, Norway, Belgium, and Italy, through to Germany and the Netherlands.

Among the selected articles, the number of participants in the quantitative studies ranged from 109 (van der Steen et al., 2018) to 6,927 (Chambaere et al., 2014), while the number of participants in the qualitative studies ranged from 11 (Anquinet et al., 2013) to 29 (Anantapong et al., 2022). Although there are no particular rules for how many people should be involved in a qualitative study, some researchers estimate that a number between 10 and 50 participants is sufficient, depending on the type of study and the research question being addressed (Weyant, 2022). Therefore, the appropriate number of participants were recruited for all the selected studies.

The framework outlined by de Souza et al. (2010) has guided this integrative review. The data analysis consisted of reduction, presentation, comparison, conclusion, and verification of the data (de Souza et al., 2010), in order to enhance the rigour and quality of the review. The guidelines for the analysis are shown in Table 4.

Table 4 Data analysis guidelines

Data analysis		
Data reduction	Aiming to facilitate analysis, selected articles are classified into subgroups according to previously set classifications. For example, in integrated reviews, classification can be made according to the type of incidence, chronology, or characteristics of the sample, or according to some predetermined conceptual classification.	The 11 selected articles were categorised into three groups; ① healthcare professionals, ② family members, and ③ healthcare professionals and family members (including 'unclear').
Presentation	Using the prepared tools, data is extracted from key sources to simplify, summarise, and organise the findings to reduce each study to a single page with relevant content. This approach not only makes the data simple to organise, but also facilitates comparisons between studies on specific topics, such as characteristics of the sample and variables.	Creation of a table to include: author(s), methods, design, participants, and important issues within the 11 articles (see Appendix 1).
Comparison	Visualising the data. Converting the findings in visual forms with subgroups. The possible visualisation modes may be charts, graphs, or tables, where all the selected studies can be compared.	Read the articles several times to find common and uncommon patterns. Then, visualised in Figure 3.
Conclusion	Identifying patterns, differences, and redistribution of these themes may be included as part of the general discussion.	Themes emerged through identified patterns.
Verification	During the process, any statement about relations or conclusions demands verification of the primary source to avoid premature conclusions or exclusion of relevant evidence.	Possible explanations for variability between studies and groups were explored.

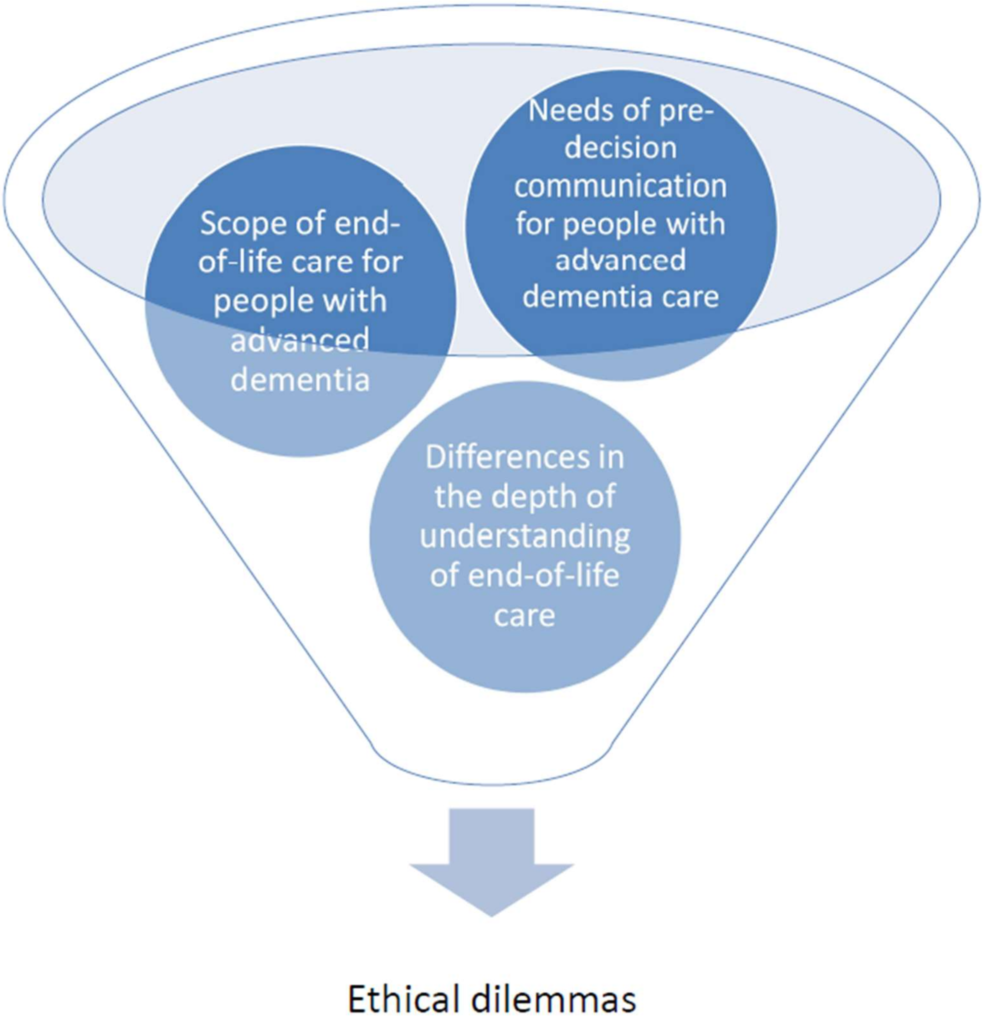
Source: de Souza et al., 2010, p. 105

First, the selected articles were categorised based on the characteristics of the respective samples, either as healthcare professionals or as family members of people with dementia. Then, sub-categories were developed after investigating the types of decision-making found in each study.

Next, all relevant information for facilitating a comparison of the characteristics, variables, and findings of the studies were included in a range of display tables. de Souza et al. (2010) recommended the use of display tables to minimise transcription errors and to serve as a record of the details of the primary studies. The tables included the name of the author(s), the methods used, study design, type of participants, number of participants, and important issues. An overview of the studies and their characteristics are presented in tabular form in Appendix 1. After summarising the detail of the selected articles, the similarities and differences between the findings of the articles were identified. This data also provided ideas for sub-group classifications (Whittemore & Knafl, 2005).

In the next step, the similarities and differences across the studies were compared and read several times to enable a visualisation of the data. A previous study by Whittemore and Knafl (2005) also suggested the use of matrices, graphs, charts, tables, and/or networks to display the data in order to enhance the visualisation of relationships and patterns among the primary sources (Whittemore & Knafl, 2005). Figure 3 presents a visualisation of the data, which was useful for finding common patterns and relationships within the data.

Figure 3 Visualisation of the data



The themes that arose were grouped under four headings: 1) Scope of end-of-life care for people with advanced dementia; 2) Needs of pre-decision communication for people with advanced dementia care; 3) Differences in the depth of understanding of end-of-life care; and 4) Ethical dilemmas. Given the complexity and inter-related nature of the caring involved in dementia care, and despite attempts to delineate the major themes, some degree of overlap was unavoidable.

Scope of end-of-life care for people with advanced dementia

Research has been conducted consistently in recent times on what treatments to provide for people with advanced dementia. Most studies have focused on whether or not antibiotic treatment (van der Steen et al., 2018; Loizeau et al., 2019; Konttila et al., 2020) would be needed, whether or not to provide artificial nutrition and hydration (Anquinet et al., 2013; Chambaere et al., 2014; Valentini et al., 2014; Smith et al., 2016; van der Steen et al., 2018; Loizeau et al., 2019; Konttila et al., 2020), and whether or not hospitalisation would be necessary (van der Steen et al., 2018; Konttila et al., 2020). In relation to some questions, the findings of several studies were similar, but in some cases, the opposite was found. For studies on hospital admission preferences, this was considered an unnecessary procedure in all the studies (van der Steen et al., 2018; Konttila et al., 2020). However, there was a major difference in the research on the use of antibiotics. One study found that providing antibiotics for pneumonia for people with advanced dementia was necessary to resolve their discomfort (van der Steen et al., 2018), but another stated that it was preferred to forgo antibiotic use (Loizeau et al., 2019). This can be judged as 'necessary' or 'unnecessary' treatment depending on whether it places greater weight on the futility of treating comorbidity through antibiotics for the relief of pain and symptoms of infection, and an increase in quality of life that can be expected after antibiotic use.

The selected articles had conflicting findings on providing artificial nutrition and hydration. In some cases, providing artificial nutrition and hydration, even though mandatory methods, was considered to be basic care. On the other hand, this can be considered an unnecessary treatment that does not help end-of-life care. Valentini et al. (2014) argued that artificial nutrition and hydration is a form of medical treatment that can be legitimately withheld if the risks, judged according to the person's values, outweigh the benefits. However, Smith et al. (2016) found that the insertion of a gastrostomy tube as a mandatory method often creates complications such as discomfort, nausea, vomiting, and diarrhoea. Moreover, inserting the tube, and indeed, the feeding procedure itself, is usually accompanied by the use of restraint (Smith et al., 2016). This means, providing artificial nutrition and hydration may be associated with more adverse effects than benefits.

In a study by Anquinet et al. (2013), some people with advanced dementia remained sedated until death to minimise the pain or discomfort they might feel upon their death, and in such cases, artificial nutrition and hydration were still provided. This suggests that there may have been a lack of consideration of 'necessary' and 'unnecessary' treatment for comfortable end-of-life care for people with advanced dementia. Some studies showed that education on end-of-life care has contributed to patients not choosing artificial nutrition and hydration (Valentini et al., 2014; Loizeau et al., 2019), but no studies have established the ultimate standard for determining 'necessary' and 'unnecessary' treatment.

Needs of pre-decision communication for people with advanced dementia care

It is impossible for people with advanced dementia to make decisions on their own on critical matters. Therefore, their family members or healthcare professionals often make such choices instead (Midtbust et al., 2018). The role of doctors is important as they create treatment orders for advanced care plans (Konttila et al., 2020). One study reported that doctors made decisions for people with advanced dementia to forgo artificial nutrition and hydration after discussing the issue with family members (76%), other doctors (41%), and nurses (62%) (Chambaere et al., 2014). Based on these figures, doctors respect the ideas of family members, other doctors, and nurses.

However, in the course of end-of-life care, there is sometimes a lack of communication between family members and healthcare professionals (Bravo et al., 2021; Anantapong et al., 2022). Family members often find different doctors and nurses taking care of their relatives with dementia, rather than the same healthcare professional team consistently, which in turn, makes them repeat the same conversations (Anantapong et al., 2022). Konttila et al. (2020) also insisted that family members constantly need to have the care process of their relative with dementia updated. In particular, they need strong support in decision-making to prevent overly aggressive treatments for end-of-life care for people with advanced dementia. In other words, doctors’ treatment orders may not be effective if there are no underlying treatment goals given to family members. Not informing family members of people with advanced dementia about the goals of life-sustaining treatment can lead to confusion. If healthcare professionals decide to provide artificial nutrition and hydration for people with advanced dementia, it can in some cases give false hope to family members that they might live longer (Smith et al., 2016). This suggests that appropriate communication with family members and healthcare professionals is important.

Most studies have shown that doctors discuss their patients' end-of-life care plans with the family members of the patients (Anquinet et al., 2013; Chambaere et al., 2014; Valentini et al., 2014; Smith et al., 2016; Karger, 2018; Midtbust et al., 2018; Loizeau et al., 2019; Konttila et al., 2020; Bravo et al., 2021), while others have shown that they experience difficulties due to disagreements with them (Midtbust et al., 2018; Bravo et al., 2021). However, family members still felt there was a lack of communication with healthcare professionals (Bravo et al., 2021; Anantapong et al., 2022). Therefore, it is necessary to provide more support to family members by providing continuous and ongoing communication on the patient's progress in dementia and palliation.

Differences in the depth of understanding of end-of-life care

The choice of life-sustaining treatment is related to attitude and knowledge as well as culture and ethic (Valentini et al., 2014). Education on end-of-life care also affects the choice of life-sustaining treatment. Doctors who were trained in end-of-life care were more reluctant to prescribe antibiotics to patients with advanced dementia than those who were not trained (Valentini et al., 2014). End-of-life care training may affect doctors' thoughts and beliefs. van der Steen et al. (2018) also found that when healthcare professionals understood the concept of palliative care, they may not consider using artificial hydration or antibiotics.

The information and knowledge received on end-of-life care make people reconsider the treatment forced on people, even those with advanced dementia. The number of cases of discontinuing life-sustaining treatment considered unnecessary increased in the period 2010-2013 compared to 2004-2009 (Konttila et al., 2020). This is because dementia and its progress have become more widely understood in recent years. In particular, healthcare professionals' understandings play an essential role in providing appropriate end-of-life care for people with advanced dementia. Smith et al. (2016) stated that the perceptions of nurses influenced the family members of people with dementia in relation to the provision of artificial nutrition and hydration. Thus, family members are more likely to make their decisions based on the recommendations of healthcare professionals. In response, it may be useful for healthcare professionals and family members to acquire knowledge about life-sustaining treatment and to learn about underlying values and end-of-life care goals.

Even when communication about end-of-life care is made in advance, the depth of discussion and understanding of each stakeholder may be different. For example, in the event of a life-threatening infection, how to be treated may not have been discussed in detail, or may not have been decided on the possibility of hospitalisation or parenteral medication administration such as intravenous injections that occur during antibiotic treatment. Without clear, well-informed advance directives, it can be difficult to choose the best approach to life-threatening infections. Therefore, in order to prepare specific and clear preliminary instructions, all stakeholders need to have a deep level of understanding of end-of-life care.

In summary, among doctors, there was a difference in understanding between those who were and those who were not trained in end-of-life care, and there was also a difference in understanding of end-of-life care among healthcare professionals and family members. Healthcare professionals dealing with advanced dementia patients may require specialised training in end-of-life care because their perceptions can influence family members' decisions about treatment options.

Ethical dilemmas

Family members and healthcare professionals often experience ethical dilemmas around the decision-making process for end-of-life care. Family members are assumed to know the wishes and preferences that would have been in place had the person with dementia been able to articulate them. It is also assumed that healthcare professionals can rely on family members to articulate and predict these preferences with assumed accuracy. However, it has been shown that these assumptions can be misplaced, as family members are often unable to accurately reflect the preferences of the person with dementia (Midtbust et al., 2018). Family members want to make the best choices for their relatives with dementia, but they often fall into the ethical dilemma of not knowing what their relative would have wanted.

On the other hand, some family members are overly-dominant in making decisions for their relative with dementia which, in turn, is a barrier to achieving the person's desired wishes (Midtbust et al., 2018). Despite the fact that most relatives make suggestions with the best intentions, there are situations where family members can be coercive or overly manipulative. Hence, healthcare professionals frequently find themselves in difficult situations when they disagree with the family's decisions about the patient, despite their actions being in the patient's best interests (Midtbust et al., 2018). Doctors may need to facilitate a resolution when relatives disagree with a patient care planning. However, when decisions by relatives will cause of additional pain or discomfort to their patients, doctors may experience conflict. Furthermore, when doctors end up changing decisions what relatives made, they may experience ethical dilemmas (Valentini et al., 2014).

In one study, some nurses experienced an ethical dilemma in relation to whether to provide artificial nutrition and hydration or not, even with parenteral therapy (Smith et al., 2016). This ethical dilemma was about preventing the pain of starving versus prolonging the pain. As it is difficult to know which decisions carry the most ethical weight, end-of-life care education for stakeholders may be needed to comprehensively evaluate all situations.

Discussion of the review

Based on an interpretation and synthesis of the selected articles, the data from the analysis has been compared to the theoretical frameworks for the present study. In addition, as there were several gaps in the literature, priorities for future research have been suggested. The limitations of the integrative review have also been explained to enhance its validity (Whittemore & Knafl, 2005).

The purpose of this literature review has been to explore the experiences of family members and healthcare professionals in relation to the decision-making challenges and ethical dilemmas they face in the provision of end-of-life care for people with advanced dementia. The analysis of the articles showed that family members and healthcare professionals often experience challenges and differences of opinion in making important decisions, such as forgoing life-sustaining treatment, using sedation, and the use of antibiotics for people with advanced dementia, due to the fact that individuals with advanced dementia are unable to make decisions about their own end-of-life care, and thus, these decisions have to be made by their family members or by healthcare professionals.

In some of the articles, healthcare professionals mentioned their concerns about making decisions for patients with advanced dementia (Smith et al., 2016). A number of previous studies also focused on healthcare professionals' considerations about continuing or discontinuing life-sustaining treatments through artificial methods (Bezerra do Amaral et al., 2012; McLennon et al., 2013; Cheon et al., 2015). One of the main concerns is that it may be impossible to make any difference through invasive action anyway, as death is inevitable (Bezerra do Amaral et al., 2012). As the study by Smith et al. (2016) suggested, these treatments would prolong suffering for people with advanced dementia. Some studies confirmed the idea that some of the treatments or therapies used in end-of-life care are ineffective and only cause suffering (McLennon et al., 2013; Cheon et al., 2015).

Family members and healthcare professionals may face difficulties in providing end-of-life care for people with advanced dementia because of a lack of understanding of the concept. Appropriate training may be helpful to improve their knowledge and skills. A recent study by Hall et al. (2023) found that increased knowledge of person-centred care by healthcare professionals could increase their awareness of the situation of people with advanced dementia. According to the findings of this literature review, healthcare professionals were uncertain about which ethical principles or values they should apply in different situations in order to act ethically in their caring role (Smith et al., 2016). Thus, healthcare professionals might require greater sensitivity towards ethical understandings of integrity and fairness, greater awareness, and an ability to see situations from an ethical point of view in order to make such decisions.

A number of studies revealed that doctors play a key role in making decisions for people with dementia, and that healthcare professionals may require effective communication with other professions and the family members of the patients (Lamahewa et al., 2018; Poole et al., 2018; Donnelly et al., 2019). However, it was found that there is often a lack of communication between doctors, especially when people with advanced dementia require end-of-life care (Cheon et al., 2015). For example, van der Steen et al. (2017) argued that doctors often withhold antibiotic therapy without consultation with the patient or their family members. The nurses in a study by Kieft et al. (2014) expressed their concerns that doctors may not always make the right decisions. Nurses in other studies also experienced conflict and ethical problems with other healthcare professionals in the decision-making process for end-of-life care (Bollig et al., 2015; Haahr, 2020). Healthcare professionals may indeed disagree with other professionals and experience conflict about treatment decisions and how to make them for patients (Kieft et al., 2014). Whitehead et al. (2015), therefore, suggested that healthcare professionals investigate and respect the relevant experiences of other healthcare professionals to minimise conflicts when they are involved in end-of-life care decision-making for their patients.

Based on the selected articles, difficulties in making decisions for people with dementia, the lack of communication and knowledge to make the best decisions to provide appropriate end-of-life care, and the possible solutions to overcome these difficulties have been discussed. It may be essential for healthcare professionals and family members of people with dementia to have adequate skills and knowledge to minimise their chances of making unethical decisions.

Research gaps from the literature review

The findings of the literature review revealed that family members and healthcare professionals who take care of people with dementia play an important role in their end-of-life care. Several studies explored the emotional burden they felt in making decisions for people with dementia, but there have been no qualitative studies exploring the ethical dilemmas they face.

Limitations of the review

Only articles published in the English language were included in the review. Hence, research from a diversity of cultural settings may have been excluded which, in turn, may have failed to discover the ethical dilemmas faced by healthcare professionals and family members of people with dementia across the globe. Although end-of-life care and palliative care are different, some of the articles used these terms interchangeably, which produced potential confusion for the reader. Finally, the integrative review involved several different types of methodologies which may have led to a lack of rigour, as well as possible bias and inaccuracies (Whittemore & Knafl, 2005). However, this review was conducted within the standards of methodological rigour.

To summarise, the literature review explored the experiences of family members and healthcare professionals in making decisions for people with dementia. As part of end-of-life care, life-sustaining treatments can produce both positive and negative outcomes. However, healthcare professionals and family members have a range of perspectives on providing end-of-life care, so they require appropriate understandings of dementia and end-of-life care. However, the selected studies failed to look at these issues through an ethical lens.

Furthermore, the findings revealed that healthcare professionals influence the decision-making of the family members of people with advanced dementia, and in turn, family members affect doctors' treatment orders. These findings support previous research suggesting that healthcare professionals and family members of people with dementia consider the values, preferences, and autonomy of people with dementia. In order to comprehensively weigh all considerations, an exploration of the ethical dilemmas faced by the decision-makers for people with dementia need to be explored.

Chapter 3 Ethics theories contributing to the conceptual framework

Theories of ethics assist people with their decision-making. Each theory emphasises a number of different points, a different decision-making style, and/or different rules for making such decisions (Pollard, 2015). It is important that all possible and potential theories are explored to construct a theoretical underpinning for this research.

The previous chapter presented a critical evaluation of the primary research on making decisions for people with advanced dementia in healthcare settings. As this study aims to explore how healthcare professionals and family members of people with advanced dementia might best make decisions for them, this chapter will provide an overview of a number of major theories of ethics for guiding people's choices and decisions. Several ethics theories will be introduced. Among the theories identified, Noddings' care ethic was selected as most useful for this study as it explains the meaning of human care in the relationship between parents and children and between education providers and recipients in a broader area of social policy.

Ethics theories

Ethics theories can be broadly separated into two categories, consequentialist and non-consequentialist (Davis, 2013). Consequentialism implies that moral reasoning is the consequence of a certain action, whereas non-consequentialist theories emphasise that moral reasoning consists of the principles that underpin the motives of the decision-maker (Crane & Matten, 2004). Actions can be morally right when their underlying principles are morally right. Deontology and utilitarianism are the two main theories of ethics in decision-making for modern medical issues (Mandal et al., 2016). It is useful to keep in mind that deontology is non-consequentialist, while utilitarianism is consequentialist.

In utilitarian approaches, decisions are to be made for the greatest number of people to obtain the greatest amount of benefit. In other words, actions are moral when their consequences maximise the outcome for the greatest number of people involved. In contrast to utilitarianism, deontology suggests that the moral duty of the individual is to act according to universal moral principles. 'Deontological' is derived from the Greek word for duty, and is a concept introduced by Immanuel Kant which is widely referred to as Kantian deontology (Mandal et al., 2016). Decisions derived from a deontological approach may be appropriate for an individual, but may not produce benefits for wider society.

Utilitarianism

There have been many definitions of utilitarianism put forward since the 19th century, and the concept of 'utility' has been considered as the key value that underpins utilitarianism (Bentham, 1948). Roberts and Reich (2002) insisted that utility is the satisfaction of individual preference in terms of a cost-benefit economic analysis. However, utilitarianism is not only concerned with the economic aspects of life, but also with the idea of maximising benefit and minimising harm (Rachels, 2014). Arora et al. (2015) stated that medicine is a costly science, and healthcare professionals may be required to perform expensive interventions for a patient's health. However, in decisions involving multiple patients, healthcare professionals may then have to consider one patient versus the many, where the underlying constraint is one of the finite natures of the resources and funding (Arora et al., 2015). Therefore, ethics and economics can both be viewed as playing a role in guiding how people should behave. However, economics deals with human actions in the marketplace, whereas ethics is the study of the ‘rightness’ or ‘wrongness’ of human action in general (Frederiksen, 2012).

As mentioned earlier, utilitarianism gauges the worth of an action by its outcome. According to utilitarianism, morally right action is the general goal of human striving in relation to health, life, beauty, happiness, love, freedom, and so on (Frankena, 1973). In addition, human goals are not necessarily moral, which means that all human actions are to be assessed for their moral worth through non-moral value. However, previous studies have argued that utilitarianism tends to treat individuals as impersonal aggregate units (Scott & Seglow, 2007; Arora et al., 2015). Utilitarianism can thus alienate people from moral feelings, because a strict utilitarian approach only calculates right and wrong and does not give weight to human emotions. As utilitarianism proposes maximizing utility for the benefit of the majority, it may lack respect for individuals.

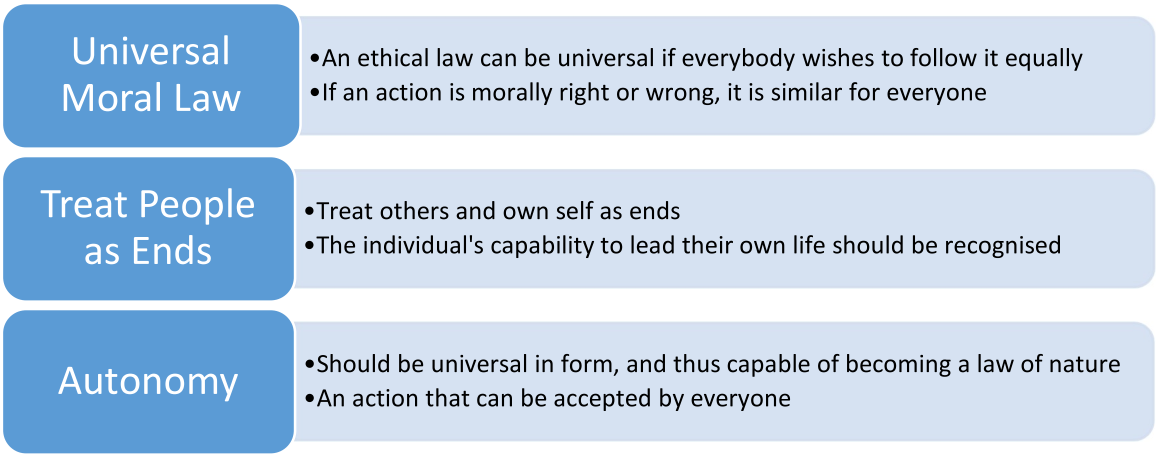
In the healthcare setting, especially in dementia care, a person-centred approach to care has been emphasised. However, utilitarianism does not allow healthcare professionals to look after each patient on an individual level. On top of this, as the theory fails to pay attention to the importance of autonomy, and to articulating a satisfactory conception of justice, it may be difficult to guide healthcare professionals and family members making decisions for people with advanced dementia through this theory and its principles.

In addition, it has been suggested that utilitarianism does not take into account the importance of the emotional element of human experience (Mandal et al., 2016). As a result, the theory may not be able to meet the aims of the present study as it explores how healthcare professionals and family members make decisions for people with advanced dementia for their end-of-life care. Therefore, this framework is not ideal for use as a tool to guide decision-making for families with relatives suffering from dementia.

Kantian deontology

The other ethics theory that has often been suggested for guiding the behaviour of healthcare professionals is known as deontology. Deontology focuses on the actions of people, and these actions can have moral worth only if they are undertaken by people of 'good will' (Timmermann, 2013). This means that people possess good will when the only motive for action is moral duty, as determined by the universal rules of obligation. Kant initially introduced three principles of his 'categorical imperative' (Kant, 1993), insisting that they can be applied to every situation. His categorical imperatives represent formulas that give instructions such as 'do not lie', 'help people in distress', and 'work to develop your own abilities' (Kant, 2005). The rules of the imperative have moral value only if a person is motivated by moral duty. For example, when Kant instructs one to 'help others in distress', this can only be achieved out of good will, and the motive behind this good will has to be to fulfil one's duty (Frierson, 2019). Crane and Matten (2004) also supported the idea that Kant's categorical imperative is applicable to all ethical issues. According to Kant's philosophy, individuals are compelled to follow the categorical imperative as a universal law, if a person is to be truly virtuous.

Figure 4 Categorical Imperatives



Universal Moral Law	•An ethical law can be universal if everybody wishes to follow it equally •If an action is morally right or wrong, it is similar for everyone
Treat People as Ends	•Treat others and own self as ends •The individual's capability to lead their own life should be recognised
Autonomy	•Should be universal in form, and thus capable of becoming a law of nature •An action that can be accepted by everyone

Source: Kant, 2005, p. 88-95

Kant went on to formulate the categorical imperative in a number of different ways, as presented in Figure 4. Although there are other formulations, Kant claimed that there are only three principles (Kant, 1993). In addition, any other formulations would be easily assimilated into the first three formulations. Kant took these as explicitly summarising the earlier principles (Kant, 1993).

The first formulation is known as the universal law of nature's formula, which states, people should always act with the will to become a universal law as much as they can (Kant, 2005). According to this formula, decisions can be made consistently, which asks which underlying principles of behaviour can be consistently followed by everyone.

The second states that one should "act so that you always treat humanity, whether in your own person or in that of another, as an end and never as a means " (Kant, 2005, p. 88). Kantian deontology respects people's dignity as autonomous and rational beings as a prerequisite, so that people are able to make their own free choices (Beauchamp & Bowie, 2004). This is a clear difference from utilitarianism, as deontology allows the free will of the individual.

The third formulation states that people should “act only so that the will through its maxims could regard themselves as the granting of universal law” (Kant, 2005, p. 90). This formulation asks whether the underlying principle of an action is acceptable to all. When people make decisions for others with dementia, they need to consider whether or not they feel morally confident with the decision as if it were to be made by the public.

For Kant, if everyone is a rational creature, and therefore, governed by the same universal moral laws, each individual possesses a unique dignity that should be respected by another rational creature. Kant’s philosophy personalises relationships with patients by emphasising common humanity, despite the difference in power between healthcare professionals and patients. It also provides a general foundation for patients-healthcare professionals relationships by respecting individual autonomy and dignity to fulfill the modern medical ethics era spirit and by claiming a common bond between patients and healthcare professionals.

The categorical imperatives mandate that any action undertaken on behalf of patients ought to be carried out by healthcare professionals, which is applicable not only in terms of ethical dilemmas, but also in terms of a general tendencies towards patients. Indeed, if ethical issues begin where they emphasise common humanity and expresses an obligation to patients, the general view of healthcare professionals on the patients may be less sensitive to the non-personal impact of modern medicine.

In the medical setting, Kant’s categorical imperatives may prove helpful in addressing contemporary medicine’s unique challenges. It easily fits into today's medical ethics culture that emphasises patient-centred care and presents a paradigm that puts one's behaviours at the centre of healthcare. Although being ‘person-centred’ is a required attitude for caring for patients with dementia, this may create a contradiction with the duties of healthcare professionals, or indeed, of people in general. According to Kant’s philosophy, the concepts of dignity and autonomy would be achieved by letting the patient choose what they wanted, while the actions of healthcare professionals need to be in accordance with their duty. Indeed, the actions of a healthcare professional may fail to satisfy the patient’s autonomy. For example, a patient may not wish to treat their disease or their symptoms of sickness, whereas the healthcare professional may have a duty to treat them.

The key aspect of deontology is that morality can be expressed through universal rules that relate to all situations, which means that morality can be applied to any circumstance (Kant, 2005). As relationships between patients and healthcare professionals, and patients and their family members are caring by nature, conflict may not occur to allow the application of Kant’s morality in such a situation. However, there appears to be no place for autonomy in this schema, and this is one of the main criticisms of Kantian ethics. Therefore, Kant’s deontology may not be the best theory to guide this present study due to the contradiction between the autonomy of the patient and the duty of the healthcare professional.

The concepts of utilitarianism and deontology contradict each other, and each of them has its own substantiated advantages and disadvantages for medical practice. Several studies have therefore suggested that healthcare systems need to balance both of these ethical frameworks to bring congruity to medical practice (Mandal et al., 2016; Roshanzadeh et al., 2020; Kaldjian, 2023). However, it is not always clear how to judge which consequences are best. Also, as one represents a consequential theory and the other a non-consequential theory, it may be difficult to use them together.

In addition, these two traditional philosophies of ethics, utilitarianism and deontology, have failed to explain how humans generally think or behave, and have also failed to take into account historical, cultural, and other relevant contexts (Kohlberg, 1981). There are modern ethics theorists (Kohlberg, 1981; Noddings, 1984) who, in response, believe that care and respect are essential elements in ethical human relationships. The present study also focuses on the principles of care and respect, and how healthcare professionals and family members of people with advanced dementia might best practice making decisions for their loved ones.

Kohlberg’s ethics theory

Kohlberg (1981), a modern ethics theorist, introduced six stages of moral reasoning which can be applied universally (Table 5). Similar to Kant, he also conducted cross-cultural research to demonstrate that diverse people followed the same sequence of moral thought as they matured.

Table 5 The six stages of moral judgement

The Six Stages of Moral Judgement	
Stage 1: The Stage of Punishment and Obedience	Obeying rules and authority, avoiding punishment, and doing no physical harm
Stage 2: The Stage of Individual Instrumental Purpose and Exchange	Serving the needs of oneself or others, and to make fair trades in terms of concrete exchange
Stage 3: The Stage of Mutual Interpersonal Expectations, Relationships, and Conformity	Motivation to play a good (nice) role, worry about others and their feelings, maintain loyalty, and trust with partners, and follow their rules and expectations
Stage 4: The Stage of Social System and Conscience Maintenance	Fulfilling one's duties in society, maintain social orders, and maintain the welfare of society or groups
Stage 5: The Stage of Prior Rights and Social Contract or Utility	Maintaining the basic rights, values, and legal contracts of a society even when they conflict with the concrete rules and laws of the groups
Stage 6: The Stage of Universal Ethical Principles	Following guidance based on universal ethical principles

Source: Kohlberg, 1981, p. 409-412

Kohlberg (1981) found evidence of Stages 1, 2, and 3 reasoning in all cultures throughout his study. However, he believed that there was a lack of people who were capable of demonstrating Stages 4, 5, and 6 reasoning in many non-Western countries. Hence, Kohlberg concluded that these societies simply lacked collective moral maturity to produce thinking found in higher moral stages (Kohlberg, 1981).

Several scholars have disagreed with Kohlberg’s stage theory of moral development (Noddings, 1984; Hwang, 1998). The first disagreement concerns cultural bias. A study by Baek (2002) revealed that children in Korean and British cultures developed moral stages at a similar rate. However, some responses from the Korean children in the study were not able to be matched with Kohlberg’s guidelines, as the children had been influenced by traditional Korean thinking, of which Kohlberg was unaware.

In Baek’s (2002) study, some responses from the Korean children contained the concept of ‘Jeong’ (pronounced ‘Chung’), which relates to an emotional concern. ‘Jeong’ is one of the most essential concepts in understanding the psychological aspects of Korean culture (Chung & Cho, 2006). Korean scholar, Baek (2002), stated that if two people feel a bond based on ‘Jeong’, the boundary between the two people will be lessened, and a sense of unity such as homogeneity, acceptance, comfort, affection and will appear. Chung (2008) also pointed out Koreans’ beliefs that individuals cannot consciously develop ‘Jeong’ towards others, but that it only occurs spontaneously and involuntarily in the heart.

Chinese culture also uses a similar concept, called Ch’ing for their moral reasoning (Ma, 1992). In this sense, Ch’ing in Chinese and Jeong in Korean are written with the same meaning with only the pronunciation being different. This indicates that Asian cultures with historical contact might have similar variants of the ‘Jeong’ concept. Therefore, ‘Jeong’ plays a significant role in moral judgment, and sometimes seems to overwhelm rational thought among Asian people from these cultural contexts (Chung & Oh, 2022), even though the concept is not included in Kohlberg’s ethical ideals.

Another Chinese scholar, Hwang (1998), also argued that the values of collective utility and filial piety were misrepresented in Kohlberg’s guidelines. Although traditional values are meant to be in Stage 5, according to Hwang (1998), they are written under Stage 3. She also insisted that this misclassification might have been made due to ignorance about the pre-eminent value of collective utility and filial piety in Chinese culture (Hwang, 1998).

Similarly, Indian culture employs a moral discourse to analyse ethical problems that are difficult to assess according to Kohlberg's stages. In turn, this has a tendency to misclassify responses into lower stages (Jensen, 2011). According to Kohlberg, the stages are immutable, and all cultures show similar development through the stages, even if the higher stages do not exist in some cultures (Kohlberg, 1981; Sunar, 2002). However, Noddings (1984) contested the validity of the stages themselves, arguing that the stages are gender and culturally biased and do not reflect a unique, universal developmental sequence.

In summary, Kohlberg's stages may not reflect particular societies. For instance, Stage 5 reasoning may be inappropriate in a Stage 2 society. This argument has been espoused by Boom et al. (2001) who agreed with Kohlberg that each classification requires different modes of moral reasoning, but disagreed with the hierarchical valuation of the stages. They also argued that reasoning may be appropriate or inappropriate to particular situations, depending on the cultural context (Boom et al., 2001). Therefore, it is important to consider moral judgements before applying them to a particular society. Due to the fact that there was no consideration of certain aspects of Asian cultures, such as filial piety, by Kohlberg, his theory and model may be inappropriate to use in the present study.

Gilligan's care ethic

Gilligan, a student of Kohlberg, developed her own care ethic (1982) with six stages of moral judgement, arguing that Kohlberg's framework rested on the assumption that justice is the foundation of the highest stages of moral reasoning (Gilligan, 1982, p. 27). After her research in comparing groups of women and men, Gilligan concluded that women were more likely to be in Stage 3, while men were more likely to reach Stage 4 (p. 18). According to Gilligan, people in Stage 3 moral judgement level consider one's desire to please others, while people in Stage 4 value law and order, not intimacy (p. 19). Gilligan contended that there are two distinct gendered ethical ways of thinking: the justice orientation and the care orientation, and that Kohlberg's moral theory was biased towards the justice orientation because it was derived from a male-only sample.

Gilligan's six stages of moral judgement may be faulty with men being found to be more morally mature than woman. A number of studies have supported the idea that education can control gender differences (Tirri, 2003; Banerjee et al., 2011). Some research has even found that females may have more sympathy than males (Tirri & Nokelainen, 2007; Zadanbeh & Zakerian, 2011; Ding et al., 2019). Therefore, the present study cannot be underpinned by Gilligan's care ethic theory.

Noddings' Care Ethic

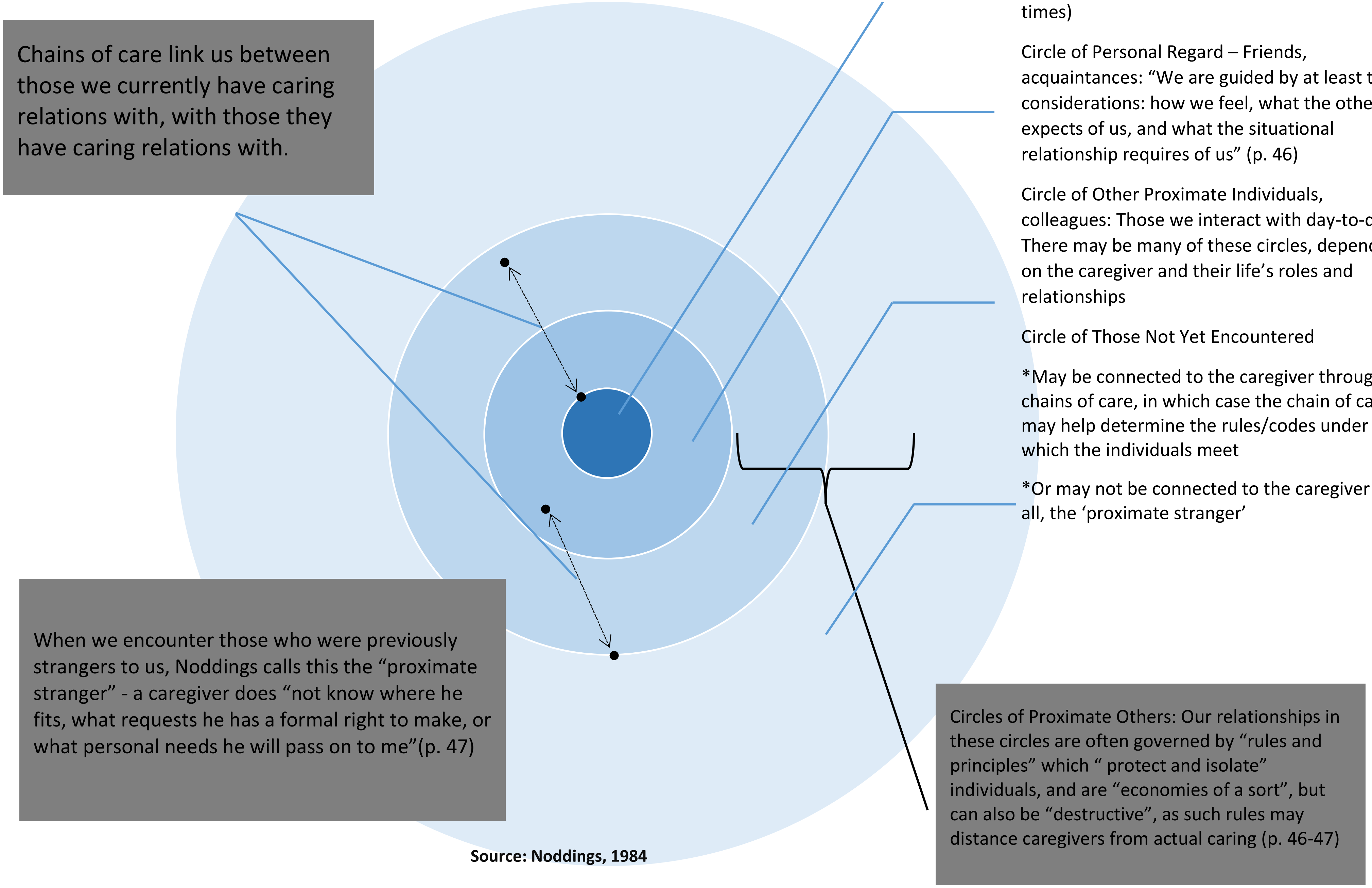
Noddings is another ethicist who introduced a care ethic. The framework of care ethics is based on the idea that moral goodness can be found in caring relations between people, and that the goal of care ethicists is to create, maintain, and enhance such relations while cultivating a caring personality. In this context, care represents a complex and dynamic process, based on the caregiver's recognition of the care recipient's needs, the caregiver's desire to have these needs met, attention to these needs, and the care recipient's response toward the caregiver.

Previous theorists have mainly focused on ‘caregivers’ and the ‘actions of caregivers’; however, Noddings emphasised the importance of human ‘relationships’ over ‘encounters’. According to Noddings, people ‘care’ more when they have a close relationship. A relationship is the connection of two individuals, which is comprised of “a set of encounter(s)” (Noddings, 2002, p. 198). In care ethic, the meaning of 'encounter' is a specific type of interaction between individuals. Noddings (2002) said that encounter is the 'fount of experience', and through each encounter, connections between each individual are established.

A caring relationship involves a caregiver who is the person giving the care, and the person receiving care who is the cared-for. Noddings used a term ‘Care for’ for the consciousness of the caregiver as being characterised by attention and motivational displacement, and which is separate from the care activity. However, the terms ‘caring-for’ and the ‘care activity’ are encompassed in the terms ‘caring encounter’ and ‘caring relation’. Therefore, it can be characterised either as an encounter or as a relation of caring.

Noddings (1984) described the individual as existing “at the centre of concentric circles of caring” (p. 46). Figure 5 below illustrates these circles of caring. The inner circles, generally, contain proximate others who the caregiver encounters directly on a daily basis. The innermost circle is made up of intimate relations with people who “care because we love” (p. 46). Outside of the innermost circles are others who are personally related to friends. Further outwards are the circles that include people encounter on a regular basis as part of a job or other commitments. These circles are a way of visualising encounters with other individuals in human lives, from frequent and regular interactions to infrequent and irregular interactions. These care circles are superimposed by caring chains that connect current care relationships with potential, future ones. Moreover, each person's web of care consists of these circles and chains. The circles of proximate others are often managed in part by codes, rules and/or cultural norms that guide all interactions. Because of their specific roles or relationships, everyone has special responsibilities towards others.

Figure 5 Diagram of Caring Circles and Chains



Chains of care link us between those we currently have caring relations with, with those they have caring relations with.

Intimate Circle – Where “we care because we love” (Noddings, 1984, p. 46), (although even here, we may summon ethical caring in difficult times)

Circle of Personal Regard – Friends, acquaintances: “We are guided by at least three considerations: how we feel, what the other expects of us, and what the situational relationship requires of us” (p. 46)

Circle of Other Proximate Individuals, colleagues: Those we interact with day-to-day. There may be many of these circles, depending on the caregiver and their life’s roles and relationships

Circle of Those Not Yet Encountered

*May be connected to the caregiver through chains of care, in which case the chain of care may help determine the rules/codes under which the individuals meet

*Or may not be connected to the caregiver at all, the ‘proximate stranger’

When we encounter those who were previously strangers to us, Noddings calls this the “proximate stranger” - a caregiver does “not know where he fits, what requests he has a formal right to make, or what personal needs he will pass on to me”(p. 47)

Circles of Proximate Others: Our relationships in these circles are often governed by “rules and principles” which “ protect and isolate” individuals, and are “economies of a sort”, but can also be “destructive”, as such rules may distance caregivers from actual caring (p. 46-47)

Source: Noddings, 1984

For example, by virtue of children being the son or daughter of their parents, when the parents are diagnosed with dementia, the son or daughter might look after their parents in their time of need. On the other hand, by virtue of someone being the parents' bus driver on their regular route, the person with dementia is less likely to tell them the story about being diagnosed with the disease, and there is no responsibility on behalf of the driver to comfort the person with dementia. Relational epistemic privilege is one way to account for this responsibility. Sometimes these roles are governed formally, such as those of a doctor or lawyer, while at other times, they are managed less formally, like community matriarch whose roles have developed over time.

The care chains run from individuals to those in the proximate others' circles, to those they care for. Due to the care chains, individuals who meet these others are connected to being "prepared to care" in "recognition of these chains" (Noddings, 1984, p. 47). For instance, a daughter-in-law prepares to care for her parents-in-law because they care for her husband, and she know he cares for them. Basically, each caregiver is chained to the care circles those in his or her proximate circles. In this way, the net of care is connected to proximate circles to other proximate circles. Outside of the inner circles of proximate others, there are "those I have not yet encountered" (p. 47). They can be connected by formal relationships, such as future patients at local general practices where doctors have never met. The caregivers fulfill all of them with the potential of care because they are connected to the caregivers by "those already anchored in the inner circles" (p. 47). Moreover, Noddings explains the proximate strangers who the caregivers encounter without any connections to the existing established care circles. This helps show to the cared-for that satisfaction of needs is neither malicious nor indicates of a lack of caring.

Noddings' care ethic is aiming to cultivate caring characters in order to establish, maintain, and enhance caring relations in the webs of care. The ethical activities of caregivers are to respond to needs with care according to the basic caring attitude. Noddings has argued that ethical caring is not superior to natural caring, due to the fact that ethical caring can take place as a result of someone's duty, while natural caring can be shown by someone's inherent attitude. Therefore, it is completely opposite to Kant's deontology which focuses on 'duty'. Noddings insisted on the importance of cultivating a caring character and developing care relations (1984), describing "three great means of nurturing the ethical ideal" (1984, p. 182), dialogue, practice, and confirmation. In her later books, Noddings added modelling as a fourth component (1992, p. 22; 1995, p. 190; 2002, p. 287). Noddings' model is described below.

1) Modelling

Noddings (1995) believed that adults have to show in their own behaviour what it means to demonstrate caring in their relationships with their children, and indeed, to care for them. Hence, adults do not tend to tell their children to care and give them texts to read about the subject. 'Showing' is the best method of teaching, which means when one has looked at what 'care', and the outcomes of 'care' are, then one can provide care. Children also learn filial piety from their parents (Chen & Wong, 2014). When the parents take care of their grandparents, the children may build a sense of filial piety by looking at what their parents do and think, and this may be a good example of modelling.

If a person has cared for his or her parents before they were diagnosed with dementia, and the children of the person had seen the person's caring activities, the children would know how to take care of the person. Healthcare professionals who have had academic role models, teachers, and their parents show them how to care for others, are more likely to have a caring character.

2) Dialogue

Dialogue is a form of communication that assists people to understand other's thoughts without pitting themselves against different perspectives. In dialogue, there is usually no counterpoint or no defending of opinions; instead, it is about letting the other person talk and allowing them to present their viewpoint. Therefore, Noddings emphasised that dialogue is a powerful method for promoting the building of the ethical ideas of the younger generation. Indeed, this approach may allow people to build positive relationships, and help adults to demonstrate good role modelling.

The children of a person with dementia would have a positive relationship with their parents if they had been taught to communicate well. Indeed, if the children were allowed to discuss 'ethics' with their parents, they would have developed their own sense of caring. This sense of a care ethic may help the adult children to become good decision-makers when providing end-of-life care for their parents or their patients with dementia.

3) Practice

Noddings (1984) stated that children should be involved in 'caring apprenticeships' with the classroom aides, gardeners, or kitchen staff. Such service opportunities may also extend into the community, in animal shelters, churches, hospitals, and parks (Noddings, 1984, p. 187). This means that children would be required to participate in caring with adult role models who would demonstrate how to care, and would communicate with them about the challenges and rewards of such work. Therefore, Noddings suggested that people learn how to 'care' though practice.

If children have been given the responsibility of taking care of someone or something when they are young, they most likely would already be good at taking care of their parents or their patients with end-of-life care. For instance, the children might have made a wrong decision about something in the past, and this experience may have made them regret their actions and decide to never do it again. The experience of demonstrating good care activities also motivates people to undertake the same actions again.

4) Confirmation

Finally, when adults discover that children have embedded ethical ideas, they need to confirm this (Noddings, 1984). Confirmation serves as a source of encouragement for children's development, as this means that adults identify the children as being a caring person. Noddings insisted that adults steer children to be better people though confirmation, whereby the children can be motivated to act in better ways (Noddings, 1984). However, adults often try to avoid giving children the burden of making ethical choices (Noddings, 1984). Children from different cultures may require extra encouragement to engage in dialogue and take part in co-exploration (Noddings, 1995). Confirming these differences will assist children to cultivate a caring character.

When people receive enough encouragement to engage in dialogue and the practice of caring from a young age, they may have a better understanding of ethics. Noddings claimed that when a person is confirmed by someone, they react with positive thoughts, such as ‘Here is someone who sees something better in me’ (Noddings, 1984). This means that family members and/or healthcare professionals may be motivated to demonstrate ‘care’ in a better way when they have experienced ‘confirmation’.

Based on Noddings’ care ethic, intimate relationships between family members play a key role in ‘caring’. Noddings also insisted that the younger generation is required to be taught how to ‘care’ for others. In order to enhance care, the older generations need to provide good role models, and communicate with the younger generation about open topics such as religion, sex, love, anxiety, hope, and hatred, so that all people can develop positive relationships. Also, the younger generation needs to have opportunities to practice how to care for others. Last, but most importantly, it is necessary for the older generations to encourage the aforementioned activities of the younger generation. Noddings believed that these four suggestions can help people to cultivate an appropriate caring character.

People with dementia are usually looked after by their spouse or their adult children (Park, 2013), and they usually become the proximate decision-maker when the person with dementia is no longer able to make their own decisions. Healthcare professionals also play a significant role in making decisions for their patients, especially those who have been diagnosed with dementia (Wolfs, 2012). According to Noddings' theory, if these decision-makers had been taught Noddings' caring development model, they would have the ability to develop and maintain a caring-for attitude towards the person with dementia at all times, and would be able to enhance their caring spectrum.

Furthermore, well-educated people who make decisions for people with dementia might demonstrate a better ethical manner. In her theory, Noddings stated that caring-about may become caring-for through 'receiving' the problem, and bringing the person into proximity, so that it turns the other into "my proximate other and must be met as cared-for by me, one-caring" (Noddings, 1984, p. 113). In this sense, healthcare professionals and family members might be required to physically be with people with dementia. Noddings suggested that physical proximity or distance is an important factor allowing a person to be 'cared-about' and 'cared-for'.

Noddings emphasised the importance of physical proximity, but this also represents a limitation of the care ethic, as being physically face-to-face can be a challenge in modern society. However, especially with current communication technology and social media, people have been able to interact with others in various ways. Despite the above limitation, Noddings' theory has provided a framework that recent studies have used (Balmer et al., 2016; Subedi & Subreenduth, 2018). Balmer et al. (2016) applied Noddings' care ethic theory to the healthcare setting to show how students learn to be caring doctors. The authors agreed that Noddings' philosophy can provide a beneficial conceptual framework to apply to medical education design (2016).

In addition, Noddings' care ethic theory replaces the traditional Western ethical framework from the perspective of autonomous moral agents who maximise utility or fulfill an obligation for themselves with social beings located in everyday face-to-face relationships with others. She argued that relationships, rather than individuals, are ontologically fundamental (Noddings, 2013). In care ethic, human encounters and emotional responses form the basis of ethics, and moral relationships are framed in terms of connection rather than traditional notions of freedom. Therefore, Noddings' philosophy is more suitable for the South Korean culture than any other theory of ethics. The interview schedule included questions about the participants' relationship with the person with dementia. Dilemmas found in moral relationships in South Korean culture will also be discussed in Chapter 6.

To summarise, as this study aims to explore how healthcare professionals and family members of people with advanced dementia might best practice making decisions for people with dementia, this chapter has provided a critical overview of the major ethical theories guiding people's behaviours. The chapter commenced with a discussion of the two major traditional theories of ethics deemed central to the healthcare setting. However, there were a number of disadvantages in applying these to modern society. It has been shown that deontological and utilitarian inclinations are mutually exclusive, and not suitable for decision-making based on human relationships. Noddings' care ethic better fits human relationships with its concept of caring which prioritises interest in relationships.

The theory of ethics selected in this chapter will provide the theoretical underpinning of the present study. With this theoretical underpinning, the study will be able to show an understanding of the research aim. A discussion of the methodological approach to the study will be presented in Chapter 4.

Chapter 4 Methodology

The previous chapter reviewed theories on the ethical issues of caring and their application to family members and healthcare professionals when they make decisions for people with advanced dementia. The philosophical standpoint will be discussed in this chapter. This present study will be conducted using an interpretive phenomenology with van Manen's approach. The chapter starts with an overview of the researcher's philosophical position and its impact on the methodology and methods to address the purpose of the study.

Philosophical Stance

When addressing the purposes of research, it is important to identify the theoretical stance of the research and the underlying framework used to explore the phenomena and how these are known (Collins & Stockton, 2018). Mason (2002) explained that the theoretical stance provides a context for the study and informs the methodology.

Knowledge can be discovered through experience as it is lived (Polkinghorne, 1983). Therefore, it is essential to explore the lived experience of the participants to develop knowledge and understanding. According to Fuster-Guillen (2019), experience is valuable for expanding knowledge, and is the basis of behaviour as well as the source of all knowing. Considering that knowledge can be developed through experience, a phenomenological approach is deemed the most suitable for the present study.

Phenomenology is rooted in the existential worldview, where individual experiences and perceptions are the fundamental basis for understanding reality (Felder & Robbins, 2021). In order to understand phenomenon, the methodology relies on the experiences and perceptions of people who have experienced that particular phenomenon. Neubauer et al (2019) stated that phenomenologists are committed to understanding social phenomena from individuals’ own perspectives, so they examine how the world is experienced by the individuals. According to Neubauer et al (2019), the important reality is what individuals perceive it to be. van Manen (1990) also believed that the common foundation of phenomenology is in the meanings inherent in experience. As he stated, “Lived experience is the breathing of meaning” (van Manen, 1990, p. 36). Given that the basis of phenomenology is based on exploring individual experiences, obtaining a rich description of the experiences of healthcare professionals and family members means that the study explores their experiences of the given phenomena.

van Manen (1990) explained that reality exist in various versions, with different possibilities for interpretation. It is fundamental to consider the influences of researchers’ beliefs about the world when they create or search for new knowledge. Willig and Rogers (2008) affirmed that it is impossible to avoid making assumptions about the world, while Creswell (2007), Barroga and Matanguihan (2022) maintained how these assumptions need to be clearly recognised as this is the starting point of the study design.

The initial interest in this study was the researcher’s experiences of family and healthcare professionals as they made decisions for people with advanced dementia. Common assumptions regarding the issues have been identified through the literature review chapter. Family members, doctors, and nurses have struggled to make decisions under different circumstances. According to Noddings' care ethic (1984), relationships play a key role when making decisions for others. All assumptions indicate how underlying structures affect individuals' attitudes and behaviours toward decision-making, through which it demonstrates the position of researcher as a realist.

To summarise the philosophical stance of this present study, experiences create understanding and develop new knowledge about phenomenon, as individuals hold different interpretations of the phenomenon. The researcher in the present study interprets the participants' understandings of their experiences as a doctor, a nurse, or a family member based on her assumptions regarding the world in which she lives.

A phenomenological approach

Because knowledge can be developed through lived experience, a phenomenological approach was chosen for the present study. This approach allows an exploration of the experiences as lived by the participants and an understanding of the structures which formed those experiences (Polkinghorne, 1983). Phenomenology is based on a humanistic paradigm and is known as the study of the lived experience or the life world (van Manen, 1997). It also explains both what appears and the way it appears (Kvale, 1996), and the subjects' perspectives of their world.

Langdridge (2007) stated that phenomenology provides in-depth understanding of individuals' experiences which, in turn, enables researchers to understand the experience to develop new knowledge. Having considered that the essence of phenomenology is based on exploring people’s experiences, the researcher seeks an understanding of family members’ and healthcare professionals’ experiences of the phenomenon through in-depth descriptions of their experiences. The following sections describe various approaches to phenomenology and the approach that was used for this study.

Descriptive phenomenology

Husserl is regarded as the principal founder of phenomenology (Scruton, 1995; Rapport, 2005). Rapport (2005) explained that the human and their world are connected, which Husserl described this as ‘conscious knowing’ (Rapport, 2005). Knowledge is, thus, consequences of human existence and experiences within the world (Langdridge, 2007). Hence, Husserl aimed to reform philosophy and establish a strict scientific philosophy to provide a firm basis for research studies (Misiak & Sexton, 1973).

To meet this aim, Husserl refined and developed the phenomenological method. A fundamental concept in phenomenology for Husserl is ‘intentionality’ linked to human consciousness. This is also explained as “the relationship between processes that occur in consciousness and objects of attention to the process” (Spinelli, 2005, p. 13). Husserl argued that the consciousness of people decides/influences people to react certain ways. When people are conscious, they are conscious of some ‘thing’, and their consciousness is dictated by ‘things’. As consciousness has been emphasised by phenomenologists, they are interested in people’s interactions with the world and how ‘things’ appear to them. In fact, the term phenomenon derives from the Greek words ‘phainein’ meaning ‘flare up’, and ‘phainesthai’ meaning ‘to appear’ (Moustakas, 1994).

Husserl tried to find a method through someone’s experiences of phenomenon to find out the ‘essential’ characteristics of the experiences. Husserl used the term ‘noema’ to refer to ‘object’, and the term ‘noesis’ to refer to ‘intentional act’. Hence, the relationship between noema and noesis is intentionality. In other words, experience is an intentional act by a subject. As the beginning point for most phenomenologists, the noema enables subjects to describe their experiences of phenomenon or “return to things themselves” (Husserl, 2001, p. 168). The noesis entails understanding how phenomena are experienced and requires subjects to reflect on their experiences and meanings (Spinelli, 2005). According to Husserl, researchers are required to use their ‘natural attitude’ to explore the experiences without stepping into their daily experience. This attitude was named as ‘phenomenological attitude’ by Smith et al. (2009). Husserl believed researchers could turn their gaze away from objects to focus on their internal understanding of the objects, and Smith et al. (2009) referred this to as the “gaze on our psychic life” (Smith et al., 2009, p. 12).

Epoché and the phenomenological reduction

Husserl insisted that researchers are required to have ability to withhold subjective perspectives to enable the phenomenon to appear. The withholding of perspectives is known as epoché or ‘bracketing’ (Racher & Robinson, 2003). In order to ‘return to the things themselves’, Husserl suggested that researchers to bracket their consciousness about what they know about the subject of investigation (Husserl, 2001; Spinelli, 2005). This includes the researchers’ development of a neutral approach to suspend their attitudes, assumptions, beliefs, and prejudices about the problems under investigation (Langdridge, 2007). Through epoché process, individuals restore the originality of their experiences and return “back to the things themselves” (Langdridge, 2007, p. 17).

However, epoché became a controversial issue among phenomenologists because of the researchers’ engagement with their social world (Spinelli, 2005; Langdridge, 2007). Criticism of epoché or criticism of ‘bracketing’ of previous experiences and attitudes laid the groundwork for further developments in phenomenology. The next stage in the process of phenomenology after epoché was ‘reduction’ consisting of three components: description, horizontalisation, and verification (Langdridge, 2007). After bracketed off their assumptions about the investigating phenomenon, researchers are required to describe the experience rather than make a hypothesis (Spinelli, 2005). In the process of description, researchers are also urged to continue to focus on their initial impressions so that the experience can be described in terms of their consciousness rather than being interpreted.

Horizontalisation, the next step, requires the researchers to consider each experience described by the participants as equally important. By considering the content of accounts of experience as equal, the researchers avoid placing any hierarchies of significance or importance to the aspects described which, in turn, reduces the level of pre-judgement (Spinelli, 2005; Langdridge, 2007).

The final stage of the reduction process is ‘verification’, which guides the researchers to revisit their understanding of the meaning of someone’s experience. In other words, researchers need to stay close to the data and repeatedly check whether they understand the meaning of the analysis unit in context (Langdridge, 2007).

This is important to remember that phenomenological reduction requires continuous effort throughout the analysis process, which is for every operation, not just once. This step does not mean achieving perfection to bracket researchers' own preconceptions. Researchers need to focus on the experience of those involved in any research project, as they live in the world of their lives.

Following the processes of epoché and reduction, the meaning of the experience can be found through 'imaginative variation' or 'imaginative free variation' (Wertz, 2016). In order to process this, researchers need to imagine alternatives to the participants' experiences. It is expected that changes to the participants' experiences through 'imaginative variation' are undertaken to discover the significance of the experiences, and to ascertain various perspectives of the experiences (Langdridge, 2007). In other words, the principles of epoché, reduction, and imaginative variation help researchers to move "return to the things themselves" (Husserl, 2001, p. 168).

Existential phenomenology

Further developments in phenomenology led to existentialism, with the main figure involved in this development being Heidegger. Heidegger was one of Husserl's students, and hence, studied phenomenological philosophy under Husserl' guidance. However, a number of Heidegger's studies were considered as a direct response to Husserl, and developed a new approach to phenomenology which challenged Husserl's beliefs regarding subject-object relationships (Spiegelberg, 1960; Rapport, 2005).

Heidegger believed that Husserl's approach to phenomenology might be too abstract to create new knowledge. He also argued that as human beings, people including researchers cannot live in isolation, so it is impossible for phenomenologists to develop knowledge without interpretation or being part of a 'lived world' (Spinelli, 2005; Neubauer et al., 2019). Heidegger trusted that the social context was fundamentally important and expressed the belief that individuals' realities are consistently influenced by the world in which they live (Neubauer et al., 2019). Whereas Husserl focused on problems of essence or "that which makes things what they are", existential phenomenologists concentrated the existence of human beings who thought they were ahead of essence (Misiak & Sexton, 1973, p. 72).

According to Heidegger, experience remained central to his belief, but this was interpreted differently from Husserl, with Heidegger insisting that it is impossible to separate researchers' understandings of the world and the phenomena which exist (Langdridge, 2007). In other words, Heidegger regarded all human beings as interpretive, leading to the idea that researchers are able to discover significance and meaning in participants' life stories (Johnson, 2000; Horrigan-Kelly et al., 2016). In this sense, it is clear that the process of epoché may not be achievable, and also showed the differences between Husserl's and Heidegger's phenomenology.

Dasein

Heidegger developed the concept of 'dasein', which offers a unique perspective on human being and what it means to exist in the world. He concentrated on the exploration of the lived experience or 'dasein', rather than on individuals or any particular phenomenon (Horrigan-

Kelly et al., 2016; Frechette et al., 2020). Instead of seeking descriptions for the world that participants perceive, hermeneutic phenomenologists focused on describing the meaning of ‘dasein’ and how it affects the decisions they make. (Frechette et al., 2020). For the process of ‘dasein’, Heidegger believed that it was important to consider the historical and cultural contexts of existence by interpreting through language rather than through simple description (Langdridge, 2007).

Temporality

Another important notion for Heidegger was ‘temporality’ which is the experience of time (Horrigan-Kelly et al., 2016). Johnson (2000) explained how the concept of time can be expressed in a linear way, as experiences within time relate to the past, present, and future. Heidegger argued that previous experiences and perceptions of the future influence current phenomenon (Langdridge, 2007). The time measurements on clock differ from an individual’s time experience; therefore, the time perception of families and healthcare professionals may vary depending on the nature of the time experience and the way it is perceived.

Facticity

For Heidegger, a more important element was ‘factuality’. This has to do with the fact that individuals are limited in some of their choices due to a range of potential restrictions, including physical, social and psychological factors and the individuals’ backgrounds (Rousse, 2016). However, Heidegger believed that such factors did not determine individuals’ ‘dasein’ or their ‘being in the world’ (Horrigan-Kelly et al., 2016).

Other existentialists, such as Sartre, Marcel, and Merleau-Ponty, studied Heidegger's theory in an attempt to understand existence (Joseph & Reynolds, 2011). In particular, Merleau-Ponty (1962) made further developments on the theories of Husserl and Heidegger and promoted the element of 'being-in-the-world', which is similar to Heidegger's interpretive approach. He also argued that even if people may have the same or similar experiences to other individuals, their experiences are never the same, as every individual's experience relates to their own circumstances in the world.

Hermeneutic phenomenology

Whereas Heidegger is regarded as the founder of the hermeneutic phenomenological approach, other scholars including Gadamer and Ricoeur are also recognised for their contributions (Horrigan-Kelly, 2016). Gadamer argued that the nature of culture-based understanding has a historical impact (Langdridge, 2007). Like Heidegger maintained, Gadamer (1975; 1996) advocated that understanding is essential to human existence, and that the understanding of the world needs to be achieved through language. According to Gadamer (1975; 1996), conversation was considered to be the mechanism through which to reveal the 'things themselves', which develops the knowledge and assists the researchers to accept the experiences of the participants.

Fusion of horizons

As bracketing researchers' judgements in relation to a phenomenon is unachievable, according to Gadamer (1975; 1996), it is important for the researchers to understand themselves before try to understand the participants' views of the world. This includes the researchers develop an understanding of their own pre-judgements as well as their own history and culture. Rapport (2005) also suggested that researchers understand phenomena through their own perspectives or horizons.

During the research process, the meanings expressed by participants are allowed to be blended with the researchers' horizon, which Gadamer referred to as a 'fusion of horizons' (Gadamer, 1975; 1996). As Gadamer (1975; 1996) explained, the fusion of horizons continues in a circular hermeneutic process whereby the interpretations of researchers are fused with the interpretations of the subject in a cyclical and iterative process. This process allows the researchers to move different levels of data back and forth which, in turn, interprets new meanings as opposed to a staged approach (Smith et al., 2009).

Ricoeur (1976) acknowledged the importance of 'being in the world' and incorporated some of Gadamer's principles into his hermeneutic approach. This approach attempts to give meaning through the process of engaging the authors of the text, the text itself, and the interpreter. Ricoeur (1976) emphasised that discourse and language are different. According to Ricoeur (1976), discourse is speech which humans speak and construct, whereas language is simply composed of symbols that contribute to discourse. Breaking down language through the interpretation of text fails to reveal full meaning; however, meaning can be revealed through discourse (Ricoeur, 1976). Therefore, Ricoeur (1976) developed a 'hermeneutic of suspicion' in which the researchers analyse texts and reveals the hidden meanings in language (Langdridge, 2007). Understanding the meanings through the analysis of metaphors and narratives, and Ricoeur’s later work moved from hermeneutics to narrative and to the use of stories to uncover meanings (Langdridge, 2007).

Descriptive versus Hermeneutic phenomenology

van Manen (1990) suggested two distinct descriptions of lived experience. The first description was that the ‘life world’ as it is experienced, while the second was that of the ‘life world’ as it is conveyed through expression such as language, which can then be interpreted. These descriptions represent significant differences between hermeneutic and descriptive phenomenology. Furthermore, descriptive phenomenologists have stated that description is fundamental to considering different types of phenomena (Giorgi, 1992; Rapport, 2005). While hermeneutic phenomenologists believe that an individual's experience is not able to be described by others without interpretation (Giorgi, 1992). In other words, experience is impossible to be separated from the world of the researchers who indirectly describes the experiences which, in turn, precludes the achievement of epoché.

Rapport (2005) described the differences in the researchers’ position within each approach as follows: (1) descriptivists attempt to explain meaning as it appears in consciousness, whereas interpretivists explicitly describe meaning in order to generate hypotheses or theoretical models; (2) descriptivists view the researchers as the primary judge of validity, whereas interpretivists look to external judges to validate findings; (3) descriptivists suggest that all interpretations can be described, while interpretivists argue that interpretation is the only goal of research because humans are inherently interpretive.

Hermeneutic approach to phenomenology has led to substantial criticism from descriptivist phenomenologists. Giorgi (1992), for instance, believed that multiple interpretations of a phenomenon may distort findings and lead to a level of uncertainty about acquired knowledge.

Some scholars have also reported their concerns about nurse researchers' misuse of phenomenology (Burns & Peacock, 2019; Neubauer et al., 2019). Burns and Peacock (2019) claimed that the majority of nurse researchers have interpreted Heidegger quite erroneously. Neubauer et al (2019) pointed out that misinterpretations of phenomenology are common if the researchers rely on secondary texts. Numerous researchers rely on interpretations of original publications, which can potentially lead to meaning being lost in the translation process. It has been acknowledged that reading Husserl and Heidegger's primary sources is compulsory for researchers (Porter, 1998; Neubauer et al., 2019).

At the same time, however, it is difficult to approach the original writings of Husserl and Heidegger, as they were written in German and French. The significant works of Husserl and Heidegger written in English were used to understand their phenomenology for this present study, as these translations still provide clear insights into the application of the phenomenological principles for the researcher. Several scholars such as Spinelli (2005), Langdridge (2007), and Smith et al. (2009) support this opinion that focusing on the substantial work of Husserl and Heidegger is more important than reading their primary sources.

A hermeneutic approach to the research and the data collection process

In relation to the present study, it would be difficult to fully explore the participants' experiences without an understanding of the social and historical contexts that influenced them. In an attempt to fully understand their experiences of the phenomena, it is essential to explore their experiences based on their past, present, and future.

As previously discussed, achieving the process of epoché is impossible. In the tradition of Heidegger and Gadamer, therefore, a hermeneutic phenomenological approach was used throughout the study. In order to move the principles of hermeneutic phenomenology into a method, van Manen's (1990) methodological themes discussed in the following section were used.

The aim of the hermeneutic phenomenological approaches is 'to turn back to the things themselves'. This methodology emphasises flexibility and openness to the objects and the way they present themselves to the world (Armour et al., 2009). It is recommended to conduct a hermeneutic methodology appropriately (Rapport, 2005), instead of fixed and exclusive methods for hermeneutic phenomenology (van Manen, 1990; Armour et al., 2009). Within this present study, the framework of the six themes of van Manen (1990) was used for data collection in an attempt to 'know' the participants' life-world. The six themes within the framework of van Manen (1990) are presented below, followed by an explanation applied to the study:

Table 6 van Manen’s framework

Turning to a phenomenon which seriously interests to the researcher
Investigating experiences as the researcher lives it, rather than as she conceptualises it
Reflecting on the essential themes which characterise the phenomenon
Describing the phenomenon through the writing and rewriting
Maintaining strong and orientated decision-making in relation to the phenomenon
Balancing the research context by considering the parts and the whole

Source: van Manen, 1990; van Manen, 2014

Turning to a phenomenon

Turning to a phenomenon is the first step that provides a structure for presenting the methodology. The philosophical foundations of the methodology will be discussed in this section, such as the research orientation, the research questions, reduction, the nature of truth in phenomenology, and aspects of writing about the phenomenon.

Patton (2002) stated that particular experiences, as individuals need to connect to the world, and phenomenologists refer to these connections as intentionality. Neubauer et al (2019) stated that subjects (human beings) are inextricably entwined in objects (all other things) in the world, and there is a connectedness between both. This intentionality is used to indicate how individuals are meaningfully connected to the world (Neubauer et al., 2019). In order to connect experience and the world, how individuals experience phenomenon needs to be methodically, carefully, and thoroughly captured and described. In other words, phenomenologists need to find out how people feel, memorise, explain, judge, remember, understand, and talk about phenomena (Patton, 2002).

Hermeneutic phenomenology involves interpretations of concrete sensory lived experiences (Neubauer et al., 2019). The aim of the phenomenology is to discover and investigate the uniqueness of experiences and to interpret those experiences to relate specific instances to universal understandings. Thus, for the direction of the researchers and the nature of the research questions, phenomenology has methodological implications. van Manen (1990) referred orientation as a “vantage point in life” (p. 40). He described himself as having many vantage points including being a son, a husband, a friend, and a person who loves. To be specific, individual orientation in phenomenon always carries a personal interest. Hence, in his research, he showed a life orientation toward himself as a parent and teacher (van Manen, 1990). In this sense, interpretation is a personal act.

The present study was conducted by a nurse who believes that all the decisions for people with advanced dementia have to be made with an ethical endeavour that serves the common good. The researcher’s orientation stems from three years of experience of working in South Korea, and five years in Australia.

The research question for this study is “How do people experience ethical dilemmas in their role as healthcare professionals or family members of people with advanced dementia?” The starting point for phenomenological research is primarily to identify what is of interest to the researcher and people in modern Korean society, and to identify this interest as a true phenomenon (van Manen, 1990). Rather than clarity being found through clear statements containing the null hypothesis to be tested, research questions require the researchers’ ability to present that the question is not only understandable and clear, but that it is 'alive' for the researchers (van Manen, 1990).

The researcher is interested in the ethical nature of making decisions for people with advanced dementia. This interest stems from an orientation as a nurse who believes the answer will help make the world a better place as a healthcare professional. This idea has grown from an interest in philosophy, beginning as a nurse in South Korea and continuing to develop in nursing in Australia.

Phenomenology emphasises an interest in the object itself. As mentioned earlier, phenomenology is a way to break through this taken for granted and reaches the meaning structure of the experiences. The basic method is called “phenomenological reduction” (van Manen, 2014, p. 215).

Moustakas (1994) stated that each experience is considered a singularity in itself. In addition, the diversity of its essential components, perceptions, thoughts, feelings, sounds, colours, and shapes can be provided by a complete description. The researcher was mindful of the singularity and uniqueness of experiences of each participant, and maintained curiosity about the research question. Later in this chapter, the concept of reduction within the context of reflecting on the phenomenon will be revisited.

The goal of researchers is to find, explore, interpret, and present the essential aspect of experiences so that meaning structures can be brought back (van Manen, 1990) and to convey it in a way that rings truthfully to others through phenomenological writing. The research method refers to validity and reliability as a means to confirm the data ‘truthfulness’ and findings in an empirical sense. Truthfulness is measured by researchers’ abilities to bring the readers closer to understanding the nature of the experiences in all their complexity and mystery (van Manen, 1990).

van Manen explained this type of truthfulness as “iconic validity” (van Manen, 2014, p. 255) which is different from empirical validity. van Manen (2014, p.255) suggests that after writing a completed anecdote, “Does this anecdote show what an aspect of your experience is / was like?” needs to be asked.

The plausibility of an account can be fulfilled by researchers’ phenomenological writing, which others judge. Researchers’ engagements reflect the importance of their own orientation as already discussed, and also the ‘prolonged engagements’ that build the trust with participants. Neubauer et al (2019) stated that validity is established primarily through the researchers’ sustained engagements with phenomenon and the participants who have experienced the phenomenon.

In this present study, engagement with the phenomena ties back to the researcher’s own orientation as a nurse, a healthcare professional, and as one who believes in healthcare as an ethical endeavour. As Creswell (2007) suggested, the researcher should solicit participants’ reviews of the credibility of the research findings and interpretations to preserve truthfulness, so in this project, the participants were asked if they wanted to review the transcripts. However, none wished to do so due to the researcher having established a credible relationship with them earlier in the study. The cultivation of participation and trust with participants begins with their choices. Trust was cultivated through the announcements and procedures guided by the Flinders University Social and Behavioural Research Ethics Committee (SBREC), the time spent together, and the cooperative nature of the interview process.

Investigating experiences

Investigating lived experience rather than conceptualising it is the second of the framework. As explained in the previous section, hermeneutic phenomenology involves reflection on lived experience. Hence, although the data includes both lived experiential descriptions and hermeneutical interpretations, the methodology begins and finishes with experience. van Manen (1990) also emphasised that the world of lived experience is the source of the phenomenological approach.

This section focuses on strategies and techniques associated with empirical data collection as a way that researchers investigate experiences in life rather than conceptualising experiences (van Manen, 1990). This includes interviews for data collection and descriptions of the opening up of conversations as an interview strategy.

van Manen (1990) suggested several approaches to collect different forms of lived experiences including art, observation, forms of language such as idioms and etymology, literature, protocol writing, exploration of personal experiences, and others. As a number scholars have suggested interviews as an appropriate method for explicating lifeworld experience (Lindseth & Norberg, 2004; Bevan, 2014; Jackson et al., 2018), this study used conversational interviews as the primary technique. In line with the requirements of the chosen approach, this stage includes an overview of the study setting, informed consent, data collection, and interview strategies, which are described in the following section.

Reflecting on the essential themes

Reflection on the essential themes that characterise a phenomenon is the third step of the framework by van Manen (1990). This section revisits reductions and provides descriptions of theme developments and phenomenological explorations, focusing on the themes and techniques used in the analysis of experiences.

Revisiting phenomenological reduction

As discussed, phenomenological methodology reduction involves two parts, bracketing (or epoché) and reduction. This parts focus on strategies and techniques related to reduction. Reduction influences the hermeneutic interview, the researcher's analysis, theme developments, and findings by paying attention to experiences as units of meaning. Reduction is a methodology for reflecting on phenomenon. Each experience was therefore viewed as a single unit and explained in its totality.

van Manen (2014) suggested approaching the texts three times, each with an eye to a different level of meaning for the process of reflection. In his example (van Manen, 1990, p. 93-94; van Manen, 2014, p. 320-323), this way of analysis starts with descriptions of lived experiences and is to be reviewed at the wholistic, selective, and detailed levels.

Table 7 Three different levels of analysis

Wholistic	At this level, the goal is to pay attention to the entire text. It is true that different readers may have different interpretations, but "one interpretation is not necessarily truer than the other" (van Manen, 1990, p. 94). Interpretations need to be reasonably plausible, but insights can be judged on top of a continuum.
Selective	At this level, the goal is to determine "what statements or phrases seem particularly essential" (van Manen, 1990, p. 93). Researchers look for rhetorical gems, especially evocative ones, and those phrases that "possess a sense of punctum" (van Manen, 2014, p. 320). Then, meaningful phrases, sentences, and passages are highlighted.
Detailed	At this level, the goal is to re-read again line by line and ask again, "What does this sentence or cluster of sentences reveal about the phenomenon?" (van Manen, 1990, p. 93). This reading approaches methods of other qualitative coding techniques but aims to ensure that the analysis does not overlook or avoid gems or insights. Therefore, not every sentence is accounted in the coding summation.

Source: van Manen, 1990; van Manen 2014

In this study, this approach has been used in the hermeneutic conversations with the participants by asking them about their own experiences through relevant anecdotes. In each re-reading, the goal was to identify and capture significant phrases that demonstrated the meaning of the experiences and to develop the experiences thematically through hermeneutical phenomenological writing.

Describing the phenomenon

Describing phenomena through writing and rewriting is the fourth of the framework for presenting the methodology. After gathering experiential considerations through conversational interviews and hermeneutical analysis to identify and develop themes, the experiences and meanings were integrated into the writing process.

In hermeneutic phenomenology, interpretation is the principal element, and the writing continues the hermeneutic component (van Manen, 2014). van Manen (2014) also stated that writing phenomenological texts is a reflective process to express how individuals experience life, and attention should be paid to the cyclical relationship between language use, writing recognition as a process, writing, reflecting, editing, and rewriting.

Language

van Manen argued that language is a central concern of phenomenological study. The creation of phenomenological writing allows the subjects themselves to speak (van Manen, 1990). To make it clear, this way of writing differs from the method described and promoted by Moustakas (1994) in his empirical approach. It rejects the explicit articulation of analytical components and instead offers the creation of complex descriptions. Hermeneutic phenomenology involves thematic analysis, as described previously, which is reflected in the writing.

Recognition of writing and writing as method

Researchers need to communicate their thought processes in their writing, which is how they demonstrate their ability to be thoughtful and insightful rather than showing only the ability to think and see (van Manen, 1990). van Manen (1990) also stated that writing is intimately fused to research activities and reflection itself. Reflection is deeply rooted in writing, and writing ‘measures’ the value of the research and the researchers’ abilities.

Reviewing, Editing, and Rewriting

Effective and rigorous approaches to the writing process include reviewing and organising multiple drafts. From the initial drafting to the final as a whole process assists with finding words and structures that bring clarity and meaning which is the cycles of reading, thinking, reviewing, and writing.

The hermeneutic phenomenological completion text that forms the thesis findings is a result of several stages of reflection, analysis, and writing. The starting point of the process of this present study was writing a literature review and a description of the methodology. Drafts of both these sections were written and rewritten a number of times as part of the development of the thesis. In this study, participants’ lived experiences described in the conversational interviews were transformed into hermeneutic phenomenological descriptions. The interviews were digitally recorded to capture the words that had been spoken. The writing of the transcript was not accompanied by modification, and the researcher directly retold the conversation while transcribing them into the transcriptions.

Lived Experience Description (LED)

A lived experience account was created as a complete narrative of the experience derived from the records of each of the 18 participants. This account differs from a transcript in that it is not a verbatim transcription of what said, but rather a narrative account of what was conveyed in the conversation.

An anecdote is a more complete edit and transformation of excerpts from a lived experience description (LED) of a specific experience. In this study, each LED spawned three or more anecdotes. An anecdote contains a unique trait that serves the purpose of hermeneutic phenomenological writing. An anecdote serves as a show rather than a tell. Anecdotes show something particular and address the universal or general (van Manen, 1990). Anecdotes are specific illustrations rather than broad generalisations. Therefore, this is the method used to characterise each participant’s beliefs, and to approach them in a sensitive manner.

Hermeneutic phenomenological texts

The hermeneutic phenomenological texts consist of the contents of the findings reported in the following chapter. The final hermeneutic phenomenological texts contained themes reflecting hermeneutic elements and anecdotes reflecting experiential elements.

van Manen (2014) suggested the value of practising phenomenological draft writing which assists in instilling and internalising a phenomenological disposition. He recommended conducting multiple drafts, each involving questioning and a guiding concern that would be helpful for phenomenological study. In addition, using these drafts results in a constant circling in all relevant directions that entices the author to extend themselves (van Manen, 2014). A notes page for each anecdote was then created and divided into multiple sections to deal with each of the draft. The drafts included writing that focused on experience, related texts, wonder, themes, insight, and poetic language.

Heuristic writing focuses on instilling a sense of wonder in readers by exploring how consideration of popular experiences may raise deep, thoughtful questions to ponder, and yet at the same time, defies easy answers. These questions can focus on the meaning of an experience at the meta-level. The next drafts focused on the experiences themselves. Hence, the experiences of ethical dilemmas were particularly focused, and the writing of the drafts involved capturing the experiences in an expressive and intelligible way. The researcher's notes on each anecdote, and the prompt questions used such as 'can you give me some examples?', were reviewed and re-focused at the time of writing.

In thematic writing, the reduced themes are expressed in concise expressions and narrative passages that describe units of meaning (van Manen, 2014). The themes were further developed through wholistic, selective, and detailed analysis of the anecdotes. Insight gained through writing draws other resources into the picture to find connections to additional expressions of experiences. As discussed in the literature review, the research topic of this thesis is one of the major issues in South Korea and even globally. Most of the participants' anecdotes reflected the issues and dilemmas of current society. The drafting consisted of attention to vocational language. The phrases from the LED were emphasised and significantly discussed by the participants.

Lastly, the goal of "inceptual drafting" (van Manen, 2014, p. 378) is to express reflections that are especially deep, insightful, or counterintuitive. The iterative process of reading, reflecting, and writing was a task that evolved into re-reading, reconsidering, and re-writing over multiple drafts. The final product consists of the findings outlined in the following chapter.

Maintaining strong and oriented decision-making

Maintaining strong and oriented decision-making in relation to the phenomenon is the fifth of the six frames for describing the methodology. Generally qualitative research, and especially phenomenology, contains strong, rich, oriented, and deep descriptions, with the aim of phenomenology not being to finish with the description, but to influence decision-making methods and actions by providing thoughtful reflections on the meanings of experiences. van Manen (1990) states that a deep understanding can transform thinking, and actions will flow from those transformations. These transformations can be made at an individual level, collectively within a profession, or politically.

He also proposes that hermeneutic phenomenology is a search for the entire life, and is validated by lived experiences (van Manen et al., 2016). The intimacy between research and life is enhanced through a phenomenological approach as "something is done by people rather than for" (van Manen, 1990, p. 156). In this phenomenological study, the nature and meaning of the experience of ethical dilemmas of people in different relationships with people with advanced dementia have been described.

Balancing the research context

The study context can be balanced by considering parts and the whole. This is the last frame the research methodology used in the present study. Phenomenological research describes the process of discovery that relies on a form of philosophical inquiry to leave the possibility open. The methods, strategies, and procedures used within the context of a hermeneutic phenomenological methodology have been discussed. This section focuses on maintaining research balance, looking at research ethics and limitations.

There is a fundamental distinction between phenomenology and qualitative and quantitative methodologies that differ. Phenomenology looks at “what teachers or parents do and tries not to be trapped in a positivist perspective that confuses the meaning of teaching or parenting" (van Manen, 1990, p. 149). Which means phenomenology begins with experience by exploring concepts, meanings, and truths that are difficult to find in other forms of research (van Manen, 1990).

The purpose of this study is not to develop a list of behavioural competencies or directions for actions in the face of ethical dilemmas, but to explore understanding of what the experiences are and what those mean to family members or healthcare professionals. The study results represent possible interpretations of the personal descriptions of a multiple individuals’ experiences. It is neither comprehensive nor professes to be the only interpretation or suggestion that all experiences will be exactly the same. The goal is to explain the types of understanding, not a generalised prediction or prescription of how people have to make decisions.

Ethical considerations

Ethics approval was obtained from the Flinders University Social and Behavioural Research Ethics Committee (SBREC) prior to the commencement of the study. Acquiring ethics approval was necessary to protect the participants from any risk of harm, and to treat them appropriately (White, 2020). The approval letter is attached as Appendix 5.

Recruitment setting

This study was conducted in Ulsan, South Korea where the participating public healthcare centre is located, and in Daegu, South Korea where the participating hospitals and a home care agency are located. The public healthcare centre and hospitals were suitable venues for distributing the recruitment flyers, as many doctors and nurses work in these facilities. As the selected home care agency sends a monthly letter to care recipients to provide updates of their work, they placed the recruitment flyer into the same envelope for the researcher to recruit family members of people with dementia. The flyers were sent to all care recipients' homes, with only the agency being involved to preserve confidentiality.

Informed consent

Informed consent is an important process to ensure that each participant has adequate information about the research (Hardicre, 2014). This information includes the advantages and disadvantages of the research, and the process of the research for the participants, as one of the governing principles was to respect their autonomy (Calloway, 2009).

The researcher also provided an introductory letter from her research supervisor, a project information sheet, and a consent form. The information sheet and consent form are attached in Appendix 6. In addition, every participant was given enough time to decide on their participation, and there was no pressure or coercion applied to the participants when they were making their choice (Kvale, 1996). The informed consent form was signed by each participant before the interview, and the researcher advised them to keep a copy of the form. Finally, the participants were informed that they could withdraw their decision to participate at any time.

Data Collection

Semi-structured interviews with each participant were conducted for the present study. The aim of this method was to participate in a "hermeneutic collaborative conversation" (van Manen, 1990, p. 99) involving conversations about the meanings of the participants' experiences. This section provides an overview of techniques for collecting data in conversations.

A series of conversational interviews were conducted with six doctors, six nurses, and six family members of people with advanced dementia to explore the research question: How do people experience ethical dilemmas when they make decisions for people with advanced dementia in their role as healthcare professionals and family members? The interviews were transcribed. From the transcription, a narrative of the LED was created. From this point on, the narrative will be distinguished from the transcript developed by referring to it as a LED.

All participants chose the time and place for their interview. Each interview lasted approximately one hour, and was conducted with a focus on confidentiality and anonymity, with each participant being given a pseudonym. Once each interview was completed, the digital recording was transcribed by the researcher. A journal of field notes was maintained to complement the recordings. Hard copies as well as digital version of the interview materials have been stored on a password-protected laptop provided by Flinders University.

Interview strategies - Conversational openness

As mentioned earlier, open semi-structured conversational interviews were used for the data collection, with the interview schedule based on van Manen's (1990; 2014) work, and included as Appendix 7.

The interviews were undertaken with the goal of developing a relationship of personal sharing and trust (van Manen, 2014) to offer for a conversational tone instead of a strict interview format. The questions stayed close to the experience being relayed and were guided by a sense of wonder. Pseudonyms for the participants, facilities, and other characters discussed were used to enhance trust and comfort.

Private rooms in a local library were booked prior to the interview. Although there were some requests from the participants wanting to choose a different venue, such as their workplace or their own home, these places were prohibited due to confidentiality and safety issues. However, all the participants were requested to choose the time for their own convenience.

All 18 participants were involved in the interviews on a voluntary basis. The experiences they discussed involved caring for someone with advanced dementia who had passed away or had been living in his or her end-of-life period. This was the main inclusion criterion for selecting the participants.

A hermeneutic approach to data analysis

As a hermeneutic phenomenological approach was chosen for the present study, interpretive phenomenological analysis (IPA) and phenomenological template analysis (TA) were considered to analyse the data. Smith (1996) developed IPA which focuses on individuals' perceptions of their experiences and what it means to them. Within IPA, the researchers have a general idea about the research questions they are aiming to explore and the participants' opinions on the subject. Hence, researchers play a key role in interpreting the participants' understandings. Studies utilising IPA are inductive and data-centred as opposed to using existing knowledge or theories (Langdridge, 2007). IPA was defined by Smith and Obsbourne (2003) that the method is an attempt to reveal the meanings contained in accounts through the process of hermeneutic engagement in texts and transcripts. In other words, a staged process assists researchers to achieve meaning from the transcripts (Smith, 1996). The researchers identify themes and develops clusters not only within each case, but across a series of cases. While IPA provides a structured system to data analysis, it may be indistinguishable from thematic analysis (Willig, 2001).

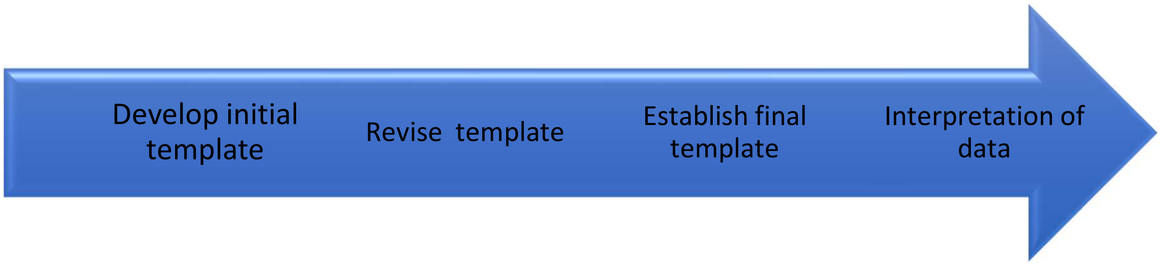
Hermeneutic phenomenology focuses on understanding the meanings of experiences through interpretations of the data. As van Manen's six themed approach was used to collect the data for the present study, the structured guidelines assisted with a thorough analysis of the data and interpretations of the participants' experiences. Developed by King (1998) and Crabtree and Miller (1999), TA provides a methodical approach for researchers to analyse data while maintaining a degree of flexibility. TA, similar to IPA, is based on the thematic analysis of experiences. The main difference between IPA and TA is that TA allows the use of coding frames or templates to structure the analysis process. Also, TA allows researchers to create 'a priori' themes. Prior to starting data analysis, researchers select several a priori themes based on the phenomenon they are investigating. These themes are then modified and developed throughout the process of data analysis. When applying TA, individual accounts are analysed in depth before consolidating them, thus reducing the time needed to undertake the analysis when analysing large amounts of data (King, 2012).

One of the advantages of TA is that it allows researchers' judgement to analyse data while compensating for a flexible and diverse epistemological position, and to determine themes (King, 2012). Such benefits of TA have resulted in increasing its popularity in a broad range of research areas. TA has been used for a number of healthcare studies (Waddington & Fletcher, 2005; Waring & Wainright, 2008; Bush et al., 2019). It is also useful for studies in different fields such as organisational culture (Shine & Westacott, 2009) and business (Kenny & Briner, 2010).

While van Manen's hermeneutic phenomenological approach guided the methods and data collection process, therefore, TA was chosen to conduct the data analysis for the present study with sound reasons. As discussed earlier, within TA, the researcher is allowed to identify and document the 'a priori' themes before analysing the data. This process allows the researcher to acknowledge her own stance, as recommended by hermeneutic phenomenologists including Heidegger, Gadamer, and van Manen (Langdridge, 2007). Especially in the context of phenomenological analysis, it is important to indicate that a priori themes are always provisional and critically consider their values throughout the analysis.

TA allows researchers to develop a template in a hermeneutic way through iterative readings and analysis of textual data. Once the template has been developed and the researchers can revisit the data, they can commence the interpretation of the participants' recall of the phenomenon under investigation. This cyclical movement of data analysis supports Gadamer's (1975; 1996) ‘fusion of horizons’, also known as the 'hermeneutic circle' as discussed earlier, thus supporting a hermeneutic phenomenological approach. This analysis followed the four steps as outlined by King (1998), as follows:

Figure 6 Analysis steps by King (1998)



As noted above, an initial template was guided primarily by the literature review and the researcher’s own experience as a nurse. TA allows codes to be used in parallel, so more than one code may be attached to a single text. The initial template developed will be shown in Chapter 5.

King points out four main types of revisions: insertion, deletion, changing scope, and changing higher-order classification. Through the process of multiple reviews of the data, the template can be continuously adjusted, modified, and re-worked, but for practical purposes, it must be considered good enough to proceed with at some point (King, 1998). The template for the present study was revised a number of times until it was clear, and significant content was not left uncoded so that the template could offer a satisfactory interpretation framework.

This study did not simply end with code lists and appearance frequencies, the template provided guidelines for discussing the themes that appeared extensively throughout the transcripts, and themes that were unique but of special meanings to the participants. The interpretations sought to find a halfway between being too open to be discussing and including themes from most to least frequent, and being too rigid in choosing among the themes that emerged. Examples of the data analysis are presented in Appendix 8.

Rigour

The rigour of naturalistic inquiry, such as phenomenology, can be ensured through application of the criteria of credibility, dependability, confirmability, and transferability (Cypress, 2017). In the present study, the following procedures were conducted to achieve these criteria.

Credibility

Polit and Beck (2012) states that credibility refers to confidence in the truth of the data and its interpretation. In the present study, the interviews were recorded, and the data transcribed verbatim. Quotes were used as examples which were written in the participants' own words.

Dependability

According to Noble and Smith (2015), validity and reliability in quantitative studies are the alternative terminology to dependability in qualitative studies. Dependability ensures the reliability of the results related to qualitative research. Every process for the data collection and interpretation were well-documented to increase dependability.

Confirmability

Confirmability relates to the interpretations of the data and to ensuring that the findings of the study are derived from the data (Nassaji, 2020). The researcher kept the audiotapes, transcripts, and the analysed data to confirm the procedures that were undertaken.

Transferability

Transferability refers to the relevance of the results for other groups and settings (Kyngäs et al., 2020). The present study is about dilemmas that people might experience when they make decisions for those without the ability to make them. The study results can be broadly generalised because there are people who have no ability to make their own decisions, or who lose their ability for various reasons, such as age and other diseases such as dementia.

In this chapter, the researcher's ontological and epistemological assumptions were discussed. Phenomenology was selected as the preferred methodology for the study, as it strives to capture the lived experience of the individual. The chapter has also included a discussion of the methods used to recruit participants and to collect and analyse the data, as well as a discussion about rigour to enhance the trustworthiness of the findings and to facilitate their transfer to similar settings. Chapter 5 reports on the findings that integrates the themes and reflections described above.

Chapter 5 Findings

This study aims to explore the experiences and decision-making of family members and healthcare professionals who provide end-of-life care for people with advanced dementia in South Korea, the data for which were collected by interviewing family members of people with advanced dementia, and nurses and doctors who take care of patients with advanced dementia. The interviews were conducted in Korean, with the transcripts being translated into English. There were three groups of participants, nurses, doctors, and family members, with six in each group. Overall, 18 participants were recruited for the present study. This chapter consists of two parts, the demographic data of the participants and the four themes that emerged from each group.

Each participant was given a pseudonym to maintain the privacy of their personal details. The tables below show the overall demographic data, such as the participants' gender, age, and practical experience. All the nurses, except for one male nurse, were female, and the departments in which they worked were different apart from two who worked in the emergency department. Their workplaces were a geriatric hospital, a GP clinic, a surgical ward, and a community public health centre. The participants’ ages ranged from 35 to 56 years, and their work experience varied from 2 to 11 years.

Table 8 Demographic data of nurse participants

No	Pseudonyms	Gender	Age	Working environment	Work experience
1	Jun	F	49	Geriatric hospital	11
2	Joh	F	51	Emergency Department	10
3	Eunbin	F	56	GP clinic	13
4	Jae	M	42	Surgical ward	9
5	Tae	F	39	Emergency Department	2
6	Young	F	35	Community Public Health Centre	4

Doctors also had a variety of workplaces, including an emergency department, a surgical ward, a medical ward, an orthopaedic ward, gynaecology, and rehabilitation. Their ages ranged from 36 to 56 years, and their work experience ranged from 2 to 7 years.

Table 9 Demographic data of doctor participants

No	Pseudonyms	Gender	Age	Major field	Work experience
1	Doctor F	M	36	Emergency Department	2
2	Doctor D	M	39	General surgeon	2
3	Doctor K	M	48	Internal medicine	5
4	Doctor K-M	M	56	Orthopaedics	7
5	Doctor K	F	41	Gynaecologist	3
6	Doctor H	F	46	Rehabilitation	4

Six family members who took care of people with advanced dementia were recruited; four females and two males, with ages varying from 46 to 73 years. In terms of their relationship with the person with dementia, there were two daughters, one husband, one wife, one son, and one daughter-in-law. One of the daughters was the first born of her siblings, while the other was the second. The care-giving experience durations of the participants varied from 2 to 8 years.

Table 10 Demographic data of family member participants

No	Pseudonyms	Gender	Age	Relationship	Order of sibling	Caregiving experience
1	Kim	F	58	Daughter-in-law	First born's wife	8
2	Park	M	73	Wife	N/A	4
3	Yu	F	62	Husband	N/A	3
4	Hwang	F	57	Daughter	First born	2
5	Nam	F	46	Daughter	Second born	2
6	Lee	M	56	Son	First born	3

The participants responded to all questions which allowed the researcher to collect sufficient data. The data were then analysed through a TA, and the initial coding template was revised and updated as necessary. Table 12 shows the final template. The data were categorised into groups of participants, with four themes arising from each group.

Table 11 Initial template

Background history	Understanding	Resilience	Decision-making	Difference in roles
•Cultural environment •Prior relationship with person with dementia •Ethical boundaries	•Understanding of dementia •Understanding of life-sustaining treatment	•Hardiness •Commitments •Challenges •Resources •Social support structure •Financial security	•Protocols •Religions	•Doctors •Nurses •Family members

Table 12 Final template

Nurses	Doctors	Family members
• Communication barriers • Lack of education • Care for people with advanced dementia • Stressful ethical dilemmas	• Difficulties managing patients with advanced dementia • Financial difficulties of patients with advanced dementia • Influences on decision-making • Healthcare professionals' lack of knowledge about dementia	• Care for people with advanced dementia • Experiencing conflicts • Decision-making for people with advanced dementia • Poor quality of life

Nurses

The analysis of the six nurses who were interviewed identified four major themes: communication barriers, lack of education, care for people with advanced dementia, and stressful ethical dilemmas. Explanations will be organised under these four themes.

Communication barriers

The participants understood their professional guidelines in communication and cooperation with colleagues. However, some noticed the incompetence of some healthcare team members and felt silenced. The majority of nurse participants did not agree with their team members' opinions on providing end-of-life care for patients with advanced dementia. Most of them stated, however, that they refused to discuss their feelings with team member(s), because they did not want to be thought of as a bully. Nurse-Jun talked about her own experience.

> *A relative of a person with palliative care made a huge complaint about my colleague. She said my colleague did not let her in to see her mum at 10pm the other night. I think*

> *she (my colleague) should have let the relative visit the patient because it is all about end-of-life care. I just did not know what to say. I only repeated the hospital general policies that visiting hour ends at 8pm. I really felt sorry for her though … yes, of course I had a few words with my colleague, but she seems still not to understand the concept of end-of-life care. I thought if I told my colleague what she did to the relative was wrong, she would think I was bullying her (Nurse-Jun).*

As teamwork was considered important, the nurse participants' stress seemed to increase when they did not have a good teamwork system. This was because they had an ethical sense that they should not look down on other team members, and should take good care of their patients.

These types of communication errors were not only a problem between colleagues in one workplace, as some nurses experienced similar communication failures with healthcare professionals in other organisations, particularly when patients were not treated well in the previous facility and were transferred to their facility. Four nurses acknowledged that people with advanced dementia who require end-of-life care should not be taken to acute hospitals, especially emergency departments. This is because the hospitals do not provide end-of-life care for patients. Most nurse participants described different hospitals as having different competencies and added that people with advanced dementia are mainly cared for in geriatric hospitals. One nurse, Tae, who worked in an emergency department, believed that healthcare professionals in geriatric hospitals may move patients without fulfilling their roles and capabilities:

> *I think they have to go to nursing homes were allowed for "not doing anything". Or this is okay to be discharged home to die with family. We receive some patients from nursing homes, and he or she has every problem that you could think of. Pneumonia, diabetics, heart issues and dementia. The person cannot make decisions and he or she gets taken by ambulance to come here. I have a feeling that the healthcare*

> *professionals toss the ball to us. They just make us make decisions or discuss with relatives (Nurse-Tae).*

In South Korea, it is common to classify hospitals into acute and geriatric in terms of their roles. One nurse, Jae, mentioned that there is a well-known perception that patients are transferred to acute hospitals when the healthcare professionals in geriatric hospitals do not fulfil their roles well. It is not known whether such perceptions are true or not, but it can be seen that there is a lack of communication when transferring patients between hospitals.

Some nurses argued that doctors often failed to communicate effectively with the family members of their patients. Hence, they felt they became doctors' secretaries, as family members often asked them to explain what the doctors were doing. According to them, receiving such requests created discomfort, especially when the doctors did not communicate with them either. This discomfort became severe when they did not agree with the doctors' decisions. Although they were not convinced that certain treatments should be administered to patients, it was part of their role to implement the doctors' orders which increased their discomfort. Nurse-Jun described her experience.

> *I really have no idea if the relatives understand the effects of the medication. All the decisions are made by the family after discussing with doctors who are in a hurry. Sometimes the family member(s) ask if it is futile treatment. However, I won't say anything because I think that is not my job to tell such things (Nurse-Jun).*

She added that the treatments prescribed by doctors sometimes reduced the quality of life of the patients or were unnecessary, and most nurse participants stated that there were often omissions in the doctors' explanations. However, all of them had never mentioned their concerns to doctors and stated that staying quiet was the wisest approach. Some mentioned this was because it was unclear whether their thoughts or experiences could actually benefit the patients, and they did not want to offend other staff, including the doctors. Most of the nurses did not prefer reporting as they felt this could harm their relationships with the other healthcare professionals.

Nurses working in hospitals where facility manager(s) participated in patient care found it more difficult to be involved in the decision-making process for their patients. In South Korea, doctors are often hospital directors in small hospitals. Three of the participants were working in such an environment, and were afraid of being disadvantaged by the directors if they voiced their opinions. Nurse-Jae stated their position as follows.

> *There's a patient who receives nutritional supplements, but it's actually meaningless. The patient's condition will not improve with it. I've met his children, and they're the people who would agree with me if I explained to them to let him go comfortably without pain. Do you think the reason is because the doctor prescribes nutritional supplements? It's because of the money. So, I don't say anything. If he loses a patient because of me, I will feel guilty. I feel bad for keeping quiet though. But I will stay quiet because what he does is not illegal anyway (Nurse-Jae).*

These structural problems in some hospitals disrupt the communication between nurses and doctors and between nurses and patients' family members. Three participants working in an environment with these types of problems mentioned that such conflicts could not be resolved without structural changes to the hospital environment.

The lack of integration between various hospital forms and patient information also caused a lack of communication. All nurse participants said they had experienced transferring patients from or to other hospitals. They all said they had the experience of not undertaking proper treatment quickly due to the omission of patient information, and that they had not received a proper handover from the hospital they transferred from. Nurse Joh said she had received a terminal dementia patient as a new patient, and when the doctor or family members of the patient felt it was difficult to make decisions, she sent the patient to the emergency room to avoid trouble. She made the following statement.

> *We as nurses working in emergency departments experience dilemmas if healthcare professionals who used to look after the patients and relatives of the patient do not have any idea what to do. It would be hard for us to make decisions for patients who we have never seen before. We are the most middle part of the sandwich (Nurse-Joh).*

Poor communication when transferring patients not only interferes with immediate treatment, but can also lead to a waste of medical resources. This problem also shows another drawback of the Korean medical system.

Lack of education

The nurses stated that they were not familiar with end-of-life care for patients with advanced dementia. They explained that end-of-life care is usually special care for terminal cancer patients, and most of them had experienced providing end-of-life care for patients with end-stage cancer. They provided details of programs they provided for patients, such as music or meditation therapies. However, they said they had not at any stage experienced providing such therapies for patients with advanced dementia.

Several institutions, including geriatric hospitals and community health centres, provided education on patients with dementia, and most participants had attended, as some of these were mandatory. Some of the nurses mentioned that the education they had attended was focused on managing patients with behavioural disorders, and on ethical issues such as the use of restraints. It appears that the contents of end-of-life care for people with dementia are insufficient. Nurse-Young believed that patients with advanced dementia did not require special care at the end of their lives:

> *By the time they almost die, the patients with advanced dementia become quiet and their behaviours decrease dramatically. They don't even eat ... that's a natural phenomenon, and I don't think there's any breakthrough pain so, they are lucky (Nurse-Young).*

Some nurses appeared to believe there is no palliation-related pain for people with advanced dementia. Inappropriate policies interfere with end-of-life care for patients with advanced dementia and take education opportunities away from healthcare professionals who take care of people with dementia. In order to be admitted to the hospice ward in Korea, the patient's consciousness must be clear. Therefore, there is no chance for people with advanced dementia to be admitted to a hospice facility, and therefore, there is no opportunity for nurses to experience providing such care for people with a confused state of mind.

All the nurse participants stated that the consciousness of the patients with advanced dementia they had cared for was not clear and communication with them was impossible. Hence, the patients with this disease may not be able to understand their medical status or the progress of their disease. In turn, they fail to understand their imminent death. Some nurses, therefore, believed there was no need to provide emotional support for patients with advanced dementia, as they do not understand their situation. Although most nurses mentioned that patients appeared to be most psychologically stable when they were surrounded by their family members, some nurses questioned whether this would be the case for dementia patients.

The nurses argued that if the patient has pain due to disease or symptoms other than dementia, it would be desirable to remove the pain. However, they had slightly different opinions on other medications. Most nurses insisted against the use of medications that would prolong life but decrease its quality. They selected high cost and low quality of life as treatments to avoid, and nutrition and pain relievers as treatments to encourage. However, most nurses did not seem to be able to distinguish what kind of intervention was needed. Nurse-Jae encouraged the use of pain relievers to reduce pain in patients, but argued that no other medication therapy was meaningful:

> *Naturally, painkillers such as morphine have side-effects such as decreased respiratory rate or constipation, but if the patient looks uncomfortable, they should be administered sufficiently. Other drugs are actually not very necessary. If you use drugs for constipation, oxygen for poor breathing, antibiotics for wounds, and fever reducers for fever, it's actually a huge medication. Then, only the patient's life will be extended. Is that meaningful? (Nurse-Jae)*

However, some of the nurses agreed to use medications apart from pain relief. This was because they believed that people need to receive essential medications for comfort, and that most essential medications do not extend one's life:

> *I don't think antipyretics prolong the patient's life. Families and other medical personnel sometimes ask certain patients not to do anything, but in fact, there is no reason not to inject drugs such as Denogan (Acetaminophen injection). Patients suffer when they have a lot of fever. Simple injections can relieve patients' pain, but rejecting these drugs can only be explained as a lack of knowledge (Nurse-Joh).*

It appears that there is not a clear distinction between life-sustaining and non-life-sustaining treatment. Furthermore, it may also mean that there is a lack of specialised education on end-of-life care for dementia patients for healthcare professionals.

Care for people with advanced dementia

All the nurse participants experienced seeing that the family members of the patients with advanced dementia seem to predict and compromise the death for the patients. Three nurses felt that it was always difficult for family members to accept their loved one's approaching death. However, nurse-Eunbin and nurse-Joh stated, 'time makes everything easier and said it is a common transit that relatives wait for their family member's death once they manage to accept and compromise it'. Nurse-Eunbin and nurse-Young shared their experiences as follows:

> *It's sad for parents to die, so the most relatives I met seemed to be sad. Still, as there is a saying that there is no good child for a long disease, relatives say that it is better for the person with dementia to die before he or she becomes horribly sicker and weaker (Nurse-Eunbin).*

> *I think this is better than sudden death anyway. At least some people can prepare for the death. I mean funeral and heritage things like that. Even if the patient does not know what is going on, the relatives can visit them to say goodbye. But I know that it is nothing to do with a good death for the actual person. Because the person would not know what is going on (Nurse-Young).*

The person who goes through the end of his or her life may have an opportunity to receive good care from their loved ones if family members understand the situation. Some nurses stated that the facilities allowed family members to visit often if their relative was having end-of-life care, with most family members visiting often. All the nurse participants said they had never seen a family member who wanted their loved one's palliation process to be miserable.

However, family members' preparation for the patient's death is separate from the patient's quality of death. Nurse-Jun experienced some families who did not want contact with the hospital until the person with dementia had died. This means that some people refused the opportunity to be with their dying relative.

> *There was a patient on the verge of death, and I thought she wouldn't last until the morning. I was doing a night shift. So, I checked who was the on-call doctor, and contacted the next of kin to ask if the family wanted to be with the patient. A daughter of the patient answered my call, and she asked me to contact her when she passed away. I could understand her at that time, and I can still understand her now too. But I wouldn ̓t do that (Nurse-Jun).*

Achieving a good death was not easy according to the participants. Three nurses reported that they sometimes saw patients' bedsores or untreated symptoms of infection, and some patients did not even appear to have received adequate basic care. Patients with advanced dementia not only failed to predict their own death, but also often failed to complain about their pain if they had any, which in turn, made it difficult to experience a ‘good death’. Nurse-Jae stated:

> *For patients with dementia, relatives decide whether to accept death as it is or fight death using all treatments. Also, the pain the patients may have must be predicted by relatives or healthcare professionals. Thus, I think it is difficult to find a good death from them (Nurse-Jae).*

Two nurse participants noted that not all family members were willing to be with people with dementia when they die. In particular, in the geriatric hospital, there were many family members who were not interested in the death of their relative with dementia, and that there were cases where they refused to be together on the deathbed. Nurse-Jun shared her experience as follows:

> *I saw a lot of my family asking us to contact them when the patient passed away. I felt sorry for those patients because they died alone (Nurse-Jun).*

All the nurse participants mentioned that, from their experience, they refused to state that people with advanced dementia had a good quality and well-prepared death. Two nurses in particular expressed their regret that people with advanced dementia did not even know their body was shutting down, so they would engage in dangerous behaviours, such as putting pieces of plastic or paper into their mouth until death.

One participant felt that family members and nurses who involved in care for patients with advanced dementia seemed to be waiting for the patients' death while the patients themself did not even know their own medical issues. Patients with advanced dementia, whom the majority of the nurse participants had been attending, did not appear to remember their identities. Therefore, the nurses appeared to believe these patients had a poor quality of death.

Stressful ethical dilemmas

The nurses reported they had experienced conflict with other nurses and doctors in their workplace, and as mentioned earlier, most of them avoided the situation in silence. The nurses responded with silence to disagreements with other healthcare professionals and stated they would follow the instructions of the doctors. In the statement below, Nurse-Jun felt uncomfortable with administering treatments which she thought had no benefit for the patient:

> *I am not playing any role in treatment plans for patients with dementia. We know some of the treatments are not useful. But I would rather stay on this side (applying treatments), so I do not take any responsibility for any consequence (Nurse-Jun).*

Nurse-Jun refused to go against the orders made by the doctors as she did not want to be responsible for any negative consequences. However, she felt this situation was problematic. Four nurses including nurse-Jun stated that they could distinguish between suitable and unsuitable care for their patients, because they saw the patients more often than the doctors did, but they would only do what the doctors had told them to do. In doing so, the nurses were considering the position of other employees, the patient's family, and the doctors, and were also aware that the patients could be disadvantaged as a result. They thought they needed to step up and provide better and necessary care for patients, but they said it was foolish to argue with other employees or doctors.

The nurses understood the appropriate professional relationships they needed to maintain with their patients and/or family members. It was felt to be important to treat the patients' families with respect to maintain a good working relationship. Nurse Kim and Nurse Lee found it too stressful when family members of the patients did not understand the hospital's situation or when their behaviours led to disadvantages for other patients. Death was considered an important moment for patients and their family members, but this should not cause other patients to lose the opportunity to be treated and respected. Nurse-Jae shared her experiences.

> *Oh my GOD. The daughter drove me mad. The patient was comfortably resting in bed, but she came out of the room every 5 minutes and asked me to reposition her dad and give him a wash. For some reason, the patient was sweaty all the time, and she wanted to change the shirts or pillowcases every 5 minutes. Trust me, she really did! I could not do anything for any other patients. She was so wrong. I said I cannot change his clothes now. Then she looked at me with bad eyes (Nurse-Jae).*

In South Korea, it is common for family members to stay with patients and engage in caregiving activities, and this is encouraged by the hospitals. Family members' excessive requests often make nurses overly busy, as each nurse has many patients to take care of. The majority of the nurse participants had the experience of making decisions about whether to ensure patient well-being or to maintain their working relationships with other healthcare professionals. They were also stressed as a result of making the family members of their patients happy and their heavy workloads. However, they chose to remain silent rather than to relieve their stress in an active way. There was no mention of how they were managing their stress during the interviews.

Doctors

Through the interviews, six doctor participants talked about their difficulties with managing patients with advanced dementia, the financial difficulties of these patients, influences on decision-making, and healthcare professionals' lack of knowledge about dementia. These four themes mentioned by the doctors will be examined in detail below.

Difficulties managing patients with advanced dementia

All the doctors stated they had experienced difficulties in examining or treating their patients with advanced dementia. Challenging behaviours, an absence of communication, and a lack of attention were cited as causes. Hence, some of the doctors reported that healthcare professionals were reluctant to treat patients with dementia. Although nursing homes or geriatric hospitals take care of most patients with dementia, they are often not welcomed. Doctor H offered insight into managing dementia wards from his experience.

> *Look, it is not easy to open and manage a dementia ward. There are many accidents compared to other wards such as falls, patient injuries, employee injuries, and facility damage, and employees do not prefer them (Doctor H).*

According to the doctors, it was difficult to cooperate with various healthcare professionals for patients with advanced dementia, because they are a low priority for healthcare professionals. Therefore, the doctors experienced poor treatment results or dissatisfaction from patients and their families. Doctor L shared his experience below:

> *There was a time when no-one noticed that a patient with advanced dementia ate less. Moreover, the patient did not talk about symptoms she was experiencing, such as gastrointestinal discomfort or loss of appetite. Then she died, and it turned out to be gall bladder cancer. We didn't have time to provide end-of-life care for her (Doctor L).*

Delays in the identification of the patients’ condition may make it difficult to provide end-of-life care on time. As people with advanced dementia are often in nursing homes or geriatric hospitals where limited medical equipment is available, the managers of these facilities transfer the patients to different institutions to identify their condition. The majority of the doctor participants have seen patients with advanced dementia transferred from other hospitals, and all of them had difficulty identifying their condition. Some of the doctors mentioned that patients with dementia often come with incorrect diagnoses from the initial facility before the transfer. Doctor F explained his experience as follows.

> *The small size of hospitals may lack medical facilities, so patients are transferred to hospitals with sufficient facilities if necessary. This is very reasonable, and I think we should cooperate appropriately as healthcare professionals. However, sometimes the*

> *patient's condition is very different from the letters they sent. This shows that they did not accurately grasp the patient's condition (Doctor F).*

The wrong information may make it difficult to check the health status of patients with advanced dementia, and it will take longer to do so than with patients transferred with a correct diagnosis. These situations may cause doctors to refuse or delay the transporting of patients:

> *It's okay if the patient's family doesn't treat him anymore and wants to die, but if not, it's right to send him to another hospital right away. Because the patient is in poor nutritional condition, even if he has a high fever or mild pneumonia, he or she can go to his or her death bed overnight. Then, whoever is in charge will try to transfer the patient to another hospital, but sometimes this try could be rejected for one reason or another, such as lack of beds and lack of consultants. In my experience, even if there are these circumstances in the hospital, I receive patients who need to come. But no patients with advanced dementia. As the hospital situation is already bad, the progress will be too slow if communication is hassled (Doctor H).*

Due to the nature of dementia, it is difficult to identify the patient’s intentions, so it appears that unnecessary or unwelcome transfer to other facilities happens frequently. In addition, there is often conflict between the facilities that transfer patients and those that receive them.

Financial difficulties of patients with advanced dementia

As an addition to the above theme, one of the doctor participants stated it was difficult to take care of patients with advanced dementia for financial reasons. This is because of excessive regulation and limited financial support from the government for the institutions that provide care for people with dementia.

> *Each hospital has “scheduled prescriptions”. This is to provide essential treatment for patients for each diagnosis. However, there are limited prescriptions that can meet the*

> *special needs of patients with advanced dementia. I think there will be financial difficulties in hospitals for providing care for patients with dementia only (Doctor G).*

From doctors' point of view, caring for patients with advanced dementia itself is burdensome, but there may also be financial difficulties compared to those of other medical departments. Some of the doctors stated that there appeared to be financial difficulties not only in the facilities but also in the home. Two doctor participants pointed out that supporting a person admitted to a nursing home or a geriatric hospital can be a significant financial burden for patients' family members. The doctors in this study have witnessed many cases where the patient's family is financially exhausted. Doctor K-M recalled one of his patient's immediate family members having disappeared.

> *Each hospital has a family that has already disappeared after hospitalising a patient. So, we had to go through administrative procedures ... those kinds of people are usually good in terms of paying the bills for the first few months, but they just become too exhausted (Doctor K-M).*

The other doctors also noticed the financial burden on most patients' families. Further than their refusal to treat the patients for financial reasons, family members were burdened with the continued cost of patient care itself.

> *Our facility is one of the few nursing homes where kidney dialysis is possible in the region. A few months ago, some people came, toured the facility, and promised to hospitalise their family members with advanced dementia. After a while, we didn't hear from them. So, our staff contacted them and found out that the family was afraid that the patient would live too long after receiving good care from us, so they decided to take care of him at home (Doctor G).*

This episode serves as an example of the financial burden on the families of people with advanced dementia. In fact, some of the doctors found that the cost of treatments played an important role for family members of patients with advanced dementia in determining whether to treat them or not. In Doctor H's experience, families in general prefer the patient to receive only minimal treatment when they are not expensive:

> *Relatives refuse to take patients to a large hospital, or treat them with expensive treatments, but, ask for basic treatments such as nutrition (Doctor H).*

The doctors also thought that patients with advanced dementia required more financial support. Doctor F's feelings on this were as follows:

> *Government support is very urgent. Unless the government's support is sufficient and the family has to pay extra, more families will be able to keep patients in appropriate facilities. Then, the stress that families experience from patients will be less. Facilities will also be able to own the necessary equipment, so there is no need to transfer patients due to lack of equipment. Doctors are bound to fall into a dilemma. If we rent equipment because we need it for patients, we have to use it to cover the cost. However, families refuse to use the equipment due to the cost, and facilities cannot maintain the equipment due to this cycle. Then, we transfer patients to another hospital as needed, but sometimes it may not be possible (Doctor F).*

Not all the doctors in this study experienced the same dilemma, but they frequently argued for more government support. The examples given by the doctors illustrate a range of current problems that are difficult to find solutions to.

Influences on decision-making

All six doctors reported being reluctant to make decisions for their patients with advanced dementia. However, they were all aware that their opinions played an important role in the decision-making of the patients' families. Most doctors stated they had experienced an active change in the patient's family members who were refusing treatment. In most cases of people with advanced dementia, their relationships with their family members are poor due to their behaviours, the financial burden, and so on, and in many cases, their family members lose interest in the treatment of the person with dementia. However, the doctors found that providing accurate information influenced the family members' engagement in treatments and support.

For example, after family members became familiar with the reasons for suggested treatments, the expected results, the costs, and government subsidies for patients or the treatments, most family members became more cooperative. The doctors believed that financial support for patients had a decisive positive effect on family decision-making for the patients. If a particular medication or test was inexpensive and there were positive aspects to the outcomes of the treatment, most families wanted the medication or test. Supplying nutrition or x-ray scans to check constipation status were the most popular inexpensive treatments. However, tests that were expensive or not covered by the National Health Insurance were not preferred by those relatives the doctors had met.

Although the doctors were responsible for providing sufficient information for family members, they also believed that most family members got their opinions and information from a variety of sources. As a result, doctors' opinions were either strengthened or complaints were raised. One of the doctor participants experienced some family members of a patient with advanced dementia wanting to leave the patient unattended until they died after receiving outside advice. The doctor interfered with their decision, as leaving the patient unattended and avoiding unnecessary treatment were different. Although the doctors tried not to make decisions for their patients, they nevertheless voluntarily provided information about end-of-life care and education about decision-making in relation to legal advice.

According to some of the doctors, they treated patients with advanced dementia to protect their human dignity. Although the participants in the doctors' group believed that respecting their patients' will was paramount, it was meaningless to consider whether or not to treat the patient if the patient could not express their opinion. Doctor K-M believes that humans want to live longer:

> *Essentially, people would desperately want to live until the last few days before they die. Even if they are unconscious. Therefore, they all need adequate treatments. There are only some people who are significantly depressed, and they may want to die immediately. However, most people with dementia would still want to live to the end for sure (Doctor K-M).*

Some of the doctors expressed that they thought it wise to continue life-sustaining treatment despite some family members not being of the same opinion. The reason why they did not want to involve family in such decisions was to avoid creating legal or ethical issues. As it is rare for all family members with advanced dementia to have the exact same opinion on end-of-life care, any decision will inevitably make some family members unhappy. Doctor K-M experienced conflict with some family members in the following example:

> *For example, after a son of the patient with dementia agreed to withdraw treatments, a daughter and son-in-law showed up next week and say they would file a lawsuit against the hospital due to failing my responsibility as a doctor (Doctor K-M)*

All the doctor participants appeared to avoid legal issues as much as possible, and a reprimand that the doctor did not value a patient's life was enough to lead them into a legal dispute. The doctors appeared to apply the same end-of-life care standards treating people with advanced dementia as they did with other patients.

Moreover, there were often more than two opinions from family members, some doctors refused to make decisions. Doctor H experienced conflict with a specific family member of a patient:

> *Doctors cannot put their doctor*'*s licenses at risk to meet the demands of the patients or their families. There are a lot of different types of family members. For example, mom and dad, or very close family members. Those people, more specifically, people who take care of patients a lot, have no quarrel with the doctors, even if the patient dies. Because they have seen what doctors did to the person and what were the reasons for the doctors to give up. They can understand and move on, but the distant family members don*'*t. For example, uncles are picking a fight and making a case (Doctor H).*

Most of the doctors appear to have prevented disputes with family members by not involving them in the decision-making process. However, the doctors indirectly influenced the decision-making of the family members by providing them with accurate information, and providing appropriate education when there were legal and/or ethical issues associated with their decisions.

Healthcare professionals' lack of knowledge about dementia

Dementia is a symptom rather than a name for the disease. Doctor L mentioned that most family members and some healthcare professionals did not seem to know much about dementia. In the case of patients with advanced dementia, not only typical life-sustaining treatments such as the use of vasopressor drugs or airway intubation, but also basic antibiotic treatments or antipyretic treatment cab be dismissed as life-sustaining treatments in some cases:

> *Since dementia decreases the function of our brain, it interferes with the part that maintains the homeostasis of our body, which is part of our brain's function. Therefore, if there is no active treatment for minor diseases such as pneumonia or urinary tract infection, the patient may die due to the lack of homeostasis maintenance ability (Doctor L).*

He also added that the use of pads for faecal or urinary incontinence is a method to help patients to maintain homeostasis. Other doctors in the study, however, failed to consider the special situation of dementia as an important factor in determining the appropriateness of treatment for dementia patients on the verge of death. Most of them stated they would proceed with treatment if it had beneficial effects, such as removing harmful substances from a patient’s body, reducing pain, or improving their quality of life, and stated that dementia itself was not a consideration. In particular, if a patient who was on the verge of death was aware of having cancer, the doctors would consider removing it, and if the patient's quality of life improved after the cancer was removed, and the patient's condition warranted surgery, they thought it would be enough reason to proceed. As Doctor D and Doctor K stated below:

> *I don’t see what background medical histories the patient has. I am only concerned about whether the patient can get through the surgery or not. If there is cancer and the body condition is okay to recover, it is right to proceed (Doctor D).*

> *It ́s our job to remove the tumour, and in fact, it ́s not a matter of whether the patient mobilises or not mobilise. If we do not remove it, they could die due to the tumour (Doctor K).*

The doctors believed that their duty was to take care of the patient to the end. However, most doctor participants were aware it was impossible to communicate directly with their patients with advanced dementia on decisions about the stage or method of treatment. This appears to be one of the main reasons for explaining all possible treatments to the patient and their family. The most common reason given by the participants was that they believed that treating patients' diseases was their role, as stated above. They argued that they could not make exceptions for patients with advanced dementia.

The doctors all agreed that dementia is related to brain function, and similarly explained the patient's physical, mental, and spiritual changes caused by dementia. However, most mentioned it was not a disease that directly leads to death, while a few doctors stated that it can cause death. As the doctors' experiences of dementia, their knowledge, and their beliefs varied, their approaches to end-of-life care for people with advanced dementia also differed. However, as the opinion of the dementia specialist who mentioned the importance of homeostasis was different from that of the other healthcare professionals, many healthcare professionals who help people with advanced dementia in various health care settings may lack knowledge of dementia.

Family members

Six participants who were family members of people with advanced dementia discussed care for their relatives with dementia, conflict, decision-making for them, and poor quality of life.

Care for people with advanced dementia

Family members noted that it was important to understand the wishes of people with dementia, and to take care of them in a way that they suspected the patient would have wanted. None of the participants had directly heard the wishes of their family member suffering from dementia. However, half of them believed that people with advanced dementia would not want life-sustaining treatments, so they would not admit them to hospital or administer medication to extend their life.

On the contrary, some family members thought that people with dementia would want to live longer, particularly when there had been previous mention of the person with dementia being afraid of death. This, in turn, made family members believe the patient would like to receive life-sustaining treatment. However, even if they believed this to be the case, some of them still refused to provide life-sustaining treatment because of the cost of the treatment. In fact, all the family members interviewed complained of financial difficulties as some were unable to work due to their caregiving activities, while others had spent a large amount of their wealth on continuing caregiving activities such as hospitalisation. Kim, who complained about the financial burdens of caregiving for her mother-in-law, was hoping to end her care:

> *My parents-in-law spent the rest of all their money for the treatments of my mother-in-law. So, they came to us to live together. Can you imagine? My grown daughters have to share a room. This cannot be continued (Kim).*

During the interviews, there were many voices calling for financial support from families or from the government. Some argued that the payment for being a family care worker was insufficient, and they regretted or resented being a primary caregiver for end-of-life care for the patient due to the high levels of mental distress and the financial burden of the situation. Hwang announced that she was experiencing a heavy emotional burden and financial difficulties because of her long-term caregiving activities, while Nam expressed sympathy for her father who was the primary care provider for her mother:

> *I receive only small payments from the government as a paid family care worker. I miss my previous work. I would have made much more money, and it is much more relaxed work. If I was a second child, I would not have to do this. My sister does want to know what is going on. She calls me and listens to my story, but she would not do anything. I sometimes envy my sister and sometimes get annoyed by her (Hwang).*

> *My mum gave my dad a hard time for a long time. Of course, I participated in caregiving activities, but my father played a lot of roles. At some point, I felt that we could no longer continue this activity. So, when my mum was diagnosed with cancer, I told my family that she had already lived enough (Nam).*

It can be seen that Nam considered the current situation of the person with advanced dementia. In addition to the burden caused by caregiving activities, she had a negative attitude towards treatments for comorbidities due to the incapacity of the person with dementia. People with advanced dementia may not be able to cooperate with simple treatments such as urine tests or blood tests due to their cognitive disability, so Hwang stated that it would be wise to limit these tests.

> *Even a urine test, you have no idea how hard it is. There is no cooperation, and she is incontinent as well. I will leave her alone. Because it is not worth it for me and for her (Hwang).*

She stressed that it was not meaningful enough to force the patient to undertake the test. In fact, it was considered more meaningless if it caused difficulties for healthcare professionals and family members. All family members thought death was not controllable by humans, and that people will die when their time comes regardless of efforts made by other people. Most of the participants agreed that it was very unfortunate to be diagnosed with dementia and that there was no other alternative but to wait for a natural death because there was no cure for the disease. All the family members who participated in the study expressed the burden of long-term caregiving activities and believed that it was right to provide end-of-life care for dying people who wanted it. Some participants thought the patient might want to postpone their death, but they added that they would not make the decision to provide life-sustaining treatment.

Experiencing conflicts

The condition and progress of a person with advanced dementia is a common concern for family members. Most participants experienced conflict with other family members. The reasons are varied, such as believing there was insufficient support or arbitrary decisions being made by some family members. Two participants pointed out they were having difficulty understanding the condition of their family members with advanced dementia due to interrupted conversations with other family members who were engaged in the primary caregiving activities. They also stated that they could not actively help with the caring activities because of opposition from the primary family care provider. This is illustrated in Nam's statement below.

> *I have never thought about withdrawing any treatments for my mum. I just did help with doing whatever my dad wanted. He did not want to know my opinions. He did not even seek any advice from any of the family members. I would make a different decision, but I cannot go against my dad (Nam).*

She disagreed with life-sustaining treatment for people with advanced dementia because she was worried about her father, a primary care provider. However, as her father refused to talk about the issue, she accepted the situation. On the contrary, most other family member participants complained about the lack of support they received from other relatives. They believed they had been working far more than their other family members, and they thought their sacrifice was more significant than that of others. Hwang stated that she did more for her mother than did her sister, and that she experienced emotional distress as a result:

> *It's my duty as a child, but I am not the only child for my parents. Now, I'm the only one responsible for it. Because I am the eldest. If I have to get my sister to come over and look after my mother, she will make sure to make me feel bad about it (Hwang).*

All six participants mentioned they had experienced financial difficulties, and four stated that only the death of the person with advanced dementia could eliminate these burdens. Kim shared her experience:

> *My sister-in-law would never let my mother-in-law go. My husband has been always at the mercy of his brothers and sisters. While my husband plays a good brother, I have been sacrificing myself to look after my mother-in-law. We have been doing everything. I mean all treatment and all medications. I have been telling my husband that his mother can be in hospice care which can guarantee at least dying with dignity. But no way. He will want to be the best son and best brother (Kim).*

Kim believes that a geriatric hospital could provide better care for patients with advanced dementia, but her other family members believed they could provide better care at home. These differences of opinion created conflict in the home. As a result, family conversations would be stifled, and some family members would stop seeing each other, as mentioned by Hwang:

> *It's inconvenient to meet other family members now after all the dramas and conflicts, and I don't want to spend more time with my mother. I no longer want my mum to live a long life at all. Come to think of it, I feel sorry for my mom though. I don't intend to meet my siblings, even after my mother dies. I didn't even get an invitation to one of*

> *my nephew's weddings anyway. My mom’s dementia disease strengthened the family conflict. It wasn't like this when my father died. Because his mental was still sharp until the last two days of his death, so he had completed all preparations for his death. For example, he said what funeral director to follow, what funeral services to use, and allowed mom to receive his pensions. However, my mother could not manage to do any of those things (Hwang).*

It can be seen that there are cases where family conflict further exhausts caregiving activities for people with advanced dementia, which may have a negative effect on the quality of the caregiving activities. Some participants, such as Hwang, showed her frustration with experiencing conflicts with her family, indicating there is a relationship between in-home support and continuity of caregiving activities.

Decision-making for people with advanced dementia

The six family members interviewed appeared to have great trust in the opinions of healthcare professionals, particularly doctors. Three of them mentioned they would allow healthcare professionals to decide for their relatives with advanced dementia. Lee had his mother stay in a geriatric hospital, and stated that he was satisfied with the caregiving activities of the healthcare professionals. Family members stated it was ideal for healthcare professionals, including doctors, to provide appropriate care, because it was difficult to ascertain the medical and physical condition of people with dementia. He explained what he thought of modern caregiving methods as follows.

> *There is no-one looking after the elderly at their place anymore, even without dementia. The facilities can do better than we do (Lee).*

He added that by signing the documents, the hospital's suggestions (decisions) were expressed as family consent. He mentioned that he often signed documents required by the hospital:

> *The facility has a consent form for me to sign. According to the nurse, everyone seems to sign up for it. These forms are varied such as not transferring my mum to acute hospital, things like that (Lee).*

This process appeared to reduce the burden of decision-making for some families. However, many people with advanced dementia are still being cared for in their home, and families often play a primary role. All the participants believed their family best knew the condition of the patient. Among them, three of family members, including Lee, stated that regular conversations with healthcare professionals were important because they knew the treatment needed for their patients. Yu shared the following anecdote about her recent meeting with healthcare professionals.

> *There would have been ways of letting her go earlier. All the family, including myself, did not want to do any life-sustaining treatments. We always say that we won't connect an artificial ventilator for her when we have meetings with doctors. But we did not know we could refuse to have some medication such as Dopamine (Yu).*

Yu had regular conversations with doctors, but did not appear to have received useful help for her decision-making. On the other hand, two family members stated they believed that doctors were encouraging treatment activities for their patients with advanced dementia, and argued that the opinions of the family were more important than those of healthcare professionals when making decisions for people with advanced dementia. Hwang had experience of when healthcare professionals' opinions were incorrect.

> *I knew the surgery would not have any point. But the doctor strongly recommended my mum to have an operation when she had a femur neck fracture. She became really bad after the surgery. She does not walk even after the surgery. The doctor said everything went well though (Hwang).*

Hwang appeared to regret following the opinions of the healthcare professionals. She also compared her mother's current situation with the experiences of her father who had died recently. She was suspicious of the difference between doctors' end-of-life care for her father, who was diagnosed with an intestinal perforation, and the end-of-life care for her mother, who was diagnosed with advanced dementia and fractures:

> *The end-of-life care for my mom and my dad is so different. When my father was ill, the whole family went to the parents' countryside house and tried to spend a lot of time with my dad, but we treated mom differently. The difference between my mom's case and my dad's case are the period of caregiving activities and dementia. The period of caregiving activities has been too much prolonged for my mom, and she has severe dementia, whereas my dad had bowel rupture so he could not stay long with us. He only survived 5 days after the issue. At that time, doctors said that surgery would not be suitable for my dad, and there was a clear recommendation that better not to do any treatment. But doctors do not give such advice to my mom … Only God decides when and how people die. I have to go through all this because of my karma (Hwang).*

Hwang insisted that her mother should receive end-of-life care as same as her father, and also hoped that the doctors would make appropriate decisions for her mother. As she had not received education in this regard, she may have experienced conflict with the healthcare professionals. Similarly, several other participants stated that some of the healthcare professionals' judgements were unhelpful. They believed that people with advanced dementia were best known by their family members, and that dementia could not be improved or cured in any way.

> *Dementia is not a curable disease. If I take my wife to the hospital, she will get tested again. To know what is the level of dementia or the current physical condition ... what's*

> *the point of this? Doctors make sure to test her when they do the consultations otherwise, they don't give any advice. So, I don't take her to the hospital anymore, and I will not go to the hospital unless it's an emergency. We only spend money if we go. Hospitals are no different from businesses, so they don't take care of our circumstances (Park).*

As Park mentioned, there was another participant who said she felt that doctors were forcing patients to be hospitalised or tested for money. Therefore, some family members thought they trusted and respected doctors' decisions, while others had the opposite opinion that doctors could not be trusted because they treated patients to fulfil their work responsibilities or for financial gain.

Poor quality of life

The family members interviewed believed that people with advanced dementia lived low-quality lives, whether they received home care or were in a geriatric hospital. Yu talked about the quality of her husband's life after suffering from dementia:

> *If I could push a wheelchair for my husband, I could sit with him on a nice day and enjoy the outside weather together, but he couldn't do that. He could impossibly sit on a chair. If I tried him to sit in a chair, the nurses would have to lift him with a machine. Oh, this is terrible. What quality of life is there? Whenever I visit him, I am very angry and sad (Yu).*

Even watching her husband with dementia upset her. Those who provided care for people with advanced dementia at home seemed to be more affected by the lack of quality of life of the patient. Most suffered from fatigue due to the long hours of caregiving activities, and the increasing physical, mental, and financial burden increased as they approached the end-of-life. Many family members confessed they had waited for the patient's death because of their declining quality of life.

> *I can live only when my mom dies. My mother has suffered from dementia for a very long time, and I have heard a lot about being a filial daughter. However, I didn't voluntarily take care of my mom, but I do it because there is no-one else who can help her. It was too expensive to take her to geriatric hospitals or care facilities, and none of the siblings could afford financial help. I couldn't give up on my mom, and I gave up my life and took care of her. I don't want to blame my mom, but I think I've already done everything I can. I don't know if there was enough treatment, but because I gave up everything I could, I don't have any more regrets. I hate someone calling me a filial daughter (Hwang).*

Among the participants, a few experienced internal conflicts when the person with advanced dementia was in a dangerous situation. They described that they were often in two minds, on the one hand hoping that their relative with dementia would be healthy, and on the other wanting to end all the fatigue they were currently experiencing. Hwang mentioned a conversation she had with her sister:

> *My sister came the day after. She saw mum and told me to feed mum very minimum food so she may get deteriorated. But I don't think she means it. She feels bad for me so she said that (Hwang).*

Nam, who had been taking care of her mother suffering from dementia and diabetes alone, stated that she agonised over whether she would end her current physical, mental, and emotional difficulties. Her mother was found in a hypoglycaemic state, and she said she thought for a while about whether to take her to the hospital or not.

> *My mum has been living with diabetes. Her blood glucose level went down to 3mmol/L, but she was still conscious. I was not sure I wanted to take her to the hospital. Because she will get perked up after the IV drips (Hwang).*

However, she eventually took her mother to the hospital, and as she expected, her mother's physical condition improved. She mentioned that she did not regret what she did to stabilise her mother's health condition, but stated that she would hesitate again if there were a similar situation happens again. People's long struggle against illness(s) can lead to a poor quality of life for themselves and their families, resulting in a situation in which family caregivers face internal conflict.

Based on the study findings, all three groups of participants were involved in decision-making for people with advanced dementia. The nurses showed a passive attitude towards making decisions for their patients because there had been a lack of education for nurses about decision-making. However, the doctors were aware that they might be held accountable for the decisions they could influence. Thus, they were reluctant to participate in decision-making for patients with dementia because of the possibility of legal disputes. In addition, as immediate family members were designated as primary care providers in Korean society, they had no choice but to take responsibility for them, even if they did not want to. The financial burden of looking after their relatives and the lack of knowledge of healthcare professionals, including nurses and doctors, and family members played a crucial role in their experiences of the ethical dilemmas involved. A number of important points associated with these findings will be discussed in the following chapter.

Chapter 6 Discussion

In the previous chapter, the four themes identified in each group of participants were presented and interpreted. In this chapter, the study findings are compared to similar studies in both the national and international contexts. The discussion will be organised into the following four sections: (1) Ethical dilemmas; (2) Decision-making; (3) Lack of knowledge; and (4) Needs for moral education.

Ethical dilemmas

Several research studies have revealed that Asians, including South Koreans, rely on the family model of decision-making on medical issues (Kim, 2015; Alden et al., 2018; Hughes et al., 2018; Ho & Lawrence, 2021; Ozdemir et al., 2021). Most family members of people with dementia who participated in the present study expressed a sense of being overwhelmed by the pressures to make medical decisions for their relative and filial conflict at the same time so that the tensions seen as unavoidable. At the same time, the family members in the present study experienced physical, emotional, and financial difficulties with their caregiving activities, and such experiences negatively affected their care and emotions (Kim et al., 2018). In this study, the family members who had provided care for their parents with advanced dementia mentioned that the death of their parents was good for both the persons with dementia and for themselves as a relief from the burdens and difficulties of caregiving. Such sentiments echo the experiences of the stress of caregiving and the relief that comes with the death of the person with dementia (Schulz et al., 2003). This does not mean they wanted their parent to die, but the idea was that death was a conclusion. According to the participants, the most challenging issue was the agony of continuing their lives and watching their parents deteriorate, with some feeling as if their lives were on hold.

Among the family members, there were cases where they suffered from depression due to emotional and financial difficulties, and some also experienced having suicidal thoughts in relation to choosing death for the patients. This finding also emerged in a number of previous studies revealing that family members of people with dementia experienced suicidal thinking due to their care activities and burdens (O'Dwyer et al., 2013; Kong & Park, 2022; Solimando, 2022). Such consequences may be a result of dementia being incurable and not improving as the disease evolves.

Although the family members in this study mentioned various burdens, they believed that it was important to commit to being actively involved in caregiving for their relative with dementia, particularly with duties, responsibilities, and decision-making. Considering that most of the family members in this present study were children of the person with dementia, they were enduring such difficulties with filial piety toward their parents. It is common in Eastern societies influenced by Confucianism to support sick parents due to a sense of filial piety (Li et al., 2021; Badanta et al., 2022). This requirement to care for parents acts as a burden and a dilemma for the younger generations in modern South Korean society.

As confirmed by the family members in the present study, Noddings (2003) stated that due to conflicts and guilt are inevitable risks of care, universal care may not be possible. In all caring situations, caregivers are overwhelmed by their responsibilities and obligations, and there is a risk of stopping caring for the care-recipients because of the burden, which in turn, may become an object of ‘caring’ (Noddings, 2005). Therefore, family caregivers may experience a dilemma about whether to quit providing care when faced with their own difficulties in providing caregiving activities.

Healthcare professionals such as doctors and nurses can usually provide access to information about patients and their families. For some healthcare professionals, investigating patients’ in-home support system may be part of their job. The doctors in the present study had access to their patients’ in-home support system which, in turn, made them directly or indirectly understand the physical, emotional, and financial difficulties of the families of their patients with advanced dementia. At the same time, the doctors believed that medicine aims to relieve patients’ suffering and cure illness(es). Most of the doctors who participated in the present study thought that patients with advanced dementia would still wish to be able to solve their medical problems and live longer without pain. This was consistent with their sense of duty to prolong the life of patients. In South Korean society, curing illness has been considered the doctor's main role, and if they fail to do so, there have been cases in which they were punished (Kim & Choi, 2015). Doctors were experiencing a conflict between the role of curing patients' diseases to prolong their lives and the concern of reducing the burden on patients and their families. In many countries where doctors make plans for patient care and care provision, they may also experience a dilemma between the responsibility they have to prolong patients' lives and the difficulties faced by family members and healthcare professionals (Crawley et al., 2002; Fulmer et al., 2018; Morrison et al., 2021).

Respect for the right to self-determination and individual autonomy are basic principles of Western medical ethics and decision-making, and are generally expressed in the desire to control the timing and way of death (Cipriani & Fiorino, 2019, Akdeniz et al., 2021). The most basic prerequisite for formal advanced care planning is that an individual is competent and make autonomous decisions. South Korea, as an Eastern country, there is a strong notion that the doctors' duty is to help patients live a long life. Therefore, doctors in South Korean society may not experience a dilemma in choosing whether the patient's quality or quantity of life comes first.

The nurses who participated in this study believed that the quality of life for patients with advanced dementia was important, and pointed out the shortcomings of the life-sustaining treatment currently provided. This confirms a study by Lundin & Godskesen (2021), nurses felt that life-sustaining treatments for patients with advanced dementia can be meaningless. According to their findings, life-sustaining treatment can cause patients to suffer longer and families to become more exhausted. Hence, it may be wiser to apply end-of-life care than life-sustaining care for some patients with advanced dementia.

All the nurse participants in the present study, however, experienced a dilemma when the doctors wanted to focus on their duty of care to provide life-sustaining treatments, while they believed the patients needed end-of-life care instead. This situation placed the nurses in an ethical dilemma because the main role of most nurses in South Korea is to follow and implement doctors' instructions (Jeong & Kim, 2023). They believed they might be disadvantaged if their opinions on patient care were different from those of the doctors (Lim

& Kim, 2021). Therefore, nurses in South Korea are often pressured to remain silent on decision-making for people with advanced dementia, and in turn, may be reluctant to inform the patients' family members or other healthcare professionals about their opinions on the treatment being provided.

The doctors, nurses, and family members of people with advanced dementia who participated in this study faced ethical dilemmas while providing care for people with advanced dementia. The dementia symptoms burdened all the participant groups due to a lack of social or institutional support. It may prepare caregivers for, or reduce, the ethical dilemmas they faced if they had adequate information and knowledge about the disease and a stronger social support system.

Decision-making

People with dementia often have difficulty making decisions for themselves, especially when their symptoms are severe. As a result, others make decisions for them, and in South Korea, immediate family members do this on their behalf. If there is no family, healthcare professionals fulfil this role. Black et al. (2009) found that family members predict the care preferences of people with dementia with moderate accuracy, while a recent study by Harrison-Dening et al. (2019) revealed that family members are confidently able to make decisions about end-of-life care based on several years of conversations about death and dying previously held within the family. The present study has explored the experiences of family members and healthcare professionals who provide end-of-life care for people with advanced dementia, and in this process, the decision-making tendencies of family members of people with dementia, and healthcare professionals including nurses, and doctors, have been revealed.

According to a study by Rolland et al. (2017), proxy family decision-makers often feel unsupported and experience emotional difficulties and post-traumatic stress. This is because there is a difference between the end-of-life process and cultural attitudes toward proxy decision-making, with many cultures not adhering to Western views of autonomy, the cornerstone of traditional advanced care planning (ACP). For example, some racial/ethnic groups have low advance directive completion rates, such as Asians and Latinos, who traditionally rely on the family model of decision-making on medical issues (Su et al., 2014; Portanova et al., 2017). As a result, decision support and caregiving are often provided by close family members during serious illnesses and at the end-of-life. Although all children have equal legal status as basic decision-makers in most cultures, some studies show that parents often recognise the first-born child as possessing a strong sense of responsibility (Kim & Chon, 2018; Theresia et al., 2023), and are therefore more likely to be designated the proxy decision-maker and caregiver than their younger siblings. The present study also showed that the elder sons play a significant role in decision-making for people with advanced dementia.

Proxy decision-makings for loved ones are often difficult and emotionally burdensome, and previous qualitative research has shown it to be isolating and overwhelming (Vig et al., 2007). Studies in Asian cultures have confirmed that first-born sons are culturally responsible for decision-making as influenced by traditional expectations of filial piety (Bedford & Yeh, 2021; Yim, 2022). Unique stressors common to first sons from various cultures include filial burden, unspoken expectations, sibling conflict, and perceived family judgement (Ng et al., 2016). In addition, the first-born participants in the present study complained about their financial responsibility.

Discussions about death are generally taboo in South Korean culture and often lead to significant stress, a finding supported in this study. Moreover, first-born children mentioned how they went through decision-making processes alone without the help of others, which added to their stress. Furthermore, the first-born child’s partner or family members were often in conflict with, or had opinions against, the first-born’s responsibilities. As a result, the social tendency that the first-born will decide on all care-related matters, including caregiving costs, may increase their stress and cause family conflict. Most of the participants in the present study felt that, in reality, the first child would have the final decision, even if other family members participated. If first-born children are not solely responsible for caregiving, including decision-making, a preference for family-centred decisions may reduce the stress of the first-born child.

Making medical decisions in the context of advanced dementia is stressful for not only family decision-makers, but also for healthcare professionals. The majority of nurses in this present study described feeling of frustration and powerless when the care plans chosen by them carefully modified and their day-to-day caregiving were over-ruled, not by individuals with more knowledge of the patient’s preferences, but solely because of doctors’ orders. Doctors sometimes overlooked the quality of the person’s life because they would pay attention to the curing of diseases, while nurses with opposing ideas did not reflect this in their decision-making. Although the nurse participants in this study were confident that they knew well the preferences of their patients with dementia, they were reluctant to participate in such decision-making. They were very anxious about the disadvantages they might face if they went against the doctor's instructions. In other words, nurses may intentionally refuse to present different opinions from those of the doctors. This is a structural issue in Korean society that may arise because doctors are often directors in small, specialised facilities such as geriatric hospitals.

Generally, there is no need of nurses to be formally involved in clinical consultations for medical decision-making. The government of South Korea strives to help families of people living with dementia to aid their decision-making on end-of-life care issues to Korean ethical, legal, and medical standards, focusing on the doctor-patient relationship and on responsibility for medical decision-making, in which nurses and care workers do not need to play a role. Most nurses who participated in the present study felt that, in reality, families or doctors would have the final say, even if they were involved. They also felt that some family members of patients only valued the doctor's opinion and would not listen to a nurse. Therefore, nurses may not be interested in participating in decision-making for people with dementia.

Unlike the nurses, most of the participant doctors showed an interest in making decisions for their patients with advanced dementia. However, this did not mean they were actively involved in the decision-making processes. The majority of doctors explained feeling burdened by participating in decision-making, as the outcomes had the potential to prolong the burden of patients with dementia and their families. As doctors witness suffering, this engenders moral obligations to reduce such burden. Uncertainty about the best actions for patients and their families was a source of moral distress. At the same time, however, they also felt a sense of obligation to prolong the patient's life and to cure their medical issues. In Korean society, the prevailing view is that doctors play a role in prolonging the lives of patients. This has created many legal disputes in the past (Yu, 2015).

As part of the view that it is the doctors’ role to cure patients’ medical issues, the doctors who participated in this study agreed to surgical treatment for fractures, emergency dialysis, and blood supply if necessary. Many doctors in previous studies have also suggested that antibiotic treatment for patients with advanced dementia should be encouraged because it can significantly improve their comfort or extend their lifespan (Givens et al., 2010; Rozzini et al., 2011; Parsons & van der Steen, 2017). Although doctors balance complex medical and ethical considerations, including cost utility problems, acceptance of the potential burdens from the treatment (Varkey, 2021), and the best interests of patients compared to patient and family preferences, doctors in South Korea choose to give full treatment to life-threatening issues when an advanced directive is unavailable.

In Netherlands, for example, it has been suggested by a number of doctors that advance directives for euthanasia (ADE) be made possible for patients with advanced dementia (Miller et al., 2019). However, ACP or ADE has not been widely used in South Korea due to the cultural constraint that forbids conversations about death. Considering this situation in South Korea as well as the thoughts of proxy family decision-makers and nurses, leads to several important implications for doctors. First, doctors assist proxy decision-makers by asking patients about the unspoken expectations of their first-born children. Second, doctors may initiate or facilitate further discussion with selected family members and nurses. Third, doctors can coordinate discussions about care preferences between the chosen proxy, the patient, and their family, especially if the decision-maker differs in their views from the day-to-day care provider. Lastly, attention to be given to the specific needs of family members when they make medical decisions for their relative with advanced dementia. Additional support may also address potential family conflict and psychological stress.

Lack of knowledge

Most of the family members who participated in the present study failed to show confidence in their ability to provide dementia care. They stated they had limitations in providing essential medical examinations at home such as x-rays or blood tests, and also in maintaining adequate nutrition or hygiene due to the lack of essential facilities in the home. Despite the limitations and burdens stated earlier, most family members preferred having their relative with dementia at home, because they thought the caregiving is the role of family. In addition to this belief, some relatives considered the caregiving activity they were providing to be a form of retribution for their misdeed. This traditional idea makes people believe that it is natural to endure it rather than to request help to overcome the difficulties, as caregiving is a way of repaying their past mistakes (Yen, 2013; Li, 2015). There is a difference in response between thinking that dementia is a disease to be treated and believing that it was punishment for past wrongdoings. Not only people in South Korea, but also for people in a range of countries, dementia is recognised as punishment for past mistakes (Hossain & Khan, 2019).

Dementia has been explained as being due to ‘karma’, a widespread belief in Indian culture and Hindu belief, that one’s fate in life is determined by a person's past and present actions (Krishnamurthi et al., 2022). The relatives who participated in this study who thought they were caring for their relatives with dementia as punishment for their karma were trying to complete their caregiving duties rather than making an effort to scientifically determine the cause of dementia or to improve the quality of life for people with dementia and their caregivers. This sentiment in South Korea may affect the decision-making for people with dementia. Family members lacked knowledge about the causes of dementia, and often lacked the willingness to find out. The thought of care as being inevitable, and the need to endure it even if it is difficult, were correlated with an absence of specialised knowledge.

However, most of the family members appreciated and wanted to hear the opinions of healthcare professionals, but they did not receive information in a timely manner due to the absence of specialised facilities and experts such as doctors. As a result, they may not have been given opportunities to correct false beliefs or knowledge. It is common for family members of patients with dementia to expect information from healthcare professionals about their relative and the progress of their dementia, as nurses perform a particularly important task in supporting family members with relatives living in nursing homes (Dorell & Sundin, 2019). Nevertheless, the healthcare professionals in this study were more interested in respecting the individual beliefs of the family members, so accurate guidance in such a situation may be elusive. The doctors’ ethical dilemma was between respecting the opinions or beliefs of the patients and their families and suggesting options as healthcare professionals.

On the other hand, the healthcare professionals in this study, including the nurses and doctors, stated that although they had been providing care for patients with advanced dementia, they lacked expertise in advanced dementia care especially in the dying phases. Dementia is the most common disease experienced by the elderly today, and is emerging as a serious issue not only in the medical realm but also in the social context of South Korea's ageing society (Shon & Yoon, 2021). Hence, many healthcare professionals who have worked in hospitals for lengthy periods have looked after patients with dementia with varying degrees of severity, regardless of which medical department they work in. However, they have acknowledged a lack of expertise in dementia compared to other diseases or care needs. The nurses working in the dementia ward who participated in this study were familiar with education on behaviour management for patients with dementia, but were under-prepared in relation to their knowledge of the quality of life and preparing for death. In addition, the nurses were reluctant to provide feedback on patient care, and in an environment in which nurses believe it is unethical to point out how to care to other nurses, this adds to their ethical dilemmas. If they can communicate more effectively with other healthcare professionals, including doctors, they may find out why a treatment has been followed, or it may help them to overcome their inner conflicts and ethical dilemmas.

Most of the doctors in the present study stated they had no knowledge of dementia. This finding confirms previously published studies that revealed that doctors lack professional knowledge about dementia (Annear, 2020; Patel et al., 2021; de Levante Raphael, 2022). The doctors who participated in this study placed greater emphasis on other diseases experienced by patients with dementia such as pneumonia, cancer, and fractures rather than on the dementia itself, which may indicate their indifference. According to some of the doctor participants, other diseases, for example pneumonia or fractures, were more curable. They also appeared to have a considerable understanding of other diseases and the possible results of not curing them. While the doctors had great knowledge of other illnesses or complications, they lacked knowledge of severe dementia. The doctors who lacked knowledge of dementia may fail to provide their patients' with quality care when making decisions about end-of-life care for patients with advanced dementia.

Family members, nurses, and doctors experienced different types of difficulties and ethical dilemmas because their situations and obligations were different. Internal conflict among family members can lead to conflict, sometimes resulting in delayed decisions for the patient, or making decisions they later regret. The nurses tended to refuse to comment if they lacked trust with the family members of patients with advanced dementia, if not in an intimate conversation environment, and if they could not participate in the patient's treatment plan. It is important for nurses to actively communicate with other healthcare professionals, including doctors, to participate in patient care plans and to present their opinions. Effective communication can be a good way of reducing internal conflict and emotional burden. Doctors may also reduce the burden of decision-making through effective communication and regular discussion with the patients' family members and other healthcare professionals. Doctors will not only consider patients as the subjects of treatment, but will also be able to become advocates when looking at the well-being of family members of patients with advanced dementia and all other healthcare professionals. Therefore, knowledge of effective communication methods is very important in the team caring for people with advanced dementia.

Needs for moral education

As mentioned previously, most of the family members of people with dementia in this study believed that karma had led to their role in caring for their relatives with dementia, but they also stated that the reason for commencing and continuing the role was to fulfil their filial piety and family love. The wife who participated in the study mentioned that she remembered the love her husband gave her, and the children stated they learned from seeing their parents do their best for their grandparents. It is common for caregiving to be provided within the family in East Asian nations, including South Korea (Tonelli et al., 2021). These circumstances explain Nodding's concepts of engrossment and motivational displacement (Noddings, 2003). Family members think about their relatives with dementia in order to gain a greater understanding of their situation, putting aside their own problems to help.

Among the family members, nurses, and doctors who participated in the study, many nurses particularly thought not providing life-sustaining treatments would be better choice for quality of life of patients with dementia. This is because the nurses believed they had a great understanding of patients with advanced dementia, which means they thought people with advanced dementia would prefer to forgo life-sustaining treatments. Nurses may understand the nature of nursing and, as Noddings stated, a deep understanding of patients is the beginning of nursing. However, as it is difficult to understand the intentions of dementia patients, it may be important to have a conversation with their families to fully understand their opinions.

Most of the doctors who participated in the study placed greater value on their duty of care than on the care needed by patients with dementia and their family members. Doctors' beliefs have varied considerably in other studies, with the research showing that doctors value extending patients' lives, and that it is desirable for doctors to allow patients to end their lives the way they want for the quality of their lives. The majority of doctors in the present study thought it was part of their work ethic to attempt to address the difficulties caused by patients' illness(s) and complications, and that conscience and even legal responsibility may follow if they failed to provide adequate treatment for symptoms. This may be a result of the punishments handed out to doctors for negligence in their work over the past few decades in South Korea. Some doctors who participated in the present study thought that patients could not articulate the care they wanted, which created a dilemma for them. However, there were many doctors who thought their duty as doctors was more important than what their patients wanted. Therefore, moral education may be necessary for doctors to attempt to understand what their patients wanted for their treatment.

As leaders of healthcare institutions, some doctors in the study believed that essential requirements for institutional management such as the working environment of employees and the cost of renting expensive equipment in the institution may affect their decision-making for patients. This is because most care institutions in South Korea are for profit (Lee, 2004; Lee et al., 2008; Kang, 2020). Non-profit and for-profit hospitals operate according to different principles. In many cases, the findings of research about non-profit hospitals cannot be applied to for-profit hospitals (Cronin et al., 2021). In other studies, on residential care for patients with dementia, nurses identified a situation in which they provided meaningless care for their patients, prolonging their life and pain, and benefiting the hospital as a moral issue (Ericson-Lidman et al., 2014; Cantarero-Prieto et al., 2020). This means that the prolonging of the patients' life may in some cases lead to the generation of additional income for the hospital.

To summarise, this study confirmed that people participating in decision-making for end-of-life care for people with dementia experience a range of ethical dilemmas. Relatives generally play the most important role in proxy decision-making, but this does not mean they experience the most significant ethical dilemmas. Healthcare professionals, including doctors and nurses, also experienced ethical dilemmas associated with their duty of care and in relation to the condition of their patients, particularly their quality of life. According to Noddings (1995), when family members and healthcare professionals put the difficulties of people with advanced dementia before their own, they are more likely to make decisions that benefit dementia patients. Acquiring relevant knowledge and moral education may be helpful for family members and healthcare professionals to make the best proxy decisions about dementia, quality of life, and end-of-life care.

Chapter 7 Conclusion

In order to explore the experiences of family members, nurses, and doctors when they make decisions for people with advanced dementia in South Korea, the research findings have been presented and discussed in the previous chapters. In this chapter, the limitations of the study, a revisiting of the research findings, and the implications for different stakeholders and for future research will be presented. The chapter closes with a conclusion drawn from the interpreted findings and the implications for education, practice, and research.

Revisiting the research findings

Nurses, doctors, and family members of people with advanced dementia who participated in this study experienced different degrees of burdens by various causes when they make decisions about end-of-life care for their patients or family member with dementia. Most of the family members mentioned the financial difficulties they had experienced. Although they faced significant physical and psychological difficulties in caring for people with advanced dementia at home, some were unable to place their relative with dementia in a care facility for financial reasons, which intensified conflicts with people with dementia. In most families, the government provides support through a pension for people with dementia, but this does not cover the cost of a facility. Also, due to the long-term nature of caregiving, the majority of families have already spent a lot of money which, in turn, results in having the relative with dementia at home. At the same time, however, the family members admitted that for those with severe long-term dementia, they struggled to take care of their relatives with dementia at home.

Healthcare professionals such as doctors and nurses also noted the financial difficulties of the patients’ families. It has been reported that patients often fail to receive proper care at home which confirms the difficulties of providing such care. Some nurses have seen patients with dementia get discharged earlier due to their families’ financial burden. According to the doctors’ view, the degree of participation in treatment differs depending on the costs of the treatment. Some families abandon the patient due to financial difficulties.

These situations may eventually exhaust the family and lead to a situation where they welcome the death of their relative with dementia. In fact, some family members made remarks as if they were waiting for the death, such as “It's time for her to die" or "she’s lived enough". This situation cannot be characterised as a bad death, but it may not be the death the patient wants.

Most family members experienced some level of family conflict. Due to the burden of caregiving activities for people with advanced dementia, conflicts were created between the main caregiver and other family members, which led to disconnection or discord within the family. Some family members expressed anger at the indifference of others, while some felt alienated. As mentioned earlier, the financial situation at home played a decisive role in this, but also a range of other variables such as family bonds, behaviours of the people with dementia, and participation in caregiving activities seemed to determine the degree of such conflict. On the other hand, healthcare professionals such as nurses and doctors did not directly mention family conflict, and family discord did not seem to affect their care activities.

Due to the nature of the disease, it is difficult for people with advanced dementia to understand the progress of their disease, and it is almost impossible for them to prepare for their death. As a result, family members, nurses, and doctors caring for them felt compassion for these people and expressed regret or resentment at the progress of the dementia. In particular, most family members played the role of agents who organised the patients' life instead, and each of them expressed different emotions depending on their role or level of intimacy with the person with dementia. Due to the long-term nature of the care involved, family members appeared to accept the patients' situations easily while still expressing resentment due to caregiving activities until the end-of-life, the burden of decision-making, and the financial responsibility involved.

Nurses were more objective in evaluating the patients' conditions with appropriate assessments, recognising that patients with advanced dementia could not experience a good death as they were cognitively impaired. Most nurse participants compared the patients with advanced dementia to cancer patients. Patients with cancer can organise their lives at the last minute and say or do things they wish for, while patients with advanced dementia often do not understand what they are going through. Therefore, the nurses who spent a relatively long time with them felt sorry that the patients with advanced dementia could not have a well-prepared death.

Doctors judged whether or not the patient had a good death by considering their objective condition, such as their pain levels and nutritional status rather than their cognitive ability. In addition, they appeared to be less interested in the patients' death than did the other two groups of participants. This is because they paid more attention to direct medical activities such as disease treatment and pain management for their patients.

Participants from all three groups made decisions for people with advanced dementia in various ways. As mentioned earlier, family members were responsible for the treatment plans and the care of their relatives with advanced dementia and were usually directly involved in their care or would cover the financial costs of caring. In addition, as direct family members were designated as patients' agents in society, they had no choice but to take responsibility even if they did not want to. In this study, some family members stated that decision-making was a burden because they were not familiar with the wishes of their relative with advanced dementia, or because of the treatment costs. Therefore, government subsidies and active advice from healthcare professionals have been useful for them in making decisions.

The nurses in this study tended not to be involved in decision-making for patients with dementia. Firstly, they did not wish to present different opinions to those held by the hospital they worked for. Doctors sometimes overlooked quality of life because they paid attention to curing the patients' diseases, and nurses with different opinions did not reflect these in their decision-making. These circumstances made some of the nurses’ beliefs misaligned with those of the hospital in which they worked. Secondly, the nurses often refused to take responsibility for the consequences of making a decision. Some decisions may or may not prolong the patient's life, and could increase or reduce the financial and physical burden of the patient and their family, so this was perceived as a situation to be actively avoided. Finally, some nurses felt that some family members of patients only valued the doctor's opinion.

Therefore, there was no need for them to make decisions for these patients. However, most of the doctors experienced participating in decision-making and their opinions were often accepted by family members. There is also possibility of legal disputes for doctors' opinion, therefore, doctors tend to be reluctant or careful to participate in decision-making for dementia patients.

The patient's family was often physically, mentally, and financially damaged by their long-term caregiving activities. They agreed that their quality of life was poor, and insisted that they had only limited time to take care of themselves as well as taking care of their relative with dementia. Most participants in the present study thought their situation would improve after the patient died.

The nurses also experienced an emotional and/or physical burden while providing care for patients with advanced dementia in the facilities, particularly when they witnessed unethical decisions being made by other healthcare professionals or the family members of patients. In these situations, the nurses were anxious about expressing their opinions, and experienced psychological stress in relation to these ethical dilemmas. In addition, while providing care to patients with advanced dementia on duty, appropriate stress management was insufficient, which sometimes caused problems such as feeling depressed.

The doctors were aware of the difficulties in managing patients with advanced dementia and were aware of the burden of care. They were also aware of the obligation to provide appropriate advice in the absence of family members or according to the needs of patients who were cognitively impaired, which eventually created a burden on the doctors due to the possibility of legal disputes. Similar to the nurses, the doctors also avoided such situations rather than actively managing their stress or improving the environment. At the same time, doctors understand that family members' level of understanding are varied so family members may mistake doctors' intention or advice which in turn make family members report the doctor for breaching of their duty. Doctors are reluctant to tell their patients that treatment is meaningless, but they try to be careful in their conversations so as not to give them false hope.

The level of knowledge of dementia that family members possessed was very diverse, but they were confident in their knowledge due to their experience of long-term caregiving. However, they still expressed anger about the behaviours of other family members. In addition, some of them had false hope that the condition of their relatives with advanced dementia might improve, which confirmed their lack of knowledge.

The healthcare professionals, including the nurses and doctors, agreed that it was difficult to provide care for patients with advanced dementia, but lacked an understanding and knowledge of dementia and pointed out the ignorance of other healthcare professionals. Although the nurses received behaviour management education for people with early or mid-stages of dementia, they had not at any stage received information on decision-making or education for quality of life for patients with advanced dementia. They also expressed a desire to receive such education.

According to the doctor participants, they were not familiar with dementia, but there was no mention of wanting to receive such education. They were primarily aiming to treat the disease of dementia. As their range of knowledge varied, one of the doctors who specialised in dementia pointed out that almost all current healthcare professionals lacked knowledge of dementia, and argued that dementia could actually lead to death due to the underlying symptoms. Most doctors concluded that there needed to be more subsidies from the government for further study into the provision of care for people with dementia.

Limitations of the study

Some of the participants found it difficult to tell their stories. The family members of dementia patients may not have been accustomed to providing a space for lengthy conversations, and it certainly seems to be the case in dementia research study. Narrating the experiences of parental dementia raises taboo subjects and the use of frank language that challenged dominant discourses on dementia and the families in South Korea.

Also, it was found to be impossible to use the exact statements that the participants made to the researcher due to language differences. The statements had to be translated, and on occasion, it was difficult to find precise English equivalents for the words or idioms used by the participants.

Implications for practice and education

The findings can be used to provide comprehensive information about the decision-making process for people with advanced dementia to stakeholders in dementia care in South Korea. Hence, the following suggestions are presented in relation to family members of people with advanced dementia, healthcare professionals including doctors and nurses, education providers, and policy-makers.

Family members of people with advanced dementia

The findings of the present study confirmed that family members play an essential role in caring for people with dementia in South Korea. However, their lack of understanding of the disease is a significant concern. Having appropriate knowledge to make decisions for persons with dementia is important. As some people with dementia live in a non-hospital environment such as their own home, family members who take a caregiver role should be able to make decisions based on medical evidence. In addition, they should have stress management strategies in place to maintain their own quality of life. Caring for a person with dementia is not only the family’s responsibility, but should also be part of the role of government. Therefore, family members need to seek out relevant government support.

Healthcare professionals

Healthcare professionals, including doctors and nurses, should be able to support their patients with dementia and their families by providing appropriate information and knowledge about end-of-life care and acute treatment for dementia patients. Providing appropriate protocols and procedures can assist in preventing the deterioration of the patient's quality of life, and to allay false hopes or guidance from family members that may result from erroneous procedures. Care strategies through appropriate care plans also need to be provided for each patient to ensure that patients with dementia prepare for their end-of-life and receive adequate care.

Education providers

The findings of the present study may assist education providers to improve the quality of education for family members, nurses, and doctors. Firstly, education for family members related to end-of-life care for people with advanced dementia is strongly recommended. As this study revealed family members' understandings of the life expectancy and quality of life of the person with advanced dementia, education sessions should include these components to avoid creating unrealistic expectations.

Secondly, ethics education for doctors is required. In South Korea, doctors' opinions and suggestions affect not only patients and their families, but also the decision-making of other healthcare professionals, so it is important to give them the space to consider the ethical issues involved. Thirdly, nurses should be taught appropriate communication skills in addition to ethics, because they are healthcare professionals and can potentially affect the decision-making of the patient's family. In addition, studies have shown that they do not express opinions that go against their superiors, especially doctors who run the facility (see p. 63), so nurses need to be provided with effective communication and ethics education.

Policy-makers

The government department of health needs to be concerned not only with the quality of life of people with dementia, but also with their end-of-life care as the number of people who die with, or from, dementia is increasing. Interest in end-of-life care is insignificant in South Korea. The government should consider ways to maintain the patients’ dignity, and to ensure that people with dementia benefit from proper treatment until the end of their life. In addition, the system needs to be supported by laws for advanced care planning and family decision-making rights.

Implications for future research

The aim of the present study has been to explore the ethical dilemmas faced by family members, nurses, and doctors when they make decisions for people with advanced dementia. The findings suggest the value of conducting further research. Firstly, as the roles of healthcare professionals, including nurses and doctors, may vary depending on their specialties or the institutions they work for, it is suggested that an investigation into the experiences of healthcare professionals from different sectors should be undertaken.

Secondly, most healthcare professionals who involved in the present study work in for-profit organisations, therefore, it is difficult to generalise the findings to not-for-profit organisations. Exploring the experiences of healthcare professionals in not-for-profit institutions may be helpful to compare the thoughts and experiences of healthcare professionals in various healthcare setting.

In summary, this is the first study to explore the ethical dilemmas of family members, nurses, and doctors when they make decisions for people with advanced dementia in South Korea. The findings have not only provided insight into their challenges, but have also revealed the underlying issues across the continuum of dementia care in South Korea.

Participants in each group experienced ethical dilemmas, but the reasons and situations each of them faced were different. Family members experienced conflict between the burden of caregiving activities and their role in the family, and when these conflicts came to the conclusion that it would be better if the family member with advanced dementia would die, they experienced an ethical dilemma. The doctors experienced an ethical dilemma between their duty of care and the patients' quality of life, while nurses faced an ethical dilemma of feeling as if they had to remain silent. A lack of knowledge and poor opportunities for ethics education for stakeholders may have contributed to such dilemmas.

Greater effort needs to be made by education providers and South Korean policy-makers. Providing education programs and care strategies, regular, clear, follow-up appraisal programs, and government financial support for families and care providers are strongly suggested. Family members of people with advanced dementia, education institutions, healthcare professionals, and the government, therefore, should work together to provide best care for people with advanced dementia when they are in the end stage of their life. Children need to take care of their parent who took care of them, and healthcare professionals should take care of their patients the way their healthcare professionals have taken care of them. Caring does not mean physical help or financial support, but is a sense of responsibility and the fulfilment of their role as a stakeholder. In conclusion, further research, education, and practice will be required as health care professionals and family members of people with dementia face a range of ethical dilemmas on a frequent basis.

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List of Appendices

Appendix 1 Overview of reviewed studies and their characteristics

Author (year)	Title	Design & Method	Type of participants	Numbers of participants	Major Findings	Significance to the issue
Anquinet et al (2013)	Similarities and differences between continuous sedation until death and euthanasia - professional caregivers' attitudes and experiences: a focus group study	Focus group study - constant comparison analyses Level of the hierarchy: 4	General practitioners (GPs)	11	◦9 of 64 people with advanced dementia were sedated. 2 of the 11 sedated people were not considered to be palliative. ◦2 patients received ANH during sedation→ Continuous deep sedation (CDS) until the death of nursing home residents did not always guarantee a symptom-free death process.	Pain may be accompanied in the dying process of people with dementia.
Chambaere et al (2014)	Forgoing artificial nutrition or hydration at the end-of-life: a large cross-sectional survey in Belgium	Cross-sectional: Postal survey Level of the hierarchy: 4	Physicians	6927	◦Forgoing ANH decision occurred in 6.6% of all deaths in the research setting (4.2% withheld, 3.0% withdrawn). ◦Forgoing ANH decision showed some life-shortening effects in 77% of cases.	◦In most case, forgoing ANH decision occurred without consultation with patients (81%). ◦Relatives of patients, doctors' colleagues and nurses were participated in decision making in 76%, 41% and 62%, respectively.
Valentini et al (2014)	Artificial nutrition and hydration in terminally ill patients with advanced dementia: opinions and correlates among Italian physicians and nurses	Cross-sectional: Survey Level of the hierarchy: 4	Physicians, Nurses	Physicians (288), Nurses (763)	◦Consent to the provision of artificial hydration higher (73%) than for artificial nutrition (48%). ◦Consent to AHN administration lower among doctors and nurses working in geriatric words in northern Italy who had received education in palliative care.	◦Feelings and thoughts about death and ethical issues play a different part for doctors and nurses. ◦The rate of artificial nutrition provision in wards where doctors who have received training in end-of-life care work is low.

Author (year)	Title	Design & Method	Type of participants	Numbers of participants	Major Findings	Significance to the issue
Smith et al (2016)	Perceptions of Home Health Nurses Regarding Suffering, Artificial Nutrition, and Hydration in Late-Stage Dementia	Semi-structured interview Level of the hierarchy: 4	Registered nurses	27	The perception of nurses influences their care to people with dementia and their families related to ANH.	◦Some nurses believe ANH provides comfort to patients with advanced dementia at their end-of-life and their family. ◦Some other nurses think ANH increase possibility of fluid overload, needs for restraints, and patients' suffering because of the invasive procedures. ◦Many nurses feel ANH gives a sense of false hope to the families that the patients would live longer.
van der Steen et al (2018)	Pneumonia in Nursing Home Patients With Advanced Dementia: Decisions, Intravenous Rehydration Therapy, and Discomfort	Observatory –Prospective Study Level of the hierarchy: 4	People with advanced dementia who diagnosed with pneumonia	109	◦Most participants agreed to antibiotic therapy (90%; 98 of 109) and intravenous rehydration therapy (53%; 58 of 109), but hospitalisation was rare (1%). ◦Decisions with antibiotics, with rehydration therapy, the prognosis was more frequently selected <15 days (34% vs 5% without rehydration therapy; P = .001).	People with advanced dementia and pneumonia in the nursing home were often received invasive rehydration therapy as well as antibiotics, but most of them were for palliative purposes → Overall, discomfort was high.
Karger (2018)	Emotional experience in patients with advanced Alzheimer's disease from the perspective of families, professional caregivers, physicians, and scientists	Semi-structured interviews during focus groups Level of the hierarchy: 4	Relatives, Certified geriatric caregivers, Physicians, Scientists	Relatives (20), Caregivers (17), Physicians (12), Scientists (14)	◦Family members of advanced dementia experiences psychological burden because of the patients' current conditions, as they remember the characteristics of the patients before developing dementia. ◦Training programmes may require helping family members to understand and respond to nonverbal emotional expressions of people with advanced dementia.	Family members or family caregivers of people with advanced dementia understand the emotional state of people with advanced dementia patient better than healthcare professionals. Therefore, they can predict the patients' wish to some extent.

Author (year)	Title	Design & Method	Type of participants	Numbers of participants	Major Findings	Significance to the issue
Midtbust et al (2018)	A painful experience of limited understanding: healthcare professionals' experiences with palliative care of people with severe dementia in Norwegian nursing homes	In-depth interviews Level of the hierarchy: 4	Healthcare professionals from four Norwegian nursing homes	20	◦Healthcare professionals often uncomfortable with the situations when they disagreed with family members of people with advanced dementia in the best interests of their patients.	◦Knowledge of how to "read" and observe people with advanced dementia are required to understand them better. ◦Having openness in cooperation with the family members and healthcare professional teams can improve the quality of care (QOC).
Loizeau et al (2019)	Fact Box decision support tools reduce decisional conflict about antibiotics for pneumonia and artificial hydration in advanced dementia: a randomized controlled trail	Randomised controlled trial Level of the hierarchy: 1	Physicians, Relatives of dementia patients, Professional guardians	Physicians (64), Relatives (100), Professional guardians (68)	Doctors, family members of dementia patients, professional guardians prefer to withdraw antibiotics, but not artificial hydration. The intervention tools reduced decision-making conflict, increased knowledge, and promoted the preference for withdrawing antibiotics in advanced dementia among a variety of decision-makers.	Information help with proxy decision makers with reducing conflict and increasing knowledge.
Konttila et al (2020)	Progress in advance care planning among nursing home residents dying with advanced dementia—Does it make any difference in end-of-life care?	Retrospective study Level of the hierarchy: 4	Nursing home residents who died between 2004–2009 and 2010–2013	403	Between 2010 and 2013, there were twice as many cases of withdrawing antibiotics or parenteral antibiotics, withdrawing artificial nutrition or hydration, and withdrawing hospitalisation than between 2004 and 2009 (PTOs were applied earlier in 2010-2013 than in 2004-2009).	◦Organising ACP is important. However, ACP alone is not enough. ◦More support is requested in decision-making to prevent overly aggressive treatment at the end-of-life.

Author (year)	Title	Design & Method	Type of participants	Numbers of participants	Major Findings	Significance to the issue
Bravo et al (2021)	Attitudes toward withholding antibiotics from people with dementia lacking decisional capacity: findings from a survey of Canadian stakeholders	Cross-sectional Survey Level of the hierarchy: 4	Family caregivers, Nurses, Physicians	1050	CDS and medical assistance in dying (MAID) was related to attitudes toward antibiotics.	Healthcare professionals need to discuss underlying values and treatment goals with people with dementia when they are in the early stages of the disease, which help them predict future treatment decisions and better prepare the care.
Anantapong et al (2022)	Communication between the multidisciplinary team and families regarding nutrition and hydration for people with severe dementia in acute hospitals: a qualitative study	Qualitative semi-structured interview study Level of the hierarchy: 4	Family carers and hospital staff	29	◦Family members usually wait for healthcare professionals to initiate discussions however experience frustration with delays and repeating the same conversations. ◦Some hospital staff are unprepared to manage conversations regarding care for people with advanced dementia.	Healthcare professionals may lack the time and/or ability to communicate with relatives of patients with dementia → This can make it difficult to provide appropriate end-of-life care to patients with advanced dementia.

Appendix 2 Evaluation of quantitative studies (Cohort Study Checklist)

Author and Date	Q1 - Clearly focused question	Q2 – Recruited in acceptable way	Q3 – Exposure accurately measured	Q4 – Outcome accurately measured	Q5 – Identified all confounding factors	Q6 – Follow up of subjects completed	Q7 – Follow up of subjects long	Q8 – What results	Q9 – How precise results	Q10 – Results applicable to local	Q11 – Results fit to other evidence	Q12 – Implication for practice
Chambaere et al (2014)	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y	Y
Valentini et al (2014)	Y	N	Y	N	N	Y	Y	Y	Y	Y	Y	Y
van der Steen et al (2018)	Y	Y	Y	N	N	Y	Y	Y	N	Y	Y	Y
Loizeau et al (2019)	Y	Y	Y	N	N	Y	Y	Y	N	Y	Y	Y
Konttila et al (2020)	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y

Source: Critical Appraisal Skills Programme (CASP) Cohort Study Checklist (2023a)

Appendix 3 Evaluation of qualitative studies (Randomised Controlled Trial Checklist)

Author and Date	Q1 - Clearly focused question	Q2 – Intervention ranomised?	Q3 - Participants accounted conclusion?	Q4 – Blinded for intervention, assessing/analysing	Q5 – Study group similar	Q6 – Groups receive same care	Q7 – Effects of Intervention	Q8 - Precision of the estimate	Q9 – Benefits outweigh harms and costs	Q10 – Applicable to context	Q11 – Intervention value
Bravo et al (2021)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

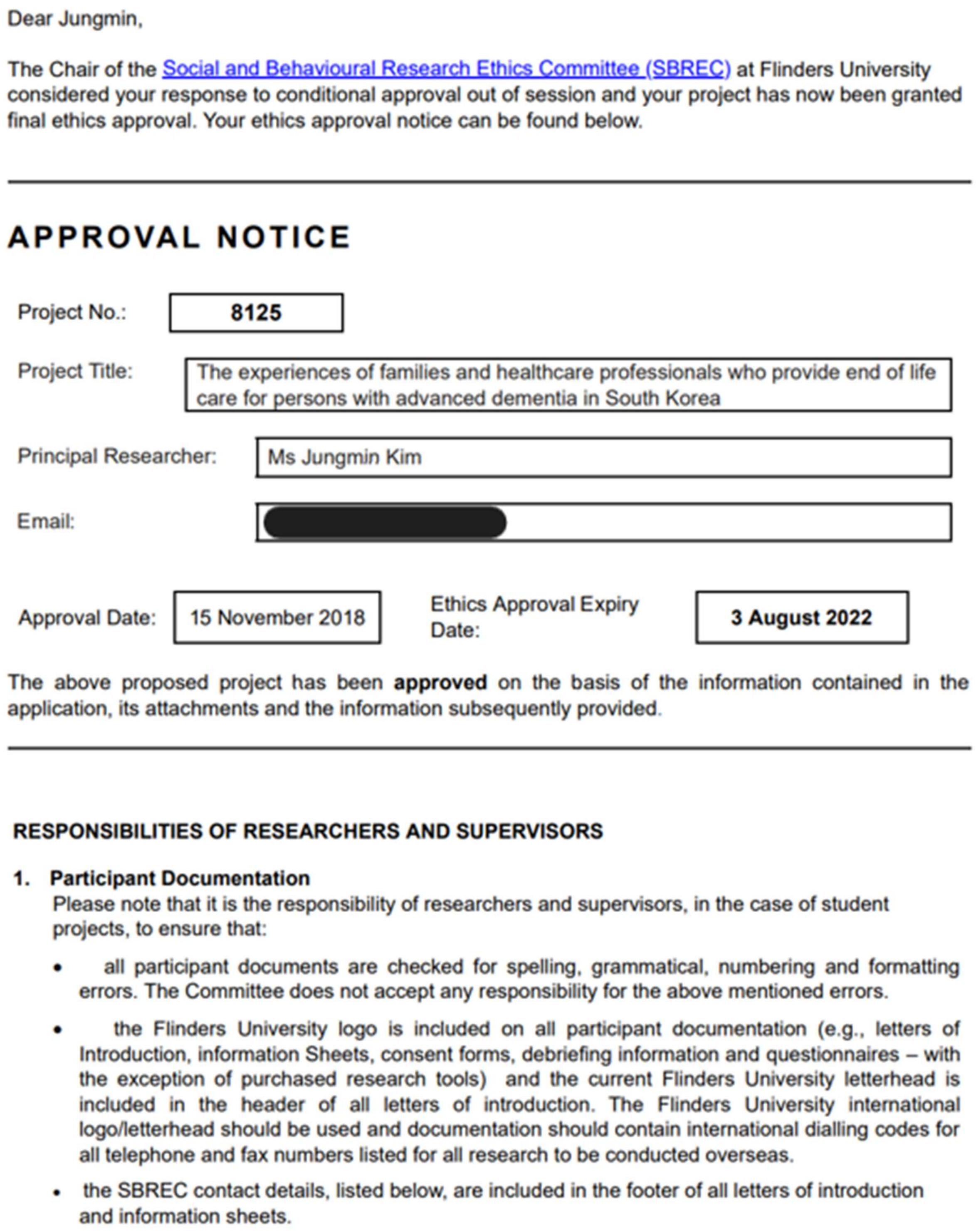
Source: Critical Appraisal Skills Programme (CASP) Randomised Controlled Trial Checklist (2023b)

Appendix 4 Evaluation of qualitative studies (Qualitative Studies Checklist)

Author and Date	Q1 - Clear research aims	Q2 - Qualitative approach appropriate	Q3 - Research design appropriate	Q4 - Recruitment strategy appropriate	Q5 - Data Collection methods appropriate	Q6 - Researcher bias recognised	Q7 - Ethical issues considered	Q8 - Data analysis rigourous	Q9 - Findings clearly stated	Q10 - Research is valuable
Anquinet et al (2013)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Smith et al (2016)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Karger (2018)	Y	Y	Y	Y	Y	N	N	N	Y	Y
Midtbust et al (2018)	Y	Y	Y	Y	Y	Y	N	N	Y	Y
Anantapong et al (2022)	Y	Y	Y	Y	Y	Y	N	N	Y	Y

Source: Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist (2023c)

Appendix 5 Ethical approval letter



Dear Jungmin,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. Your ethics approval notice can be found below.

APPROVAL NOTICE

Project No.: **8125**

Project Title: The experiences of families and healthcare professionals who provide end of life care for persons with advanced dementia in South Korea

Principal Researcher: Ms Jungmin Kim

Email: [redacted]

Approval Date: 15 November 2018

Ethics Approval Expiry Date: **3 August 2022**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

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 ethical 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 (2007-Updated 2018)* an annual progress report must be submitted each year on the **15 November** (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 **15 November 2019** 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:

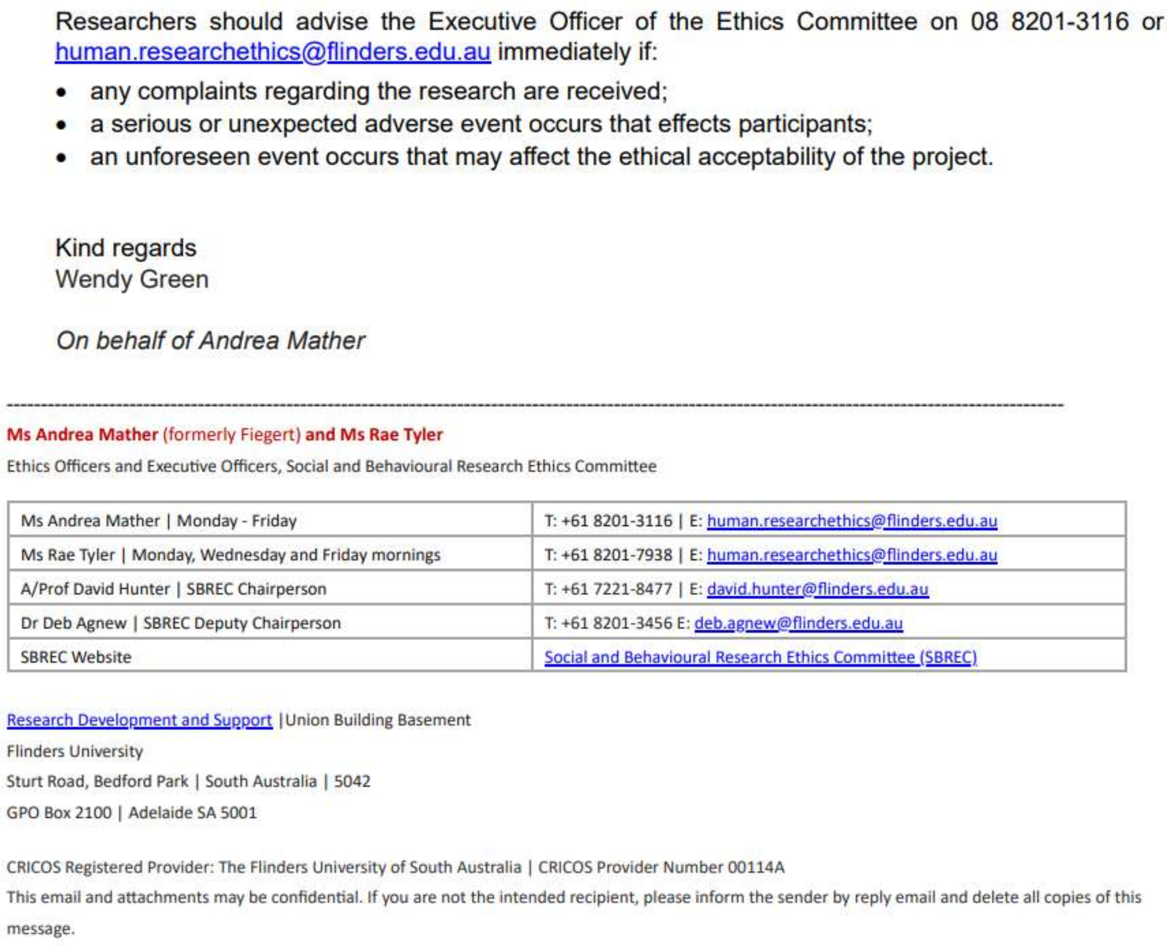
- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of 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 complete and submit the *Modification Request Form* which is 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 unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Wendy Green

On behalf of Andrea Mather

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

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Appendix 6 Consent form

Flinders
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CONSENT FORM

I ....

being over the age of 18 years hereby consent to participate as requested in the ………………………………… for the research project on '*Ethical Perspectives of End-of-Life Dementia Care in South Korea'*

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature……………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………….……………………………..................

Researcher's signature…………………………………..Date……………………

Appendix 7 Guide for the conversational interview (Derived from van Manen 1990, 2014)

Preparing for a conversation

In addition to the re-orienting strategies described in the methods section of this study, what facility the healthcare professional works for have been searched. In fact, phenomenological protocol requires that bracket any judgments, hypothesis or conclusions. Therefore, the activity focused on familiarising some terms or name of surgeries the potential participants may use. However, nil preparation required to interview family members of people with dementia.

Interview questions for family members of people with advanced dementia

Some demographic data was collected about the participants and people with advanced dementia as background information. Below questions are for family members.

Demographic data for family members of persons with advanced dementia	
Gender	Male / Female
Age	
Occupation	Yes / No If yes, what is your occupation? If yes, How many hours are you working per week?
Are you currently looking after or have you ever looked after a person with dementia?	Current / Past
Are you the Next of Kin of the person with dementia?	Yes / No If no, who is the Next of Kin?
Describe your relationship to the person with dementia. ***If son/daughter (Are you the first-born)?**	Yes / No
How long have you looked after your family member with dementia?	_____years / months

Demographic data for people with dementia	
Gender	Male / Female
Age	
Previous occupation of the people with dementia	
Number of years the person with dementia	_____years / months
Does the person have any other diseases?	Yes / No If yes, what other illness(s) the person have?
Does the person with dementia takes medication(s)?	Yes / No If yes, what medication(s)?
Does the person with dementia receive artificial nutrition or hydration?	Yes / No If yes, what types?

The following questions will be used to prompt discussion with participants. The questions could be asked in different order upon the participants' responses.

Research objectives	**Questions for family members**	**Prompting questions**
What are the experiences, decision making challenges and ethical dilemmas of family members of people with advanced dementia?	• What do you know about dementia? • Can you tell me your thoughts about end-of-life care? • What types of decisions do you need to make for your relative with dementia? • Have you experienced uncomfortable feeling with making decisions? • What do you think about giving artificial nutrition or hydration for persons with dementia? • What do you think about connecting ventilation for persons with dementia? • What do you think about providing chemotherapy for persons with dementia?	Anything else would you like talk to me? Could you give me some examples?

Interview questions for healthcare professionals

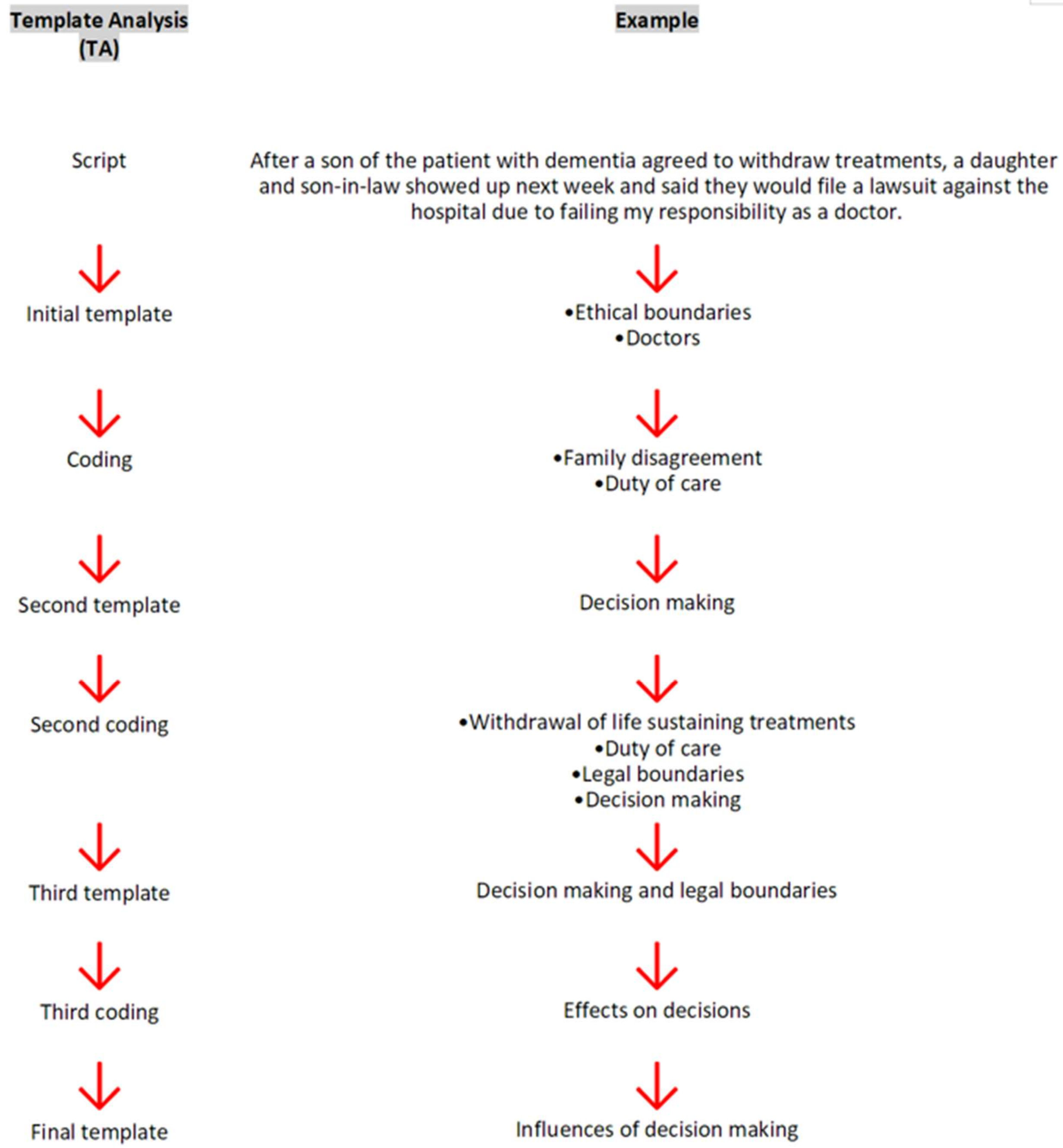
Demographic data from healthcare professional was also collected as background information. Below questions are for healthcare professionals.

Demographic data for healthcare professionals	
Gender	Male / Female
Age	
Education level	
Occupation	
How long have you been doing this job?	_____years / months
Have you ever made any decision for your patients with dementia?	Yes / No If yes, what was it?
Describe your relationship to the patient you made decisions (if applicable).	

The following questions will be used to prompt discussion with participants. The questions could be asked in different order upon the participants' responses.

Research objectives	Questions for healthcare professionals	Prompting questions
What are the experiences, decision making and ethical dilemmas of healthcare professions who are involved in advanced dementia care in hospitals, residential aged care and the community?	• Can you tell me what you know about dementia? • Can you tell me what you know about end-of-life care or palliative care? • Can you tell me your thoughts about good death? • What are you experiences of decision making for your patients with dementia at the end of their life? • Can you describe any conflicts you or others may have had in regard to decision making for patients with dementia? • What do you think about giving artificial nutrition and/or hydration to people with advanced dementia? • What do you think about providing other life sustaining treatment for people with advanced dementia such as antibiotic treatment or blood transfusion? (ventilation or chemotherapy etc) • What do you think about giving pain relief medications to people with advanced dementia?	Anything else would you like talk to me? Could you give me some examples?

Appendix 8 Example of data analysis



Template Analysis (TA)	Example
Script	After a son of the patient with dementia agreed to withdraw treatments, a daughter and son-in-law showed up next week and said they would file a lawsuit against the hospital due to failing my responsibility as a doctor.
Initial template	•Ethical boundaries •Doctors
Coding	•Family disagreement •Duty of care
Second template	Decision making
Second coding	•Withdrawal of life sustaining treatments •Duty of care •Legal boundaries •Decision making
Third template	Decision making and legal boundaries
Third coding	Effects on decisions
Final template	Influences of decision making