Exploring family death preparation in Taiwan: Perspectives from family members and healthcare professionals

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Abstract

Background: Preparing families for a relative's death is fundamental in palliative care, as it can improve both the dying process and bereavement outcomes. However, current guidelines remain vague and offer limited practical direction. Research has predominantly focused on Western contexts, restricting its cultural relevance. Evidence from non-Western societies is needed to inform culturally sensitive and appropriate care.

Aim: To explore Taiwanese families' experiences of preparing for a relative's death and to examine how they can be better prepared during this process.

Methods: A qualitative approach underpinned by critical realism was employed, comprising three complementary studies. A systematic review with narrative synthesis examined Taiwanese families' bereavement experiences following an expected death, offering insights into family death preparation. These findings informed a qualitative interview study, analysed with reflexive thematic analysis, which explored how family caregivers prepared for a relative's death within specialist palliative care. Building on this, a nominal group technique study with specialist palliative care professionals was undertaken to develop and prioritise recommendations for supporting families in this process.

Findings: The systematic review of 17 studies identified family death preparation as a key element of end-of-life care that shapes bereavement experiences. The interview study with 22 family caregivers showed that preparation was needed during and after death. The overarching theme of "getting everything right to have no regrets between the dead and the living" was seen as crucial to ease bereavement. Four themes were developed: (1) 'making the right end-of-life decisions is crucial but complex', exploring how family-centred and protective approaches were applied, with an emphasis on maintaining family harmony through consensus-building; (2) 'becoming a competent caregiver is the priority', addressing preparations for fulfilling responsibilities and ensuring the dying relative's comfort to reduce future regret about not having done enough; (3) 'having a good ending but not the end of the relationship', addressing preparations for appropriate conduct at the moment of death, meaningful funerals, enhancing the deceased's afterlife, and maintaining continuing relationships; and (4) 'using religious beliefs and cultural norms to guide preparation', examining how these values shaped understandings of a good death and encouraged emotional restraint before and after death as culturally and religiously appropriate. Finally, the nominal group technique study with 10 specialist palliative care professionals generated 42 recommendations that were refined into four finalised recommendations. It also highlights the need for a multidimensional approach to strengthening family death preparation across individual, systemic, societal, and national levels. Based on the methodological reflections upon the experience of conducting the nominal group study in Taiwan, methodological guidance was developed for applying this technique in future research.

Conclusion: A Taiwan-specific conceptual model integrating clinical, relational, cultural-religious, and socio-structural dimensions of family death preparation was developed. The findings extend the continuing bonds theory by demonstrating bereavement as a continuation of family death preparation, positioning appropriate preparation as proactive care that can prevent poor bereavement outcomes. The study reframes palliative and end-of-life care by emphasising family involvement, the enduring role of religious beliefs, and culturally specific understandings of a good death. The Taiwanese experience underscores the need to decolonise palliative care and bereavement by incorporating religious beliefs and cultural norms into care models.

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Glossary

Advance care planning – a process that enables individuals to discuss their values, goals, and preferences for future medical treatment and care with family members and healthcare professionals in case they lose decision-making capacity in the future. In Taiwan, advance care planning is strongly shaped by the Patient Right to Autonomy Act, which requires the formal involvement of at least one family member.

Ancestor worship – a practice rooted in Confucian values and common across East Asia. It involves placing ancestral tablets on household altars or in communal ancestral halls and serves as an expression of filial devotion beyond death, as well as the continuation of family bonds and care for deceased parents and elder relatives.

Bereavement – the state of having experienced the death of someone significant and the process of adapting to that loss. In this thesis, bereavement refers to the death of an adult relative; bereavement following the death of a child under 20 years of age is beyond the scope of the study.

Conceptual model – a representation of key concepts relevant to a topic and the relationships between them in explaining a phenomenon. It is often presented as a structured explanation or diagram to illustrate the current state of knowledge on a specific topic, identify gaps in understanding, guide methodological approaches to address these gaps, and demonstrate how research findings contribute to existing knowledge.

Cultural humility – a lifelong process of critical self-reflection, recognition of power imbalances, and openness to learning from diverse individuals and communities in order to provide respectful and culturally responsive care.

Decolonisation – a call to challenge the dominance of influential Western palliative care and bereavement models and to emphasise the need to decentre Western-centred assumptions. Decolonising involves engaging with diverse cultural perspectives and recognising local traditions, values, and beliefs as central to shaping culturally sensitive palliative care and bereavement support.

Epistemology – concerns what knowledge is possible and how researchers can obtain it. It examines what can be known, how it can be known, and the relationship between the researcher and the researched, which is informed by ontology.

Family death preparation – a process involving the achievement of cognitive, emotional, and behavioural readiness. For families to feel prepared, they require support with medical, psychosocial, spiritual, and practical tasks.

Filial piety – the expectation, rooted in Confucian values, that children honour, obey, and care for their parents.

Grief – the physical, cognitive, emotional, and behavioural responses to loss. In this thesis, the term refers specifically to grief following the death of a relative.

Medicalisation of dying – the increasing management of death and dying within the medical system, in which death is framed as a clinical event and medical responsibility rather than primarily a social, familial, or spiritual process. This phenomenon is also evident in Taiwan, although family involvement and religious practices continue to play important roles in end-of-life care.

Mourning – the external expression of grief, manifested through social behaviours and rituals shaped by cultural values and social norms.

Ontology – concerns assumptions about the nature of reality and shapes decisions made throughout the research process, including views about knowledge and the ways in which data are collected and analysed.

Positionality – the researcher's social, cultural, and professional positioning, and the ways in which this may shape interactions with participants, as well as data collection and interpretation.

Reflexivity – an ongoing process of critically reflecting on how the researcher's subjectivity and positionality influence the research process and the knowledge produced.

Theory – a set of related concepts and propositions used to explain and understand the meaning, nature, and relationships associated with a phenomenon. In this thesis, theory is used primarily as an interpretive lens for understanding research findings, rather than as a framework guiding study design or data analysis.

Appendices

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Author’s Declaration

I declare that this thesis is my own original work and has not been submitted for the award of any other degree or qualification elsewhere. I also confirm that the conception and design of this work, data collection, analysis, and thesis writing were undertaken by me. This work was carried out under the supervision of Professor Nancy Preston and Dr Qian Xiong within the Division of Health Research, Faculty of Health and Medicine, Lancaster University.

Parts of this thesis have been disseminated through peer-reviewed journals, conference presentations, and the Blog of the European Association for Palliative Care (EAPC Blog). I declare that I am the main author of these works, with substantial contributions to their conceptualisation, manuscript preparation, and overall documentation. The details are listed below:

(a) Peer-reviewed journal articles

- Liang, H.-J., Xiong, Q., Remawi, B. N., & Preston, N. (2024). Taiwanese family members’ bereavement experience following an expected death: a systematic review and narrative synthesis. *BMC Palliative Care, 23*(1), 14.
- Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2024). ‘A good ending but not the end’: Exploring family preparations surrounding a relative’s death and the Afterlife–A qualitative study. *Palliative Medicine, 38*(10), 1184-1193.
- Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2025). ‘Regrets become a lasting source of pain’: A qualitative study on family caregivers’ experiences leading up to a relative’s death. *Palliative Medicine, 39*(3), 401-412.
- Liang, H.-J., Xiong, Q. & Preston, N. (2025). Methodological reflections to support good practice in using nominal group techniques: Insights from applications in palliative care studies. *Palliative Medicin*e. First published online 28 September 2025.

(b) Conference presentations

- Poster presentation: *Preparing family caregivers for the death of a loved one: a mixed-methods study*. Faculty of Health and Medicine Postgraduate Symposium, Lancaster University, 29 March 2022.

- Oral presentation: *Preparing family caregivers for the death of a relative: A qualitative research*. Faculty of Health and Medicine Postgraduate Symposium, Lancaster University, 29 March 2023.
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- Oral presentation: *Preparing family caregivers for the death of a relative: A qualitative research*. International Observatory on End of Life Care Online Symposium, Lancaster University, 10 January 2024.
- Oral presentation: *Family caregivers' experience of preparing for the death of a relative: A reflexive thematic analysi*s. The 13th World Research Congress of the European Association for Palliative Care, Barcelona, Spain, 16-18 May 2024.
- Poster presentation: *How can Healthcare Professionals prepare patients and families for death? A nominal group study*. The 13th World Research Congress of the European Association for Palliative Care, Barcelona, Spain, 16-18 May 2024.
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- Abstract submitted: *Decolonising global palliative care and bereavement: Rethinking Western frameworks through theoretical insights from a Taiwanese stud*y. The 20th World Congress of the European Association for Palliative Care.

(c) The Blog of the European Association for Palliative Care (EAPC Blog)

- *Cultural matters: A good death is one of life's five blessings*. Posted on 24 September 2024.
- *'There will be no chance to do it again': how to prepare for a relative's death*. Posted on 15 April 2025.

Ethical approval for the empirical studies presented in this thesis was obtained from the National Cheng Kung University Hospital Institutional Review Board (Taiwan) (Ref: A-ER-111-193) and Lancaster University Faculty of Health and Medicine Research Ethics Committee (Ref: FHM-2022-0972-ExRev-1) (see **Appendix 4**).

CHAPTER 1: INTRODUCTION

The focus of this thesis is on how families in Taiwan can be better prepared for the death of a relative. Supporting families through this process is recognised as a critical component of high-quality palliative and end-of-life care. Previous research has shown that such preparation enhances the quality of care during the dying process (Hovland-Scafe & Kramer, 2017) and positively influences bereavement outcomes for family members (Virdun et al., 2017). Understandings of death and dying are shaped by cultural, religious, and social contexts. However, palliative and end-of-life care services in many countries are structured around frameworks that reflect Western values and assumptions (Ntizimira et al., 2024). These frameworks may have limited relevance or effectiveness in societies where beliefs and practices surrounding death differ significantly from those in Western societies. In response to this gap, scholars have called for culturally sensitive evidence to inform care practices that are more responsive to the needs of diverse populations (Ntizimira et al., 2024).

The overarching aim of this thesis is to examine how families in Taiwan can better prepare for the death of a relative. Families' experiences of death preparation are explored through retrospective perspectives, and recommendations are developed to guide healthcare professionals in assisting families during this process, with the goal of improving practice. While the central focus is placed on family death preparation, broader themes of death, dying, and bereavement are also addressed to provide a comprehensive understanding of how these experiences unfold within a specific cultural context.

A personal reflection on the motivations for undertaking the research is included in this chapter, together with an introduction to key concepts of the thesis and an overview of its structure.

1.1 Personal statement

As a Taiwanese specialist palliative care nurse, I have long been interested in how to provide culturally appropriate guidance and support to families preparing for a relative's death. Since 2008, I have worked in specialist palliative care settings in Taiwan, where services are largely modelled on Western frameworks. My professional training and education have also been primarily shaped by Western-oriented evidence. However, Taiwanese cultural values often differ from Western approaches, particularly in relation to the role of the family and understandings of autonomy.

Reflecting on my own upbringing in a large rural Taiwanese family, I have come to regard death as a collective family event shaped by complex interpersonal relationships and familial obligations. In contrast, Western healthcare models often emphasise individual autonomy and personal decision-making. Merging these models can lead to tensions between healthcare professionals and families during the process of preparing for death, especially when the needs of family members are not fully aligned with the principles guiding clinical care.

My personal experiences with the deaths of close family members have deepened my understanding of how important preparation is for those who are alive. The words of Cicely Saunders, a pioneer of modern palliative care, "*How people die remains in the memory of those who live on*", resonate deeply with me. Nearly twenty years ago, my grandmother received hospice home care and died peacefully at home. The palliative care nurse alerted us that her death was near, which allowed our family to gather and be present during her final moments. This opportunity to prepare was profoundly meaningful and helped support our grief. More recently, while writing this thesis, my mother was admitted to the intensive care unit following an unexpected motorcycle accident. She died eight days later. Although her death was sudden, the time we had to prepare was deeply valuable. Without those eight days, my bereavement would have been even more difficult. In this experience, I found myself sharing the emotions and challenges described by many of the families I interviewed. Further reflection on this personal connection is provided in the discussion chapter.

These clinical and personal experiences have inspired my commitment to understanding how families in Taiwan navigate the process of preparing for a relative's death and how cultural values shape their actions and decisions. This research aims to generate culturally grounded evidence to inform care practices that are responsive to the needs of families facing similar experiences within comparable cultural contexts.

1.2 Why should research on family death preparation in the context of non-Western societies be conducted?

While an in-depth review of the existing literature on family death preparation is presented in the background chapter, this section outlines the rationale for investigating this topic specifically in non-Western societies.

Supporting family members in preparing for a relative's death is a core element of palliative and end-of-life care (Hudson et al., 2012; Keegan et al., 2021). Palliative care aims not only to alleviate the suffering of patients by addressing physical, psychological, social, and spiritual needs but also to support their families during this challenging time (Radbruch et al., 2020). Assisting families in preparing for death can help ease emotional distress, enhance acceptance of the impending loss (Hovland-Scafe & Kramer, 2017), and facilitate the bereavement process by reducing the risk of complicated grief (Kim et al., 2017). However, the evidence base informing these practices has been largely developed in Western contexts, including the United States (Hebert et al., 2009; Hovland-Scafe & Kramer, 2017; Supiano et al., 2020), Canada (Durepos, Ploeg, Sussman, et al., 2020), and Australia (Breen et al., 2018). Cultural beliefs play a significant role in shaping how death is understood, experienced, and managed (Gire, 2014), raising concerns about the applicability of Western frameworks in culturally distinct societies. Such cultural differences may hinder the delivery of care that is sensitive to the values and expectations of families in non-Western societies, such as those in East Asia.

Although studies from East Asia, such as Japan (Matsuzaka et al., 2024) and Taiwan (Tang, Hsieh, et al., 2021; Wen et al., 2022a, 2022b), have begun to address family death preparation, most rely on quantitative methods. These studies often focus on measuring levels of preparedness for death (Matsuzaka et al., 2024) or on examining relationships between preparation and factors such as caregiving burden (Wen et al., 2022b). While these findings are informative, quantitative approaches may not fully capture why families have these experiences or how their beliefs and actions shape the process of preparing for a relative's death.

I focus specifically on family caregivers, who face complex challenges as death approaches. Their responsibilities often intensify, requiring coordinating with healthcare professionals, participating in end-of-life discussions, and providing direct care (Reigada et al., 2015). Although the nature of these tasks varies according to the patient's condition, they typically involve a combination of physical caregiving, emotional labour, and anticipatory decision making. As discussed in the background chapter, the distinct role of family caregivers makes their perspectives essential to understanding the process of death preparation.

Given these considerations, culturally contextualised research is required to deepen understanding of how family caregivers in non-Western societies experience and manage the preparation for a relative's death. This study addresses this gap by examining family death preparation within a Taiwanese cultural context. In doing so, it contributes culturally grounded knowledge that may inform the development of more responsive palliative and end-of-life care in non-Western societies. A detailed discussion of the study's contribution to knowledge is provided in the discussion chapter.

1.3 Key concepts in this thesis

1.3.1 Family death preparation

A range of terms have been used in the literature to describe how families anticipate and respond to an impending death. Among these, preparedness for death is the most frequently cited (Barry et al., 2002; Breen et al., 2018; Durepos et al., 2019; Hebert et al., 2006; Hovland & Kramer, 2019; Hovland-Scafe & Kramer, 2017). Related terms include preparedness for death and bereavement (Hebert et al., 2009), preparedness for end-of-life (Durepos et al., 2021; Durepos, Ploeg, Sussman, et al., 2020), preparedness for death and caregiving (Alvariza et al., 2020), and preparedness for loss (Caserta et al., 2019).

Although the term death preparedness is widely used, this study adopts the term family death preparation to emphasise the process through which family members prepare for a relative's death, rather than a single state of readiness. This process involves completing a range of medical, psychosocial, spiritual, and practical tasks to achieve multidimensional readiness, encompassing cognitive, emotional, and behavioural aspects (Durepos et al., 2019; Hebert et al., 2009). The conceptualisation of family death preparation is discussed further in the background chapter.

1.3.2 Brief introduction to the research context: Taiwan

Taiwan's demographic changes, palliative care developments, and cultural traditions shape families' end-of-life care experiences, making it a significant context for examining how families prepare for a relative's death. Cancer has been the leading cause of death in Taiwan for more than four decades (Ministry of Health and Welfare of the Republic of China/Taiwan, 2021). Meanwhile, the population is rapidly ageing, with 16.9% of citizens aged 65 or older in 2021 (Ministry of Health and Welfare of the Republic of China/Taiwan, 2022) and an average life expectancy of 80.2 years as of 2023 (Ministry of Health and Welfare of the Republic of China/Taiwan, 2024). These demographic shifts have intensified the demand for end-of-life care and underscored the important role of palliative care in this process. Taiwan has established a well-developed palliative care system that ranked third out of 81 countries in the 2021 Quality of Death and Dying study (Finkelstein et al., 2022), making it a valuable setting for examining family death preparation in non-Western societies.

As an East Asian society with a population of over 23 million, Taiwan is predominantly composed of ethnic Chinese, along with Hakka, Indigenous peoples, and a growing population of new immigrants who have settled and acquired legal residence or citizenship through marriage, naturalisation, or other migration pathways (Kasai, 2022). These new immigrants, distinct from temporary labour migrants, have increasingly contributed to Taiwan's social and cultural diversity.

Linguistic and religious diversity further characterise Taiwanese society. Taiwanese Mandarin (written in Traditional Chinese), Taiwanese Hokkien, and Hakka are widely spoken, reflecting the country's multicultural identity. Religious pluralism, supported by constitutionally protected freedom of religion, is equally prominent. Major traditions include Buddhism, Taoism, Christianity, and Taiwanese folk religion, which synthesises Buddhist, Taoist, and Confucian elements (Weller, 2020). These cultural and religious influences shape beliefs and practices surrounding death, dying, and bereavement, and inform how care and death preparation are understood within families.

The social, cultural, and institutional factors that influence end-of-life experiences in Taiwan, and their relevance to family death preparation, are discussed in greater depth in the background chapter.

1.4 Format and structure of this thesis

This thesis is presented in an alternative format and comprises ten chapters, including four original papers that have been published in peer-reviewed journals. **Table 1** below shows how each paper addresses different aspects of the research objectives and questions. A summary of the structure and content of each chapter is provided below.

The opening chapter outlines the overall rationale and conceptual framing of the thesis. A personal statement describing the motivations for undertaking the research is included, followed by a justification for focusing on family death preparation in a non-Western context, particularly Taiwan. Key concepts underpinning the study are briefly introduced, and an overview of the thesis structure is provided.

Chapter Two focuses on the research background and a review of theoretical frameworks. The development of modern palliative care is summarised, and its relevance and limitations in non-Western societies are critically examined. Existing research on family death preparation is reviewed, highlighting conceptual and empirical gaps, particularly in relation to cultural variability. The role and needs of family caregivers at the end of life are discussed, together with an overview and critique of dominant bereavement theories. The conceptualisation of family death preparation is also outlined. The chapter concludes with an introduction to Taiwan as the research context, focusing on its cultural characteristics, healthcare systems, and palliative care services.

The methodological framework and research design are described in Chapter Three. The overarching research question, overarching aim, and specific objectives are presented, and the qualitative methodological approach is explained and justified. Methods of data collection and analysis are outlined, along with the involvement of patients and the public in the research process.

Chapters Four to Six present three original research papers. The first article (Chapter Four, i.e., Paper 1) reports a systematic review using a narrative synthesis approach (Popay et al., 2006) of family death preparation. Bereavement experiences among Taiwanese family members following an expected death are explored, and the relevance of different bereavement theories to the Taiwanese context is considered. The second and third papers (Chapters Five and Six, i.e., Papers 2 and 3) present findings from a qualitative interview study with family caregivers in specialist palliative care settings in Taiwan, analysed using reflexive thematic analysis (Braun & Clarke, 2022b). Chapter Five (Paper 2) focuses on preparations that occur in the period leading up to a relative's death, while Chapter Six (Paper 3) addresses preparations for the moment of death and its immediate aftermath, including concerns related to the afterlife.

Chapter Seven presents the findings of the nominal group technique study involving specialist palliative care professionals in Taiwan. This method was employed to develop and prioritise recommendations for supporting families in preparing for a relative's death. Methodological reflections on the use of the nominal group technique (Jünger & Payne, 2020) in a palliative care context are presented in Chapter Eight (Paper 4), offering methodological insights and recommendations for future research.

Chapter Nine includes a synthesis of the main findings from the three studies and a reconsideration of the research question and aim. The chapter also outlines the development of a conceptual model of family death preparation in Taiwan. A critical comparison of the Taiwanese model with established frameworks and a theoretical interpretation of the findings are provided. The study's contributions to knowledge are presented, its overall strengths and limitations are discussed, and a reflexive commentary on the interpretation process is included.

The final chapter concludes with a summary of key implications for future research, clinical practice, education, and policy, based on the evidence and insights generated through this study.

Table 1: Overview of the four original papers addressing this thesis's overarching research question: How can families in Taiwan be better prepared for the death of a relative?

Paper	**Paper 1 (Chapter Four)**	**Paper 2 (Chapter Five)**	**Paper 3 (Chapter Six)**	**Paper 4 (Chapter Eight)**
	Taiwanese family members' bereavement experience following an expected death: a narrative synthesis review. Published in *BMC Palliative Care.*	'*Regrets become a lasting source of pain*': A qualitative study on family caregivers' experiences leading up to a relative's death. Published in *Palliative Medicine.*	'*A good ending but not the end*'- Exploring family preparations surrounding a relative's death and the Afterlife: A qualitative study. Published in *Palliative Medicine*.	Methodological reflections to support good practice in using nominal group techniques: Insights from applications in palliative care studies. Published in *Palliative Medicine*.
Topic	Families' bereavement, culture	Family death preparation, bereavement	Family death preparations, culture	Methodological, recommendation development
Perspective	Secondary synthesis of families' accounts	Families' accounts	Families' accounts	Methodological reflections, specialist palliative care professionals' accounts
Design	Systematic literature review	Qualitative interview study	Qualitative interview study	Nominal group technique study
Aim of the article	To explore Taiwanese families' bereavement experience, aiming to expand the understanding of family death preparation from retrospective perspectives.	To explore Taiwanese family caregivers' preparations leading up to a relative's death and how these preparations influence their bereavement.	To explore how cultural context influences Taiwanese family caregivers' experiences of preparing for a relative's death.	To develop and prioritise recommendations for healthcare professionals on family death preparation, and to enhance their applicability in the Taiwanese context. To provide methodological reflections on the use of the nominal group technique in palliative care research.

CHAPTER 2: BACKGROUND

This chapter includes an introduction to the development of modern palliative care and critically examines its relevance and limitations in non-Western societies. Existing literature on family death preparation is presented, outlining the current understanding and the continuing need for research in non-Western contexts. The conceptualisation of family death preparation is described, and dominant Western-oriented bereavement theories are reviewed to consider the topic from multiple perspectives. The chapter further discusses the role and needs of family caregivers during end-of-life care, providing a rationale for their inclusion as participants. It concludes with an overview of Taiwan's social and cultural context and its health and palliative care services, establishing the background for examining family death preparation in non-Western settings.

2.1 Global development in palliative care and the role of the family in end-of-life care

2.1.1 The emergence of modern palliative care

Death is a universal aspect of human existence, yet individuals' perceptions of and responses to it are shaped by the social and cultural contexts in which they live (Howarth, 2007). Advances in scientific medicine and modernisation have reshaped the processes surrounding dying and death (Howarth, 2007; Lewis, 2007; Zaman et al., 2017). Over time, the leading causes of death have shifted from communicable diseases to cancer and other chronic, degenerative conditions (Lewis, 2007). As a result, people now often experience longer disease trajectories, extended illness periods, and more intensive care needs. While these developments may provide individuals with more time to prepare for death, they have also transformed the nature of end-of-life experiences.

One significant transformation concerns the location of death. Historically, death often occurred at home or within community settings. In recent decades, however, it has more commonly taken place in institutional environments such as hospitals (Howarth, 2007; Jiang & May, 2021; Lewis, 2007). A study of 30 European countries between 2005 and 2017 found that hospital deaths ranged from 26% to 68%, with a median of 52% (Jiang

& May, 2021). This shift has important implications, including greater involvement of healthcare professionals in end-of-life care and a corresponding decline in the role of family and community. Alongside these institutional changes, modernisation has diminished the influence of religion in many Western societies (Howarth, 2007; McNamara, 2001; Zaman et al., 2017). As religious authority declined, clergy such as priests became less central to end-of-life care, while healthcare professionals assumed a more dominant role. This transition marked a movement from religious support, such as through prayers and rituals intended to comfort the soul, to a medical emphasis on physical management, particularly pain relief (Lewis, 2007; Zaman et al., 2017).

These developments have contributed to the medicalisation of dying, a process through which death becomes framed as a clinical event and its management as a medical responsibility. Within this framework, death is often perceived as a failure of medicine, prompting aggressive efforts to prolong life, even when cure is no longer possible (Lewis, 2007). Consequently, patients, families, and professionals may become more focused on resisting death rather than preparing for it.

The modern palliative care movement, originating in the United Kingdom in the 1960s, emerged as a response to the medicalisation of dying. It reshaped approaches to end-of-life care by reintroducing holistic values such as comfort, dignity, and compassion (McNamara, 2001; Zaman et al., 2017). This reorientation laid the foundation for reimagining death not merely as a biological endpoint, but as a personal, familial, and social process requiring preparation and relational support.

In line with this holistic approach, the World Health Organisation (2002, pp. xv - xvi) defines palliative care as:

> “*an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual*”

While this definition has been widely adopted, including by the Asia Pacific Hospice Palliative Care Network, a more recent consensus-based definition has been proposed:

> “*Palliative care is the active holistic care of individuals across all ages with serious*

> *health-related suffering because of severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers."* (Radbruch et al., 2020, p. 761)

Both definitions emphasise the holistic nature of palliative care in alleviating suffering and promoting a good death, while supporting families throughout the dying process and bereavement. The more recent definition further underscores the role and well-being of caregivers (Radbruch et al., 2020). However, its focus is limited to individuals with serious illness rather than extending to the wider population with palliative care needs through public health approaches that have been prompted within global palliative care policy (Stjernswärd et al., 2007b).

The meaning of a good death, a central goal of palliative care, is shaped by cultural values and social expectations. In Western societies, where individual autonomy is highly valued (Gómez-Vírseda et al., 2019; Inglehart, 2008), a good death is often associated with control over the dying process, particularly its timing and location (Howarth, 2007; Kehl, 2006; Meier et al., 2016). This understanding aligns with broader secular trends in which the influence of organised religion has declined, and healthcare professionals have assumed central roles in end-of-life care. It also shapes the delivery of spiritual care in many Western societies, where greater emphasis is placed on existential concerns rather than on religious beliefs and practices (Lewis, 2007).

Although palliative care was initially established to resist the medicalisation of death, it has gradually become more procedural and professionalised, often mirroring the scientific and institutional frameworks it originally sought to reform (Zaman et al., 2017). However, such Western-oriented perspectives risk overlooking that, for many cultures, death remains a deeply religious and relational experience. End-of-life care is often embedded in cultural values, spiritual worldviews, and community rituals (Ntizimira et al., 2024; Schuster-Wallace et al., 2022; Zaman, 2025). Recognising this diversity is essential for developing palliative care models that are both globally relevant and culturally responsive. Nevertheless, much of the global body of palliative care research has originated from Western settings, shaping international norms and reinforcing Western assumptions (Pastrana et al., 2010). Consequently, research and practice may inadvertently marginalise the perspectives and needs of families in non-Western societies. These limitations have important implications for how the family's role is understood within palliative and end-of-life care, as discussed in the next section.

2.1.2 Family roles in palliative and end-of-life care

An essential component of the Western-oriented palliative care model is the inclusion of family members and caregivers as part of the unit of care, with an emphasis on preparing them for a relative's death and offering bereavement support (Radbruch et al., 2020). The Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients highlight the importance of ensuring that families are adequately prepared when death becomes imminent (Hudson et al., 2012). Similarly, a European consensus on bereavement care in palliative care, developed using the Delphi technique, underscores the need to assist families in recognising and preparing for approaching death (Keegan et al., 2021).

Despite these principles, the Western palliative care model continues to focus primarily on patient autonomy and individual preferences. In many cases, this approach prioritises the patient's wishes over those of the family, creating tensions in contexts where decision-making is fundamentally relational (Zaman, 2025; Zaman et al., 2017). This emphasis on individualism may not align with the family-centred cultural values common in many East Asian societies, including Taiwan, where collective responsibility and interdependent relationships often take precedence over personal choice (Lee et al., 2024).

Although the Western palliative care model has been widely implemented in East Asia, it often assumes universal applicability, potentially overlooking important cultural differences. Even within the region, notable intra-regional variation exists (Hwang, 1999). While societies such as Taiwan and Japan share Confucian values that emphasise filial piety and collective responsibility, they differ in the degree of family involvement in care decisions and in the influence of religious and cultural traditions on dying and death (World Values Survey, 2023). Taiwan's greater religious diversity, including Buddhism, Taoism, folk religions, and Christianity, has fostered practices that extend beyond religious expectations, placing stronger emphasis on cultural expression and shaping distinctive end-of-life rituals and meanings (Shih, 1982). These differences illustrate both the necessity and the complexity of developing culturally sensitive palliative care models that respond to local norms and values (Ntizimira et al., 2024; Zaman, 2025; Zaman et al., 2017).

To address these gaps, this study focuses on examining how Taiwanese families prepare for the death of a relative within the context of specialist palliative care. Through this culturally situated approach, the aim is to contribute to a more inclusive understanding of family death preparation and to support the development of culturally responsive palliative care practices. The research context of Taiwan is described in greater detail later in this chapter.

While these cultural perspectives highlight the importance of understanding how families prepare for a relative's death within their specific social contexts, the diversity of families' needs and expectations also reveals practical challenges for healthcare professionals in providing appropriate support during end-of-life care, as discussed in the next section.

2.1.3 Challenges in supporting families during end-of-life care in clinical practice

There remains a continuing need to strengthen clinical practice to better support families and caregivers as they prepare for the death of a relative. A key aspect of this support involves providing clear, timely, and appropriate information about the dying process and what to expect during the final stages of life (Angelo et al., 2013). However, research consistently identifies gaps in how these information needs are met. For example, a Canadian study found that even in specialised palliative care settings, family caregivers often lacked a sufficient understanding of what the dying process entails (Gallagher & Krawczyk, 2013). In the United States, a study involving 226 family caregivers of patients with cancer receiving palliative care reported that 49% felt emotionally unprepared and 35% felt practically unprepared for their relative's death (Caserta et al., 2019). Similarly, a Swedish study found that 54% of bereaved spouses reported low to medium levels of preparedness for their partner's death (Hauksdóttir et al., 2010). These findings illustrate persistent challenges in equipping families for end-of-life experiences, even within healthcare systems where palliative care is available. These challenges highlight the need for more nuanced, evidence-informed guidelines that acknowledge the relational and emotional complexities of family involvement in end-of-life care.

One contributing factor to these ongoing challenges is that most existing clinical guidelines on death preparation are primarily patient-centred and provide little specific guidance for supporting families during this critical time. For instance, the National Institute for Health and Care Excellence (NICE) in the United Kingdom has issued two relevant guidelines. The End of Life Care for Adults: Service Delivery guideline recommends providing emotional and practical support to caregivers as death approaches (NICE guidline [NG142], 2019). Similarly, the Supporting Adult Carers guideline encourages healthcare professionals to involve family members in discussions about death and dying, including helping them understand the patient's diagnosis and prognosis (NICE guideline [NG150], 2020). While these documents acknowledge the importance of engaging families, their recommendations are often broad and general, offering limited practical guidance on how to support families effectively in clinical practice.

Providing effective family support in preparing for a relative's death during end-of-life care must also be culturally sensitive. Understandings of what constitutes a good death and what it means to be adequately prepared are shaped by cultural norms and social expectations (Zaman, 2025; Zaman et al., 2017). These perspectives vary considerably across populations according to their cultural background, making it difficult for universal guidelines to address the diverse needs and values of families facing the death of a relative. This highlights the importance of developing contextually grounded and culturally informed guidance that can assist healthcare professionals in supporting families more effectively. Understanding how families experience, interpret, and respond to the process of preparing for a relative's death is essential for developing strategies to guide healthcare professionals. To inform such developments, it is necessary to first consider how family death preparation has been theorised and conceptualised in existing literature. The following section reviews current theoretical frameworks and empirical research on this topic, establishing the foundation for its conceptual and empirical understanding.

2.2 Theorising and conceptualising family death preparation

2.2.1 Theoretical frameworks on family death preparation

Awareness of an impending death is a key factor that prompts families to begin preparing for the loss of a relative (Breen et al., 2018; Glaser & Strauss, 1965). This awareness is typically triggered by the disclosure of the patient's medical condition, such as the severity of illness, disease progression, or limited life expectancy (Parker et al., 2007). It signposts families to that death is approaching and initiates a process of preparation that unfolds during the period between this recognition and the actual time of death (Glaser & Strauss, 1965). Family death preparation is therefore understood to occur in the context of an expected death, commonly associated with a life-threatening diagnosis, progression to a terminal stage, or a noticeable decline in physical or cognitive functioning. However, despite growing scholarly interest, there remains a limited theoretical understanding of how families engage in this process, as discussed below.

To date, only a few theoretical frameworks have explicitly addressed how families prepare for the death of a relative. One of the most widely cited is the Theoretical Framework of Preparedness for End-of-Life developed by Hebert and colleagues (Hebert et al., 2006). Drawing on existing literature, this model focuses on how family caregivers of terminally ill patients engage in preparation. It emphasises the interconnectedness of communication between healthcare professionals and family caregivers, caregiver preparedness, and caregiver outcomes such as satisfaction with care, mental health, and bereavement adjustment. The framework conceptualises preparation as a multidimensional process, encompassing medical, psychosocial, spiritual, and practical aspects, and underscores the role of end-of-life discussions, particularly those involving healthcare professionals (Hebert et al., 2006). However, it gives limited attention to the internal strengths or resources that family caregivers may contribute to the preparation process.

Building on this earlier work, Hebert and colleagues (2009) developed a refined model through qualitative research with family caregivers of terminally ill patients in the United States. This updated framework identifies several key themes, including caregivers' prior life experiences, communication dynamics, uncertainty, and dimensions of preparedness. It underscores the importance of effective communication in managing uncertainty across medical, psychosocial, spiritual, and practical domains. The model also expands the concept of preparation to include cognitive, affective, and behavioural dimensions. Notably, it integrates the role of advance care planning as part of the preparation process, helping families anticipate and manage what to expect as death approaches (Kishino et al., 2022). While support from healthcare professionals remains central, this version places greater emphasis to the caregiver’s own life experience.

A third framework, the Caregiver Preparedness for End-of-Life in Dementia model, was developed by Durepos and colleagues based on a concept analysis of the literature (Durepos et al., 2019). It defines preparedness for death in the context of dementia as “a cognitive, emotional, and behavioural quality (or state of readiness) to minimise uncertainty, maintain self-efficacy, and control over current and future losses and death in persons with dementia” (Durepos et al., 2019, p. 439). This model incorporates Hebert’s earlier work (Hebert et al., 2006) and categorises preparedness into medical, psychosocial, spiritual, and practical domains (Durepos et al., 2019). Unlike the previous frameworks, it places greater emphasis on caregivers’ coping strategies, distinguishing between problem-focused (cognitive and behavioural) and emotion-focused (affective) approaches, and recognising the unique challenges of caregiving in the context of dementia. It also conceptualises family death preparation as a process that progresses from antecedents, such as illness-related symptoms and advance care planning, to outcomes, including bereavement adjustment and family well-being after death. By supporting this transition process, the model suggests that adequate preparation can enhance post-death outcomes for families (Durepos et al., 2019).

Collectively, these frameworks have primarily focused on family caregivers of patients in the terminal stage of illness or those with dementia. This focus likely reflects the distinct challenges these groups face. While terminal illness presents the immediacy of an expected death, dementia involves prolonged uncertainty, both of which shape different trajectories of preparation. Although these models do not always explicitly reference expected deaths, their emphasis on end-of-life contexts implies such a focus.

Importantly, all three frameworks were developed in Western, English-speaking contexts, primarily involving adult participants from North America. Their applicability to other cultural settings, particularly in non-Western societies, remains limited (Ntizimira et al., 2024; Zaman, 2025). Building on these theoretical insights and recognising their limitations, there remains a need to explore how families in culturally distinct contexts, such as Taiwan, prepare for a relative’s death. Understanding these culturally embedded practices in family death preparation is central to the focus of this thesis. To further develop this understanding, the following section reviews existing empirical research on family death preparation, providing the foundation for its conceptualisation within this study.

2.2.2 Critique of existing research on family death preparation

Research on how families prepare for a relative’s death remains relatively underexplored globally. Existing studies have largely focused on assessing families’ levels of preparedness for death (Barry et al., 2002; Kim et al., 2017; Schulz et al., 2015; Yu et al., 2021) or on examining the relationship between preparedness and factors such as caregiving burden (Wen et al., 2022b), typically using quantitative methods and standardised measures. For example, a study conducted in Japan found that insufficient preparedness was associated with poor psychological health, limited social support during caregiving, and the way in which end-of-life discussions with physicians were conducted (Matsuzaka et al., 2024). While these studies provide useful insights into levels of death preparedness and associated factors, they are not designed to capture the nuanced and multifaceted nature of the family death preparation process.

Current measurement tools for assessing family death preparation primarily focus on evaluating levels of preparedness for death. Most rely on single-item (Barry et al., 2002; Schulz et al., 2015; Yu et al., 2021) or two-item measures (Caserta et al., 2019; Kim et al., 2017), administered either prospectively or retrospectively (**Table 2**). Prospective assessments typically ask family caregivers to evaluate how prepared they feel for a relative’s possible death. For example, studies conducted in the United States, Denmark, and China have used questions such as: "If your loved one were to die soon, how prepared would you be for his/her death?" (Schulz et al., 2015, p. 129); “To what extent do you feel prepared that your relative might die from the illness?” (Nielsen et al., 2017, p. 2050); and “To what extent do you think you have prepared for the patient’s death?” (Yu et al., 2021, p. 371).

The Carer Support Needs Assessment Tool (CSNAT), originally developed in the United Kingdom to identify caregivers' support needs, also includes some relevant aspects of family death preparation, such as understanding the dying process and discussing end-of-life matters with the dying person, including funeral planning and opportunities to say goodbye (Ewing, Brundle, et al., 2013; Ewing, Grande, et al., 2013). However, this tool does not provide a comprehensive account of how families actually prepare for death, which involves addressing medical, psychosocial, spiritual, and practical tasks (Durepos et al., 2019; Hebert et al., 2006; Hebert et al., 2009).

Retrospective assessments have similarly relied on brief questions. For instance, studies conducted in the United States, Iceland, and Sweden asked bereaved individuals: "How prepared did you feel for the death?" (Barry et al., 2002, p. 450) and "How prepared were you for your wife's death?" (Asgeirsdottir et al., 2013, p. 2765; Hauksdóttir et al., 2010, p. 390). Other U.S.-based studies have used two-item measures assessing emotional and practical preparedness, including taking new responsibilities or making funeral arrangements (Caserta et al., 2019; Kim et al., 2017). The Views of Informal Carers-Evaluation of Services tool (VOICES) was developed in the United Kingdom to assess informants' overall satisfaction with care during the last three months of life (Hunt et al., 2019; Young et al., 2009). It also includes items related to family death preparation, such as recognising signs of dying or spending time with the dying person. However, its primary focus remains on evaluating the quality of care provided during the final months of life.

Some studies have examined emotional preparedness for death using indirect instruments not originally designed to assess family death preparation. In Taiwan, for example, several studies have employed the five-item "Preparation for End-of-Life" subscale from the Quality of Life at the End of Life scale, which was initially developed in the United States to evaluate the quality of life among seriously ill patients (Steinhauser et al., 2002; Steinhauser et al., 2004). This subscale has been adapted for use with family caregivers and focuses on emotional concerns such as fear about the dying process, worries about financial burden, and anticipated regret (Tang, Chang, et al., 2021; Tang, Hsieh, et al., 2021; Wen et al., 2022a, 2022b). Specific items include statements such as: "I worry that I am not prepared to cope with the future without my loved one", and

“Thoughts of my loved one’s dying and death frighten me”(Wen et al., 2022a). Although these studies provide valuable insight into the emotional dimension of death preparation, the use of instruments not specifically designed for family caregivers highlights a broader issue: emotional preparedness is often assessed in isolation, while other critical aspects of death preparation, such as relational, spiritual, and practical elements, are overlooked.

A few tools have sought to offer a more holistic assessment. In South Korea, the 11-item Preparedness for Death scale was developed to measure both understanding of death preparation (seven items) and practical considerations (four items), such as funeral planning, among family caregivers in palliative care settings (Jung et al., 2021). Although broader in scope, the tool excludes psychosocial and spiritual aspects and was developed through expert consultation rather than family member perspectives. Similarly, the 30-item Caring Ahead questionnaire, developed in Canada for caregivers of individuals with advanced dementia in long-term care facilities, covers medical, relational or personal, spiritual, and practical domains (Durepos et al., 2021). While more comprehensive, this tool is specific to a particular illness trajectory, institutional care settings, and cultural context, which may limit its relevance in other healthcare systems, diagnoses, or cultural environments, such as those in East Asia.

The development of multidimensional instruments represents an important advancement in measuring family death preparation, recognising that preparing for a relative’s death encompasses more than a single dimension of readiness. Preparation is not merely a matter of being ready; it is a complex, ongoing process that involves both a state of readiness (Nielsen et al., 2016) and the completion of various tasks (Hebert et al., 2009). This readiness spans cognitive, behavioural, and emotional aspects (Durepos et al., 2019; Hebert et al., 2009; Nielsen et al., 2016), while the associated tasks involve addressing medical, psychosocial, spiritual, and practical needs (Durepos et al., 2019; Hebert et al., 2006; Hebert et al., 2009). These needs may include reconciling relationships with the dying relative (Durepos et al., 2019; Supiano et al., 2020), expressing thoughts and emotions before death, and giving permission to let go (Hovland-Scafe & Kramer, 2017).

Although multidimensional instruments have broadened the conceptual scope of preparedness for death, they still tend to define and assess family death preparation in relatively narrow and static ways. This highlights the need to move beyond quantitative assessments that simply measure whether families feel prepared, and instead to explore how they understand, engage with, and interpret the preparation process. Such an approach underscores the value of qualitative research in providing a richer and culturally grounded understanding of how families prepare for a relative’s death.

Table 2: Measurement tools in assessing family death preparation.

Author (year), Country	Description of tools for assessing family death preparation Terminology/No. of measures/Content	Response options
Prospective assessment		
Ewing, Brundle, et al. (2013); Ewing, Grande, et al. (2013), UK	Carer Support Needs Assessment Tool (CSNAT) - Items related to family death preparation: • Managing the dying relative's symptoms (e.g., administering medication) • Providing personal care for the dying relative • Knowing what to expect next during the dying process • Talking with the dying relative about the closeness of death (e.g., funeral arrangements, saying goodbye) • Knowing what to do when death occurs at home	no, a little more, quite a bit more, very much more
Schulz et al. (2015), USA	"If your loved one were to die soon, how prepared would you be for his/her death?"	not at all, somewhat, very
Nielsen et al. (2017), Denmark	"To which extent do you feel prepared that your relative might die from the illness?"	low, high
Yu et al. (2021), China	"To what extent do you think you have prepared for the patient's death?"	1=none, 2=insufficient, 3=sufficient, 4=more sufficient, 5=complete
Jung et al. (2021), South Korea	Preparedness for death scale (11-item): understanding of preparation for death (7), practical preparation for death (e.g., funeral preparations) (4)	1=not at all, 2=somewhat, 3=agree, 4=strongly agree Scores range 11-44
Durepos et al. (2021), Canada	Preparedness for end-of-life scale (30-item): medical (9), relationship/personal (8), spiritual (5), practical preparation (6)	Not mentioned response format
Tang, Chang, et al. (2021); Tang, Hsieh, et al. (2021); Wen et al. (2022a, 2022b), Taiwan	Assess emotional preparedness through the five-item Preparation for End-of-Life subscale of the Quality of Life at the End of Life (QUAL-E) scale (Steinhauser et al., 2002; Steinhauser et al., 2004): • I worry that I am not prepared to cope with the future without my loved one.	1=not at all, 2=a little bit, 3=a moderate amount, 4=quite a bit, 5=completely

	• I have regrets about the way my loved one has lived his/her life. • At times, I worry that care of my loved one may burden my family. • Thoughts of my loved one's dying and death frighten me. • I worry that caring for my loved one may cause a financial strain to my family.	
Retrospective assessment		
Barry et al. (2002), USA	"How prepared did you feel for the death?"	1=well prepared, 4=somewhat, 7=totally unprepared
Hauksdóttir et al. (2010), Sweden	"How prepared were you for your wife's death?"	7-point scale: 1=not at all prepared, 7=very well prepared Preparedness levels: 1-2 (low), 3-5 (medium), 6-7(high)
Asgeirsdottir et al. (2013), Sweden	"How prepared were you before your wife's death?"	7-point scale: 1=not at all prepared, 7=very well prepared Preparedness levels: 1-2 (low), 3-5 (medium), 6-7 (high)
Kim et al. (2017), USA	"I was prepared for his/her death", "My family was prepared for his/her death"	5-point: 1=strongly disagree, 5=strongly agree
Caserta et al. (2019), USA	"Emotionally, how prepared do you think you were for the death of your spouse/partner?", "In terms of your daily life, how prepared were you for the death of your spouse/partner, for example, taking on new responsibility, planning ahead, funeral preparation, etc.?"	5-point: 1=very little if at all, 5=very prepared Overall preparedness range: 2 (low) -10 (high)
Hunt et al. (2019); Young et al. (2009), UK	Views of Informal Carers-Evaluation of Services tool (VOICES) – Items related to family death preparation include: • "Were you involved in decisions about the treatment and care of the deceased as much as you wanted?" • "Were you told that she was likely to die shortly?" • "Were you contacted soon enough to give you time to be with her before she died?" • "Do you feel that the deceased died in the right place?" • Communication about the approaching death (e.g., being kept informed about the dying relative's condition and care)	Likert-type scale (e.g., excellent, good, fair, poor; strongly agree, agree, neither agree nor disagree, disagree, strongly disagree, don't know, not applicable), multiple choice & open-ended questions

USA: United States; UK: United Kingdom

Research using qualitative or mixed-methods approaches to explore family death preparation remains limited and is predominantly based in Western countries, including the United States (Hebert et al., 2009; Hovland & Kramer, 2019; Hovland-Scafe & Kramer, 2017; Supiano et al., 2020), Canada (Durepos, Ploeg, Sussman, et al., 2020), and Australia (Breen et al., 2018). These studies are discussed below and summarised in **Table 3**, which presents six qualitative studies (Breen et al., 2018; Durepos, Ploeg, Sussman, et al., 2020; Hebert et al., 2009; Hovland & Fuller, 2022; Hovland & Kramer, 2019; Hovland-Scafe & Kramer, 2017) and one mixed-methods study (Supiano et al., 2020).

All of these investigations involved family caregivers, typically adult children or spouses/partners, who were primarily responsible for providing informal care at the end-of-life while simultaneously preparing for the death of their relative. Across these studies, family caregivers played a central role in the preparation process, yet faced distinct challenges in managing this dual responsibility. Although caregiving can heighten awareness of impending death, it also demands time, emotional energy, and practical attention, which may limit caregivers' ability to engage fully in preparation. This dual role places family caregivers at the intersection of care and grief, making them a critical focus of research on death preparation.

Most existing qualitative studies have focused on caregiving for patients with dementia, likely because the prolonged disease trajectory and extended caregiving period provide greater opportunity to observe and participate in the death preparation process (Durepos, Ploeg, Sussman, et al., 2020). Research conducted in palliative care settings, where end-of-life planning is often emphasised, is also common within this body of work.

Collectively, these studies have advanced the understanding of families' experiences of preparing for a relative's death; however, several limitations remain. Given that family death preparation is deeply shaped by social and cultural factors, findings from Western contexts may not reflect the experiences of families in non-Western societies, such as those in East Asia. Moreover, most research has focused on specific illness trajectories, particularly dementia, and has been conducted within palliative care settings. While such studies are valuable, they may not capture the broader variations in how families prepare for death across different diagnoses, care environments, and cultural contexts.

As a result, there is still a lack of qualitative research examining how families in East Asia, including Taiwan, understand and navigate the death preparation process. This gap underscores the need to investigate family death preparation beyond Western frameworks. The present study, therefore, adopts a qualitative approach to explore how family caregivers in Taiwan engage with this process. Family caregivers are the primary participant group, given their central role in preparing for a relative's death. The study includes caregivers of patients receiving specialist palliative care, regardless of diagnosis, to provide a comprehensive understanding of family death preparation within Taiwan's cultural and healthcare context. Taiwan's social context and palliative care system are introduced later in this chapter to further situate this focus.

This inquiry aims to develop a culturally grounded understanding of family death preparation and to inform the design of culturally sensitive and contextually relevant approaches to palliative and end-of-life care in Taiwan. Insights generated from this research may also be applicable to other societies with similar cultural backgrounds. The methodology and methods guiding this study are discussed in the following chapter.

Table 3: A summary of studies using qualitative and mixed methods on family death preparation.

Author (year), Country	**Aims & Design**	**Participants**	**Primary relationship & patient illness/ Palliative care (PC)**	**Themes/ Key Findings**
Hebert et al. (2009), USA	Identify key factors in death preparation and bereavement & develop a preparedness model Qualitative interview	33 family caregivers: 6 (current), 27 (bereaved) Time bereaved: < 12 months	Adult children Cancer PC: current patients	A conceptual model produced: life experiences (e.g., duration of caregiving, advance care planning), uncertainty (medical, practical, psychosocial, and religious/spiritual), communication, preparedness (cognitive, affective, and behavioural)
Hovland-Scafe and Kramer (2017), USA	Determine definition and perceived importance of preparedness Qualitative interview	30 bereaved family caregivers Average time bereaved: 9 months	Spouse/partner, adult children Dementia PC: most patients	Five themes regarding death preparedness: accepting reality, knowing death is near, getting your house in order, saying what you need to say & giving permission to die Benefits of being prepared: eliminating surprise, reducing fear, making death easier to accept, facilitating presence at the end of life, easing transitions into bereavement & managing post-death responsibilities
Breen et al. (2018), Australia	Explore family caregivers' preparations for death Qualitative interview Grounded theory	16 current family caregivers	Spouse/partner Cancer PC: all patients	Two themes regarding death preparedness: here and now (the privilege and demands of caregiving, family cohesion and conflict & experience with health and social services), negotiating the Here/After (unpredictable illness trajectory, trying to prepare while being unable to plan, preparing while living with hope and fear, and self-reproach over future uncertainty)
Hovland and Kramer (2019), USA	Identify barriers and facilitators in preparing family caregivers for death Qualitative interview	36 bereaved family caregivers Average time bereaved: 9.5 months	Spouse, adult children Dementia PC: most patients	Barriers to preparedness: barriers to information, obstacles to hospice care, ineffective comfort efforts & challenges of death in dementia Facilitators of preparedness: religious or spiritual belief, caregiver initiative, prior experience, witnessing decline, professional guidance on impending death & culture and caregiving legacies
Durepos,	Identify components,	16 bereaved family	Adult children	Four Themes regarding death preparedness: a crazy rollercoaster at the

Ploeg, Sussman, et al. (2020), Canada	barriers, and facilitators of preparedness for death Qualitative interview	caregivers Average time bereaved: 9.6 months	Dementia No PC	end (challenging caregiving and end-of-life preparation), a sense of control (managing patient care and needs), doing right (fulfilling societal obligations) & coming to terms (adapting to patient decline, losses, and identity changes) Barriers to preparedness: patients' sudden decline, poor communication with healthcare providers Facilitators to preparedness: good relationships with healthcare providers, planning ahead to fulfil obligations
Supiano et al. (2020), USA	Examine how death preparedness affects grief and the role of meaning-making in death preparation Mixed methods	100 family caregivers: 50 (current), 50 (bereaved) Time bereaved: < 6months	Adult children, grandchildren Dementia No PC	Adequate death preparation: positive memory-making, viewing death as the end of suffering, resolving relationships, understanding dementia & shared meaning of dementia with family at end-of-life Inadequate death preparation: perception of the dying process as traumatic, loss of the caregiver role & lack of support Perceived preparedness for death: a more constructive grief experience (anticipatory grief & post-death grief)
Hovland and Fuller (2022), USA	Explore how African American caregivers prepared for the death of an older adult family member Qualitative interview	6 bereaved family caregivers Average time bereaved: 9.5 months	Adult children Dementia No PC	Five themes regarding death preparedness: accepting reality, I just kind of knew, person with dementia was ready, spending time & getting your business in order Benefits of being prepared: getting finances in order, arranging living situations, planning the funeral, seeking emotional support, avoiding shock & saying final words

USA: United States, PC: palliative care

As previously discussed, existing theoretical frameworks on family death preparation emphasise the role of advance care planning in shaping how families prepare for a relative's death (Durepos et al., 2019; Hebert et al., 2006; Hebert et al., 2009). These frameworks also indicate that the extent and quality of family death preparation may influence bereavement outcomes. The following section builds upon these insights by examining in greater detail the functions and impact of advance care planning and its relationship to bereavement within the broader context of family death preparation.

2.2.3 Advance care planning and its role in family death preparation

Advance care planning enables individuals to discuss their values, goals, and preferences for future medical treatment and care, communicate these preferences with family members and healthcare professionals, and document these decisions in case they lose capacity in the future (Rietjens et al., 2017). Although this definition acknowledges the potential involvement of families, their participation in advance care planning is not a formal requirement. However, when families are included, advance care planning can enhance their understanding of what to expect as death approaches, thereby supporting emotional, practical, and relational preparation (Hebert et al., 2009; Kishino et al., 2022; Schulz et al., 2015; Sellars et al., 2019). For example, a systematic review found that advance care planning helped family caregivers of people with dementia manage fear of loss and come to terms with the inevitability of death (Sellars et al., 2019). Similarly, a qualitative study involving family caregivers of patients with cancer showed that advance care planning provided clarity about the end-of-life process and enhanced their preparedness for death (Hebert et al., 2009). In the United States, a prospective longitudinal study also identified a strong association between engagement in advance care planning and increased feelings of preparedness among family caregivers of patients recently admitted to nursing homes (Schulz et al., 2015).

Despite these recognised benefits, relatively little research has examined how advance care planning supports families' preparation for a relative's death. Much of the existing literature focuses on evaluating its effectiveness (Dixon et al., 2018), often using healthcare utilisation metrics such as hospital admissions (Garden et al., 2016), length of hospital stay (Caplan et al., 2006), place of death (Garden et al., 2016; Livingston et al., 2013), healthcare costs, and use of intensive care (Nicholas et al., 2014). Other studies prioritise patient-related outcomes, including quality of life, emotional and physical distress (Korfage et al., 2020), decisional conflict (Hilgeman et al., 2014), and care coordination (Livingston et al., 2013). Research examining family outcomes has generally centred on healthcare satisfaction (Garden et al., 2016; Livingston et al., 2013) and on caregivers’ anxiety, depression, and self-care prior to bereavement (Hilgeman et al., 2014). Although these studies offer valuable contributions, they tend to emphasise measurable clinical and psychological indicators while overlooking the relational, spiritual, and anticipatory dimensions of how families prepare for death. Consequently, they fail to capture the broader potential of advance care planning to support families in navigating the multifaceted and complex nature of death preparation (Durepos, Ploeg, Akhtar-Danesh, et al., 2020; Durepos et al., 2019; Malhotra et al., 2022).

Qualitative research has provided further insight into how patients and families engage with advance care planning, particularly the emotional challenges they may encounter during the process. For example, patients with advanced cancer have reported difficulty discussing future-oriented topics, including their preferences for end-of-life care (Zwakman et al., 2021). Similarly, families described initial discomfort with advance care planning conversations, although they later perceived these discussions as meaningful and beneficial (Kodba-Čeh et al., 2022). Despite these challenges, advance care planning can foster hope for both patients and families, as shown in earlier studies involving individuals with advanced cancer and their families (Kodba-Čeh et al., 2022), as well as those with end-stage renal disease (Davison & Simpson, 2006). A recent systematic review further found that advance care planning can help families develop a shared understanding of what matters most to the patient and prepare them for making difficult end-of-life decisions (Malhotra et al., 2022). In light of these broader functions, the review proposes reframing advance care planning as ‘advance care preparation’ to better reflect its preparatory role for both patients and families.

Taken together, these insights highlight the need to reorient advance care planning research and practice to place greater emphasis on how families prepare for death, a critical but underexplored aspect of end-of-life care. This study addresses this gap by examining the experiences of family caregivers in Taiwan and their engagement with death preparation within specialist palliative care settings.

2.2.4 Bereavement outcomes and family death preparation

Before reviewing the literature on bereavement in relation to family death preparation, it is important to clarify key terms. Grief refers to an individual's response to loss, such as the death of a relative, and encompasses a wide range of physical, cognitive, emotional, and behavioural reactions (Keegan et al., 2021; Worden, 2018). Bereavement denotes the state of having experienced the death of someone significant and the process of adapting to this loss (Keegan et al., 2021). In contrast, mourning is the external expression of grief, manifested through social behaviours and rituals shaped by cultural values and social norms (Howarth, 2007; Stroebe & Schut, 1998).

Family preparation for a relative's death has been shown to influence both family members' perceived end-of-life experiences and their subsequent bereavement processes. Adequate preparation can reduce emotional distress, including fear and anticipatory grief, facilitate presence at the end of life, and promote acceptance of death's inevitability (Hovland-Scafe & Kramer, 2017). Anticipatory grief refers to the sense of loss experienced in anticipation of a relative's death (Nielsen et al., 2016) and has been associated with inadequate preparation in a large Danish population-based study (Nielsen et al., 2017). Similarly, Canadian research has emphasised the importance of emotional adaptation to loss during the end-of-life period as a form of preparatory work (Durepos, Ploeg, Sussman, et al., 2020). These findings highlight that family death preparation involves not only practical arrangements but also emotional and psychological adjustment, with anticipatory grief playing a central role (Durepos et al., 2019).

Feeling adequately prepared for a relative's death is associated with more positive bereavement outcomes (Kim et al., 2017; Virdun et al., 2017). Studies in the United States have shown that family caregivers who felt well prepared experienced lower levels of complicated grief (Kim et al., 2017; Schulz et al., 2015), less intense grief, and fewer symptoms of depression (Kim et al., 2017). In contrast, systematic reviews have found that insufficient preparation is linked to complicated grief, depression, and anxiety (Nielsen et al., 2016; Treml et al., 2021). These findings demonstrate the vital role that family death preparation plays in shaping bereavement experiences (Durepos et al., 2021; Durepos, Ploeg, Akhtar-Danesh, et al., 2020).

However, it remains unclear which specific components of family death preparation shape bereavement outcomes and how these processes occur (Nielsen et al., 2016). The present study explores how families experience and engage in preparing for a relative's death and how this preparation influences their bereavement experiences, drawing on bereavement theory to guide the interpretation of findings. Key bereavement theories are reviewed in the following section, while additional theoretical perspectives relevant to the cultural interpretation of these findings are addressed in the discussion chapter. In doing so, this study aims to deepen the understanding of how family death preparation relates to bereavement outcomes and to generate insights that may inform more effective approaches to supporting families prior to death and reducing adverse bereavement outcomes.

2.3 Critique of Western-oriented bereavement theories

Influenced by Freud's work on grief published in the 1910s (Freud, 1917), mainstream bereavement theories, largely grounded in Western psychological traditions, have shaped contemporary understandings of grief and loss since the twentieth century (Howarth, 2007; Rothaupt & Becker, 2007). While often referred to as bereavement frameworks, many of these theories focus primarily on the psychological and emotional processes of grief rather than wider familial, social, and cultural contexts in which bereavement occurs (Keegan et al., 2021). Early research sought to distinguish between normal and pathological grief, often emphasising detachment from the deceased person as a necessary step in healthy adaptation to loss (Howarth, 2007). During this period, phase and stage models were particularly influential. A key example is John Bowlby's attachment and loss theory, introduced in the 1960s, which remains foundational in bereavement research. Bowlby argued that early-life attachment patterns influence how individuals cope with loss and that grief is resolved when emotional separation from the deceased person is achieved (Bowlby, 1961, 1977). For much of the twentieth century, this notion of detachment dominated psychological understandings of grief. Over time, however, these psychologically oriented perspectives have faced growing criticism.

Later developments have placed greater emphasis on the social context and cultural variability that shape bereavement processes. For example, Parkes' four phases of mourning, which include numbness, yearning and protest, disorganisation, and reorganisation, conceptualise the death of a significant other as a transformative life event involving psychological adjustment and the reorganisation of social roles and expectations (Parkes, 1970, 1985). The once-dominant assumption that detachment from the deceased person is essential for healthy grieving has been increasingly challenged since the 1990s. In response, the continuing bonds theory emerged, proposing that maintaining an ongoing connection with the deceased person can be a normal and meaningful aspect of bereavement (Klass & Silverman, 1996; Steffen & Klass, 2018). This shift is also reflected in subsequent theoretical models of bereavement.

The dual process model describes how bereaved individuals oscillate between confronting the pain of loss and engaging in restorative, everyday activities (Stroebe & Schut, 1999, 2010). It acknowledges the importance of sustaining emotional ties with the deceased person while adapting to new roles and relationships. Similarly, Worden's task model outlines four tasks of mourning: accepting the reality of the loss, processing the pain of the grief, adjusting to a world without the deceased person, and maintaining an enduring connection with them (Worden, 2018). This model evolved from advocating detachment to promoting emotional relocation, encouraging the bereaved to carry forward a continuing relationship with the deceased person while re-engaging with life.

Meaning-centred approaches to bereavement have also gained prominence in recent decades. Theories such as meaning reconstruction (Gillies & Neimeyer, 2006; Neimeyer, 2000) and the meaning-making model (Park, 2005) highlight the role of personal significance and narrative in emotional adaptation to loss. Meaning reconstruction theory, for example, integrates psychological and social dimensions by encouraging bereaved individuals to resolve unfinished emotional matters, often through expressive practices such as writing letters to the deceased person, which facilitates an ongoing inner dialogue (Neimeyer, 2019). These approaches align with the continuing bonds perspective and expand the conceptualisation of grief beyond symptom-based or pathological frameworks. **Table 4** summarises how these major Western bereavement theories conceptualise the relationship between the bereaved and the deceased person.

Table 4: Bereavement theories on the deceased-bereaved relationship.

Relationship between the deceased relative and the survival family		
Emotionally detach	***Relocate emotionally***	***Continuing relationship***
Freud’s work Bowlby’s attachment and loss theory Worden's task model (first edition)	Worden's task model (revised in the second edition) Dual process model	Continuing bonds theory Meaning reconstruction theory

While these theoretical developments represent a more flexible and relational understanding of bereavement, most bereavement theories continue to focus primarily on post-death experiences. They tended to overlook the significance of the dying process and the role of family death preparation in shaping bereavement. However, evidence indicates that feelings of regret or guilt about perceived inadequacies in caregiving or actions before death can intensify grief (Holland et al., 2014; Holtslander et al., 2017; Ishida et al., 2012; Milberg et al., 2008; Stroebe et al., 2014; Tang, 2019; Tey & Lee, 2025). These findings suggest that families’ experiences prior to death can influence how bereavement is experienced. While the central focus of this thesis is family death preparation, its findings may also contribute to bereavement theory by offering preventive insights into how preparation before death can influence bereavement outcomes.

Although contemporary Western bereavement theories increasingly acknowledge the influence of social and cultural factors, their applicability to non-Western settings, such as Taiwan, remains uncertain. Social and cultural norms surrounding emotional expression and spiritual belief play a central role in shaping grieving processes, often in ways that diverge from Western assumptions (Aeschlimann et al., 2024). Applying Western-oriented theories to interpret findings from non-Western contexts, therefore, requires careful cultural consideration. The present study examines bereavement experiences among Taiwanese family members following an expected death to critically reflect on the cultural relevance and limitations of existing Western bereavement models. Before introducing the social and cultural context of Taiwan, the key components of family death preparation are defined in the next section, providing the conceptual and analytical foundation for this study.

2.4 Conceptualising family death preparation

It is essential to conceptualise how families prepare for a relative's death based on existing literature to clarify the current state of knowledge, identify conceptual and empirical gaps, and establish the methodological orientation of this thesis (Varpio et al., 2020). This conceptualisation provides an analytical lens for examining how families engage in the process of preparing for a relative's death and supports the development of a culturally grounded understanding of this phenomenon.

Drawing on established theoretical frameworks (Durepos et al., 2019; Hebert et al., 2006; Hebert et al., 2009) and related empirical studies, family death preparation is conceptualised as a multifaceted and evolving process that occurs in the context of an expected death. It is typically initiated when signs of imminent death are indicated by a decline in health and involves both achieving a state of readiness (Durepos et al., 2019) and completing various preparatory tasks (Durepos et al., 2019; Hebert et al., 2009). Readiness is multidimensional, encompassing cognitive, emotional, and behavioural aspects (Durepos et al., 2019; Hebert et al., 2009; Nielsen et al., 2016), and requires attention to medical, psychosocial, spiritual, and practical needs (Durepos et al., 2019; Hebert et al., 2006; Hebert et al., 2009). These components frequently overlap and interact, reflecting the complexity of how families navigate the process of preparing for a relative's death. Their expression and prioritisation are influenced by social and cultural contexts, contributing to the diversity in how family death preparation is practised across settings.

Existing theoretical frameworks and empirical research recognise the potential role of advance care planning (Rietjens et al., 2017) in supporting family death preparation, particularly by enhancing families' understanding of what to expect as death approaches (Hebert et al., 2009; Kishino et al., 2022; Schulz et al., 2015; Sellars et al., 2019). However, the contribution of advance care planning to family death preparation remains insufficiently understood. Similarly, although research has demonstrated associations between family death preparation and bereavement outcomes (Kim et al., 2017; Virdun et al., 2017), it remains unclear how specific components of this preparation shape post-death adjustment.

Most theoretical models and empirical studies addressing this topic have been developed in Western contexts and rely predominantly on quantitative approaches. Consequently, they provide limited insight into how family death preparation is experienced in non-Western societies, such as Taiwan, where social and cultural values may shape how families approach this process in ways that differ from Western norms. Evidence derived from Western contexts may not be directly transferable and could hinder the development of culturally sensitive palliative and end-of-life care. In response, a qualitative approach is employed to explore how Taiwanese families prepare for a relative's death, using these conceptual frameworks as pre-understandings rather than fixed analytical categories for interpreting participants' experiences. Through this approach, current conceptual understandings are extended by illustrating how culturally embedded values and practices influence the ways families engage in death preparation. The following section provides a detailed discussion of Taiwan's social and cultural context.

2.5 Family death preparation in Taiwan

The social and cultural context of Taiwan, together with its healthcare system and the development of palliative care services, is outlined below to provide a deeper understanding of the research context for this thesis.

2.5.1 Social and cultural context in Taiwan

Taiwan, like many East Asian societies, is deeply influenced by Confucian values that emphasise mutual dependence, relational harmony, and collectivism (Hsu et al., 2009; Yum, 1988). These values promote concern for others and a strong sense of interconnectedness (Hui & Triandis, 1986). Taiwan's constitution guarantees freedom of religion, resulting in a diverse religious landscape that includes Taiwanese folk religion (a synthesis of Buddhism, Taoism, and Confucianism), Buddhism, Taoism, Christianity, and Yiguandao (a syncretic faith that incorporates elements of Confucianism, Taoism, Buddhism, Christianity, and Islam) (Weller, 2020). It is common for individuals to engage in multiple religious practices simultaneously, such as identifying as Buddhists while participating in Taiwanese folk rituals (Weller, 2020). This religious inclusivity reflects an adaptive and pluralistic worldview that shapes beliefs about family, relationships, and death. Collectively, these cultural and religious influences play a significant role in how Taiwanese families prepare for the death of a relative.

A family-centred orientation is deeply embedded in Taiwanese society and is strongly shaped by Confucian values and collectivist traditions. In Taiwanese culture, the family is regarded as a vital support system (Yum, 1988), and the principle of filial piety, where children are expected to honour, obey, and care for their parents, is central (Hsiung et al., 2025; Wu, 2006; Yeh et al., 2013). Harmony and respect for hierarchical familial relationships are reflected in the saying "Jia He Wan Shi Xing" (家和萬事興), meaning "family harmony brings prosperity" (Hsu et al., 2009; Penson, 2004; Yick & Gupta, 2002). These values influence not only family dynamics but also interactions within healthcare systems, where deference to professional authority and collective forms of decision-making are commonly observed (Brewer & Chen, 2007).

Attitudes towards death in Taiwan are shaped by Confucian ideals and diverse religious beliefs. Although the growth of palliative care has increased public awareness of death-related issues, the traditional belief that discussing death invites misfortune remains prevalent (Hsu et al., 2009). Nevertheless, Taiwanese cultural and religious practices provide structured ways of engaging with death, particularly through ancestor worship and rituals such as the Ghost Festival (Weller, 2020), which is similar to All Saints' Day. Ancestor worship, a practice rooted in Confucianism and common across East Asia, serves as an expression of filial devotion and the continuation of family bonds (Hsu et al., 2009; Yao, 2000). It often involves placing ancestral tablets on household altars or in communal ancestral halls (Weller, 2020). This practice, however, generally excludes deceased children, whose deaths are addressed through distinct ritual traditions (Weller, 2020), which are beyond the scope of this thesis.

The tradition of caring for the deceased person's afterlife reflects a widespread belief in Taiwan that the well-being of the dead continues to influence the living (Hsu et al., 2009). Taiwan's religious diversity further reinforces this emphasis on continuity between life and death. For example, the Buddhist concept of 'rebirth' (往生, wǎng shēng), widely accepted in Taiwan even among those who do not identify as Buddhist, views death as a transition rather than an end, offering hope of renewal in another realm. Such beliefs highlight the importance of religious and spiritual preparation for death and shape how families engage with the dying process.

Taiwan's social and cultural values contrast with those of many Western societies, where individualism and autonomy are emphasised (Inglehart, 2008) and religious participation in death is less pronounced (Lewis, 2007). This contrast highlights Taiwan as a valuable setting for examining how family death preparation unfolds within non-Western cultural frameworks. Moreover, the expansion of palliative care services in Taiwan has encouraged greater public engagement with death and dying, influencing how families navigate the end-of-life process within healthcare systems. Building on this cultural foundation, Taiwan's palliative care services, along with the legal and policy framework shaping end-of-life care and decision-making, are introduced in the following section.

2.5.2 Palliative care, legal framework, and advance care planning in Taiwan

Taiwan has developed a comprehensive palliative care system supported by legal and policy frameworks that influence how families prepare for a relative's death during end-of-life care. A summary of key developments is presented in **Figure 1**. Palliative care was first introduced in the 1980s and has since been integrated into the national healthcare system, with services covered under the National Health Insurance scheme. Specialised care is provided by multidisciplinary teams with advanced training and includes hospice inpatient units, hospital-based consultations, and home-based care. In addition, community-based palliative care is delivered by primary care providers with basic palliative care training. As of 2021, Taiwan's palliative care network comprised 81 inpatient units, 158 consultation teams, 122 home care teams, and 352 community care teams (National Health Insurance Administration, 2021).

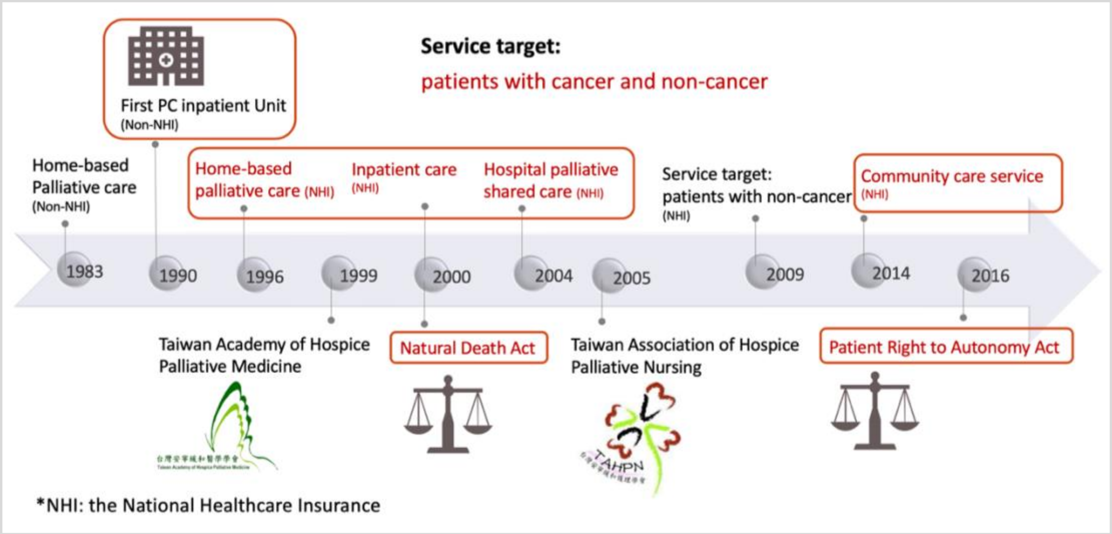

Figure 1: Development of palliative care in Taiwan (created by the researcher).

Palliative care in Taiwan is available to patients with both cancer and non-cancer conditions. However, access remains uneven. In 2017, 60.95% of patients with cancer received palliative care in their final year of life, compared with only 14.21% of those with non-cancer diagnoses (Control Yuan of Republic of China/Taiwan, 2019). This disparity suggests that palliative care continues to be closely associated with cancer trajectories, reflecting its historical roots in oncology and the ongoing predominance of cancer as the leading cause of death in Taiwan (Ministry of Health and Welfare, 2020).

To improve end-of-life care and safeguard patients’ rights, Taiwan has enacted two landmark pieces of legislation: the Natural Death Act (2000) (Laws & Regulations Database of The Republic of China/Taiwan, 2000) and the Patient Right to Autonomy Act (2019) (Laws & Regulations Database of The Republic of China/Taiwan, 2019). Both laws highlight the family’s role in end-of-life decision-making. The Natural Death Act permits family members to sign Do-Not-Resuscitate orders on behalf of patients based on their previously expressed wishes. The more recent Patient Right to Autonomy Act mandates the inclusion of at least one family member in advance care planning consultations, thereby formalising family involvement in end-of-life decisions.

Under the Patient Right to Autonomy Act (2019), advance care planning consultations must involve the patient, a physician, a nurse, a social worker or psychologist, and at least one family member (Laws & Regulations Database of The Republic of China/Taiwan, 2019). This requirement contrasts with international definitions of advance care planning, which often do not specify family participation or just recommend it (Rietjens et al., 2017). In Taiwan, advance care planning discussions focus on the individual's preferences for future treatment decisions, such as life-sustaining interventions and artificial nutrition and hydration in specific clinical conditions (e.g., terminal illness, irreversible coma, permanent vegetative state, severe dementia, or incurable disease causing unbearable suffering). These preferences can be formalised through legally binding advance directives. Between 2019 and 2022, approximately 43,500 individuals in Taiwan participated in advance care planning consultations and signed advance directives (Wang, 2023).

Although Taiwan's legal framework actively promotes family participation in advance care planning consultations, little is known about how these experiences shape families' own preparations for a relative's death. Existing research on advance care planning in Taiwan has primarily evaluated its effectiveness through clinical and administrative indicators. These include documentation rate of advance directives (Chu et al., 2018), healthcare utilisation and place of death (Yen et al., 2022), the use of life-sustaining treatments (Yen et al., 2018; Yen et al., 2022), patient outcomes such as quality of life and psychological distress, including anxiety and depression (Tang et al., 2019), satisfaction with the advance care planning process (Yen et al., 2021), and the concordance between patients' and those of their surrogates (Ke et al., 2020). However, these studies have largely focused on patient and healthcare outcomes, offering limited insight into the family perspective, particularly how families interpret, negotiate, and prepare for death within these legal and institutional frameworks.

2.5.3 Personal reflection on palliative care approaches between Taiwan and the United Kingdom

Based on my professional experience in Taiwan and voluntary work in a hospice in the United Kingdom, both similarities and differences can be observed in how palliative care is delivered in these two contexts. Both countries provide inpatient care, hospice home care, and consultation services, but notable distinctions exist. In Taiwan, palliative care is primarily hospital-based, whereas in the United Kingdom it is more commonly delivered through hospice and community settings. Taiwan's services are fully funded through the National Health Insurance scheme, while in the United Kingdom, charitable donations play a significant role in sustaining palliative care provision.

Another key distinction concerns the role of the family. In Taiwan, palliative care teams routinely collect detailed information about the patient’s family, such as through genograms, reflecting the family’s central role in the care process. This practice is less common in the United Kingdom, where a more individualised approach to care generally prevails. Both countries also provide designated viewing rooms in inpatient settings for the period following a patient’s death, although their design and purposes differ. In Taiwan, the viewing room (往生室, wǎng sheng shì) allows the deceased patient to remain for several hours, enabling family members to conduct religious rituals according to their beliefs. These rooms are often decorated with religious symbols, particularly Buddhist and Christian, whereas viewing rooms in the United Kingdom tend to be secular and contain few religious features.

These differences reflect how healthcare systems and cultural values shape the practice of palliative and end-of-life care. Taiwan adopts a more family-centred and religiously integrated approach, while the United Kingdom generally prioritise patient autonomy and incorporates religion to a lesser extent. Understanding these contrasts provides an important backdrop for exploring how Taiwanese families prepare for a relative’s death within palliative care settings, as examined in the next section.

2.5.4 Family death preparation in palliative care settings in Taiwan

Supporting patients and their families in preparing for death is a core component of palliative care training in Taiwan. The Taiwan Academy of Hospice Palliative Medicine and the Taiwan Association of Hospice Palliative Nursing regularly provide professional training that includes the use of the Checklist of Good Death Preparation. Originally developed by Taiwanese palliative care experts based on a literature review and published by the Department of Health, Executive Yuan (now the Ministry of Health and Welfare) in 2000, the checklist is intended to guide healthcare professionals in addressing the physical, psychosocial, spiritual, and funeral-related aspects of death preparation (Chao, 2000a, 2000b) (**Table 5**). Despite its widespread use in palliative care clinical practice for more than two decades, the checklist was developed from an expert perspective and does not fully incorporate the perspectives or lived experiences of family members. It also combines patients' and families' tasks for preparing for death into a single framework, rather than distinguishing between them, a design that may reflect Taiwan's family-centred cultural orientation.

Table 5: The checklist of death preparation used in palliative care in Taiwan.

Areas	**Tasks of death preparation**	
	Families	**Patient**
Physical	Educate family members on recognising pre-dying signs, providing physical care, and performing post-mortem body care	n/a
Psychosocial	Educate family members on effective communication with the patient Guide family members in providing companionship to the patient during the dying process Offer support to family members at risk of complicated grief Facilitate open and supportive communication among family members	Encourage the patient to express their final words Assist the patient in completing any unfinished business
Spiritual	Encourage family members to engage in religious preparations (e.g., religious rituals and relevant materials for the moment of the death) in accordance with the patient's religious beliefs or preferences	Relieve the spiritual distress of the patient if needed Guide the patient based on their beliefs regarding the direction after death or their afterlife
Funeral	Educate family members about obtaining death certificates Educate family members about preparing funeral rituals	Assess the patient's preferred place of death

n/a: Not applicable

2.6 Chapter summary

In this background chapter, an overview of existing evidence on family death preparation has been provided, together with an outline of the social, cultural, and healthcare context of Taiwan. The need for further research to understand how family caregivers engage in death preparation within non-Western cultural settings is highlighted. The present study seeks to explore family members' perspectives on preparing for the death of a relative and to develop recommendations for healthcare professionals to better support families in this process. The aim is to contribute culturally grounded evidence that extends beyond Western contexts, informing clinical practice, professional education, and the broader delivery of palliative and end-of-life care in Taiwan. They may also have relevance for culturally diverse populations living in Western societies. The overarching research question, overarching aim, specific objectives, and the methodological approach adopted to address these are described in the following chapter.

CHAPTER 3: METHODOLOGY AND METHODS

In this chapter, the overarching research question, aim, and specific objectives of this thesis are outlined. The choice of critical realism as the research paradigm is introduced, followed by an explanation of how this philosophical stance informs the study design used to explore family death preparation in Taiwan. The analytic methods employed in the study are also described, and their suitability within a critical realist framework is justified.

3.1 Research question, aim, and objectives

The overarching research question of this thesis is:

> *"How can families in Taiwan better prepare for the death of a relative?"*

Accordingly, the overarching aim of this thesis is to explore how families in Taiwan can better prepare for the death of a relative. To address this overarching research question and aim, four specific objectives were formulated:

1. To systematically analyse published literature on the bereavement experiences of Taiwanese family members following an expected death and to identify culturally appropriate bereavement theories relevant to the Taiwanese context.
2. To explore Taiwanese family caregivers' experiences of preparing for a relative's death within specialist palliative care settings.
3. To examine how Taiwanese families' approaches to death preparation are influenced by cultural context and how such preparations shape their subsequent bereavement experiences.
4. To develop and prioritise culturally sensitive recommendations for healthcare professionals to better support families in preparing for the death of a relative within the Taiwanese context.

3.2 Critical realism as the paradigm for exploring family death preparation

3.2.1 Understanding and positioning the research paradigm

Understanding the philosophical paradigm underpinning a study is essential for ensuring coherence between the researcher's assumptions, research questions, and methodological choices. A research paradigm provides a worldview for understanding the nature of reality and knowledge, shaping every aspect of the research process. It encompasses three interrelated components: ontology, epistemology, and methodology (Esposito & Evans-Winters, 2021; Rehman & Alharthi, 2016). Ontology concerns assumptions about the nature of reality and what exists. These ontological positions, in turn, inform epistemology, which addresses what can be known, how it can be known, and the relationship between the researcher and the researched. Methodology is shaped by these philosophical assumptions and guides the strategies and procedures used to gather and analyse data. In essence, the selected ontology informs the epistemological stance, which subsequently guides methodological decisions throughout the research process.

In positioning this research within an appropriate paradigm, the overarching research question was considered. This study seeks to explore how families in Taiwan can better prepare for the death of a relative. Family death preparation is recognised as a complex process involving multiple dimensions of readiness (Nielsen et al., 2016) and a range of tasks (Hebert et al., 2009), shaped by the broader social, cultural, and clinical contexts in which families are situated (Howarth, 2007). It was also important to reflect upon my own assumptions as a researcher. As a Taiwanese specialist palliative care nurse and researcher, I believe that while the reality of optimal family death preparation exists, it is inevitably shaped by contextual factors. Furthermore, the belief that families should be adequately supported in this process forms a central motivation for undertaking this research, with the broader aim of contributing to improvements in palliative and end-of-life care. These assumptions align with the principles of critical realism, which was identified as the most appropriate paradigm to underpin this study (Clark et al., 2008).

3.2.2 Core assumptions and application of critical realism

Critical realism, developed by Roy Bhaskar (1975), provides the philosophical foundation for this research by combining ontological realism with epistemological relativism. Ontological realism holds that an independent reality exists, characterised by complexity and openness (Bhaskar, 2008). Within critical realism, reality is conceptualised across three domains: the empirical domain, referring to what can be observed or experienced; the actual domain, referring to events that occur whether or not they are observed; and the causal domain, referring to the underlying mechanisms that generate these events. In contrast, epistemological relativism recognises that while various methods can be employed to explore reality, our understanding of it remains inherently partial and contextually mediated. What can be accessed is not independent reality itself but rather a contextual truth shaped by social, cultural, and experiential factors (Bhaskar, 2008). Thus, knowledge is approached through multiple methods and understood as situated, provisional, and open to refinement. Critical realism further emphasises the dynamic interaction between mechanisms and contexts, with an overarching aim of improving practices (McEvoy & Richards, 2016). These theoretical assumptions guided the methodological choices made in this study and ensured the coherence between its philosophical foundations, aims, and methods.

Informed by the assumptions of critical realism, a qualitative approach incorporating multiple methods and perspectives was employed to explore the complex experience of preparing for a relative's death in Taiwan. The overarching research question was examined through three interconnected perspectives: the bereavement experiences of family members following an expected death, the experiences of family caregivers who had engaged in the process of death preparation, and the views of specialist palliative care professionals who provide support. Accordingly, a systematic review and two empirical studies were conducted. The systematic review, using a narrative synthesis approach (Popay et al., 2006), examined the bereavement experiences of Taiwanese family members following an expected death. Its aim was to gain insights into family death preparation through post-bereavement reflections.

The second study employed a qualitative interview design with reflexive thematic analysis (Braun & Clarke, 2006, 2022b) to explore family death preparation from the perspectives of family members. It examined how Taiwanese family caregivers prepared for a relative's death within specialist palliative care settings, how cultural context shaped these preparations, and how such processes influenced subsequent bereavement.

The third study employed the nominal group technique (Jünger & Payne, 2020) combined with framework analysis (Parkinson et al., 2016; Ritchie & Spencer, 2002) to explore the perspectives of specialist palliative care professionals. The aim was to develop and prioritise culturally sensitive recommendations for improving support for families preparing for a relative's death in the Taiwanese context.

The systematic review (Paper 1) (Liang, Xiong, Remawi, et al., 2024) and the qualitative interview study (Papers 2 and 3) (Liang, Xiong, Lin, et al., 2024, 2025) have been published in peer-reviewed journals. A fourth article, which reflects on the methodological application of the nominal group technique, has also been published (Paper 4) (Liang, Xiong, & Preston, 2025). Details of the research methods used in this thesis are summarised in **Table 6**. Although the four papers outline the methodological approaches employed, the word limits imposed by peer-reviewed journals required concise reporting. In particular, Paper 4 focuses primarily on methodological reflections on the use of the nominal group technique and therefore provides limited details on how this method was applied within this thesis. Additional information on the methodological and analytical procedures is presented in the following sections.

Table 6: The methods used in this thesis.

Research paradigm	Critical realism Qualitative approach			
Study in this thesis	Systematic review	Qualitative interview study		Nominal group technique study
Research article	**Paper 1** Taiwanese family members' bereavement experience following an expected	**Paper 2** '*Regrets become a lasting source of pain*': A qualitative study on family caregivers'	**Paper 3** '*A good ending but not the end*'- Exploring family preparations	**Paper 4** Methodological reflections to support good practice in using nominal group techniques: Insights from

	death: a narrative synthesis review	experiences leading up to a relative's death	surrounding a relative's death and the Afterlife: A qualitative study	applications in palliative care studies
Methodology	Systematic review with narrative synthesis	Qualitative interview with reflexive thematic analysis		Nominal group technique, framework analysis

3.3 Systematic review: Understanding family death preparation through the lens of bereavement (Paper 1)

3.3.1 Rationale for conducting the systematic review

A systematic review using a narrative synthesis approach (Popay et al., 2006) was conducted to explore the bereavement experiences of Taiwanese family members following an expected death. The aim was to provide a deeper understanding of family death preparation by examining it through post-death bereavement perspectives, offering insight into how families retrospectively made sense of the preparation process. This review was designed in accordance with a critical realist orientation, recognising that family death preparation is shaped by context-dependent realities and that multiple perspectives are required to capture its complexity (Bhaskar, 2008).

The review focused exclusively on expected deaths, intentionally excluding sudden or unexpected deaths such as those caused by accidents, disasters, or suicides. This decision was based on evidence showing that unexpected deaths are associated with more complex bereavement outcomes, including higher risks of post-traumatic stress disorder and prolonged depressive symptoms (Kaltman & Bonanno, 2003; Kristensen et al., 2012), as well as abnormal grief responses (Djelantik et al., 2020; Krychiw et al., 2018).

Bereavement experiences among Taiwanese families have been examined using diverse research designs, including both qualitative and quantitative approaches. To construct a more comprehensive understanding of these experiences following an expected death, a systematic review integrating empirical studies employing varied methodologies was required. A synthesis method capable of accommodating such methodological diversity was therefore essential. The narrative synthesis approach (Popay et al., 2006) was selected as the most suitable method. This approach is particularly effective for synthesising findings from studies using diverse methodologies while relating them to established theories and concepts. It enables an interpretative synthesis rather than a purely aggregative approach and is therefore well aligned with the aims and philosophical underpinnings of this review.

Alternative synthesis approaches were also considered but ultimately deemed unsuitable. The integrative review method allows for the inclusion of both theoretical and empirical evidence (Whittemore & Knafl, 2005) and is commonly used to define concepts, review theoretical frameworks, or analyse research methodologies. As this review focused exclusively on empirical studies rather than theoretical or methodological literature, the integrative review was not appropriate. Similarly, critical interpretive synthesis (Dixon-Woods et al., 2006) was considered as a potential option, but it is primarily designed to generate new theoretical constructs and conceptual innovations. By contrast, this review sought to apply existing bereavement theories, predominantly developed in Western contexts, to evaluate their cultural relevance in Taiwan and to highlight any emerging insights within Chinese communities. For these reasons, the narrative synthesis approach (Popay et al., 2006) was identified as the most methodologically and philosophically coherent option.

3.3.2 The narrative synthesis process

While the process of conducting the narrative synthesis is presented in Paper 1, additional details are provided in this section to enhance methodological transparency. The section outlines how the synthesis was carried out in accordance with the four key elements proposed by Popay et al. (2006, p. 11) and how empirical evidence was interpreted and integrated to address the review aim.

Element 1: The role of theory in evidence synthesis

This element concerns how theory is used to guide the interpretation of findings. Theory refers to a set of related concepts and propositions used to explain and understand the meaning, nature, and relationships associated with a phenomenon (Varpio et al., 2020).

In the context of a narrative synthesis approach, theory provides a foundation for understanding how interventions operate, the mechanisms through which they produce outcomes, and the contexts in which they are most effective (Popay et al., 2006). However, this review did not examine the effectiveness or mechanisms of interventions. Instead, it focused on understanding the lived experiences of a specific phenomenon. Therefore, an inductive approach, without reliance on predefined frameworks or concepts, was adopted to analyse and synthesise data. Nevertheless, existing Western-oriented bereavement theories were subsequently used to interpret and contextualise the findings, including the continuing bonds theory (Klass et al., 1996; Steffen & Klass, 2018), Worden's task model (Worden, 2018), and the dual process model (Stroebe & Schut, 1999, 2010).

Element 2: Developing a preliminary synthesis

This element involved constructing an initial synthesis of the findings from the included studies using techniques such as tabulation, data transformation, and data translation (Popay et al., 2006). Tabulation was used to organise key study characteristics, including participant details, study design, definitions of bereavement, theoretical frameworks, and relevant key findings into structured tables. These visual representations facilitated the identification of patterns and variations across the studies.

Data translation was then employed to explore thematic similarities and to identify key themes and concepts that captured the main findings (Popay et al., 2006). All extracted data from the included studies, including qualitative, quantitative, and mixed methods designs, were imported into ATLAS.ti, a qualitative data management tool. A line-by-line, inductive coding approach was used to generate initial codes without using a priori categories. Codes were then grouped into preliminary themes, with iterative refinement of theme labels and data allocations throughout the synthesis process.

Element 3: Exploring relationships within and between studies

Relationships within and across the included studies were explored to identify thematic patterns, divergences, and sources of heterogeneity (Popay et al., 2006). Particular attention was given to factors such as bereavement timeframes, relationships to the deceased person, patient diagnosis, and varying definitions of bereavement. To deepen the analysis, concept mapping was used to develop a visual model that illustrated key concepts and their interrelationships, thereby highlighting the current state of knowledge on bereavement experiences in Taiwan. Several versions of the conceptual model were developed and refined in consultation with supervisors during the synthesis.

Element 4: Assessing the robustness of the synthesis

The final element involved evaluating the robustness of the synthesis. Two strategies were used to enhance the quality and transparency of the process: critical appraisal and reflexive evaluation. Hawker's critical appraisal tool (Hawker et al., 2002) was used to assess the methodological rigour of the included studies. In addition, a second reviewer participated in the article screening process to strengthen methodological rigour (Tong et al., 2012); this procedure is described in more detail in Paper 1 (Chapter 4). Reflexive considerations regarding the strengths and limitations of the synthesis process are explored further in the discussion chapter.

Summary

The systematic review has been published (Paper 1; see Chapter Four) (Liang, Xiong, Remawi, et al., 2024). Its findings indicate that family death preparation is a significant issue in end-of-life care and should be recognised as a key factor shaping bereavement experiences. However, there remains a limited understanding, particularly outside Western contexts, of how families prepare for a relative's death and how this preparation influences their subsequent bereavement. This gap in the literature highlighted the need for further empirical research. To address this, a qualitative interview study was conducted, as presented in the next section.

3.4 Application of qualitative interviews to explore family caregivers' experiences of death preparation (Papers 2 and 3)

3.4.1 Rationale for qualitative interviews

Semi-structured interviews were used as the primary method of data collection to explore family caregivers' experiences of preparing for the death of a relative. Interviewing is a widely used qualitative research method that involves direct engagement between researchers and participants. It can be implemented in three main formats: structured, unstructured, and semi-structured interviews (Carter & Henderson, 2005), each suited to different research paradigms and aims.

Structured interviews involve administering a fixed set of predetermined questions in the same order and manner across all participants (Carter & Henderson, 2005). This format is typically associated with quantitative or survey-based research, aiming for generalisability and hypothesis testing. However, such an approach is inconsistent with the philosophical underpinnings of this study, which adopts a qualitative approach grounded in critical realism. The aim here is not to test hypotheses but to gain an in-depth understanding of how family caregivers prepare for a relative’s death within specialist palliative care settings in Taiwan.

At the opposite end of the spectrum, unstructured interviews are fully participant-led, allowing individuals to share their experiences freely with minimal direction from the researcher (Carter & Henderson, 2005). While this format can elicit rich and nuanced narratives, it may also lead to data that moves away from the central focus of the study. Given these considerations, semi-structured interviews were deemed the most appropriate method for this research. This approach offers a balance between structure and flexibility. Interviews were guided by a topic guide developed in line with the research questions and piloted prior to formal data collection (Carter & Henderson, 2005). This ensured the core areas of interest were addressed while allowing participants the freedom to introduce and elaborate on issues they perceived as important. The researcher could adapt the order and phrasing of questions in response to the conversational flow and participants’ accounts, enabling deeper exploration where appropriate while maintaining alignment with the study’s aims.

The use of semi-structured interviews aligns with the study’s critical realist positioning (Bhaskar, 2008), which acknowledges that while an independent reality exists, individuals’ understandings of that reality are shaped by social and cultural contexts. This method enabled the generation of rich and contextualised accounts of family caregivers’ lived experiences and allowed the researcher to engage interpretively and reflexively throughout the data collection process.

Information on this study's participant criteria, sampling strategy, recruitment procedures, and data collection is detailed in Papers 2 and 3. A pilot interview was conducted in September 2022, followed by formal interviews undertaken between October 2022 and March 2023. The interview topic guide for family caregivers and the interview distress protocol are included in the supplementary materials of Papers 2 and 3.

3.4.2 Reflexive thematic analysis to capture the complexities of family death preparation

Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2022b) was applied to explore the complexities of Taiwanese family caregivers' experiences in preparing for the death of a relative. Thematic analysis is a method for analysing qualitative data through coding and theme development (Braun & Clarke, 2024). Several variants of thematic analysis exist, each underpinned by different philosophical assumptions and methodological practices (Braun & Clarke, 2022a, 2022b, 2023, 2024).

One variant, coding-reliability thematic analysis, aligns with a small-q theoretical position and adopts a positivist or post-positivist stance (Braun & Clarke, 2022b). Small q qualitative research refers to the use of qualitative techniques for data generation and analysis within a positivist framework, with an emphasis on coding reliability and accuracy. This approach typically seeks to minimise researcher bias through procedures such as inter-coder agreement or member checking. In contrast, reflexive thematic analysis (Braun & Clarke, 2022b), the approach adopted in this study, is grounded in a Big Q perspective within a non-positivist paradigm. While both Big Q and small q qualitative research use qualitative methods, they are underpinned by different research values (Braun & Clarke, 2025). Big Q qualitative research rejects objectivist assumptions and norms, and adopts an interpretative stance, acknowledging that knowledge is situated, partial, subjective, and shaped by context (Braun & Clarke, 2025). Researcher subjectivity is not seen as a potential threat to research quality and to be eliminated, but as a valuable resource for research, with reflexivity playing a central role in the research process. A third approach, codebook thematic analysis (Braun & Clarke, 2022b), occupies a middle ground between the coding reliability and reflexive approaches, combining elements of both to meet different theoretical and practical needs.

Braun and Clarke’s reflexive thematic analysis, underpinned by a Big Q approach, was selected for this study because of its alignment with the critical realist paradigm that underpins the research (Braun & Clarke, 2022b, 2023). Within a critical realist framework, reflexive thematic analysis seeks to generate meaningful interpretations of participants’ accounts that reflect socially and culturally situated realities, rather than to represent objective truth (Braun & Clarke, 2022b). In this study, I examined how participants perceived and articulated their experiences of preparing for a relative’s death, shaped by their specific social and cultural contexts. What was accessed were context-dependent understandings of reality, conveyed through qualitative interview data and interpreted through the lens of my professional and cultural background. While the possibility of an optimal family death preparation experience is acknowledged, the findings presented here reflect situated knowledge constructed through participant narratives and shaped by my interpretative engagement with the data.

Braun and Clarke’s reflexive thematic analysis also facilitates the development of shared patterns of meaning across a dataset while remaining sensitive to the social and cultural contexts in which experiences are embedded (Braun & Clarke, 2006, 2020, 2022b). This method supports the generation of insights that can inform clinical practice, making it particularly suited to the aims of this study. Specifically, it was used to explore how Taiwanese family caregivers prepare for a relative’s death within specialist palliative care and how these experiences are shaped by cultural contexts. The resulting thematic findings provide evidence to inform and enhance palliative and end-of-life care practice.

In reflexive thematic analysis, themes are understood as patterns of meaning across the dataset rather than as meanings located within individual cases (Braun & Clarke, 2023, 2024). Themes are not simply summaries of data domains or grouped topics that lack shared meaning, nor do they pre-exist within the data, awaiting discovery or passive emergence (Braun & Clarke, 2022b). Instead, they are actively developed by the researcher through reflexive and systematic engagement with the dataset (Braun & Clarke, 2022a). In this approach, themes represent analytic outputs, each underpinned by a central organising concept and constructed iteratively through the generation and refinement of codes (Braun & Clarke, 2022a, 2022b, 2024).

Two types of codes are recognised within this approach: semantic and latent codes

(Braun & Clarke, 2022a, 2022b, 2024). Semantic codes operate at a surface level, reflecting meanings that closely align with participants' explicit language. In contrast, latent codes capture underlying or implicit meanings that are more interpretative in nature, often involving abstraction beyond the surface content. When developing code labels, it is important that they convey specific and contextually grounded meanings, as reflexive thematic analysis aims to capture the richness and diversity of meaning relevant to the research questions (Braun & Clarke, 2022b).

In this study, data were inductively analysed using Braun and Clarke's reflexive thematic analysis, following a six-phase process: (1) familiarisation with the dataset, (2) coding the data, (3) generating initial themes, (4) developing and reviewing themes, (5) refining, defining, and naming themes, and (6) writing up (Braun & Clarke, 2022a, 2022b). The inductive approach informed both data collection and analysis, allowing coding and theme development to be guided by the content of the data itself (Braun & Clarke, 2022a). These phases were undertaken in a manner consistent with the values and assumptions of a Big Q theoretical position (Braun & Clarke, 2022b). The analysis process and thematic maps for this study are presented in Papers 2 and 3 and their supplementary materials. Additional details of the reflexive thematic analysis procedure are provided in **Appendix 1**.

Reflexivity is a key component of reflexive thematic analysis, which emphasises that researchers should critically reflect on how their personal and professional assumptions influence the research process and shape the knowledge that is generated (Braun & Clarke, 2022b). A common strategy for maintaining reflexivity is keeping a reflexive journal throughout the research process, which was also applied in this study. Further details on how reflexivity was maintained are presented later in this chapter.

Summary

The qualitative interview study has been written up and published (Papers 2 and 3; see Chapters Five and Six) (Liang, Xiong, Lin, et al., 2024, 2025). The findings highlight the pivotal role of healthcare professionals in supporting family death preparation, particularly in relation to end-of-life decision-making and caregiving. In response, a nominal group technique study with specialist palliative care professionals was subsequently conducted to develop practical recommendations on how better to support families preparing for a relative's death.

3.5 Application of the nominal group technique to develop recommendations for supporting family death preparation (Paper 4)

3.5.1 Rationale for using the nominal group technique

The third study employed the nominal group technique (Jünger & Payne, 2020), combined with framework analysis (Ritchie & Spencer, 2002), to explore family death preparation from the perspectives of specialist palliative care professionals. Its purpose was to develop and prioritise culturally sensitive recommendations for improving support for families in Taiwan as they prepare for a relative's death.

The nominal group technique was chosen because it facilitates structured group discussion and consensus-building, particularly in areas where empirical evidence remains limited (Jünger & Payne, 2020). Among formal consensus approaches, the Delphi method and the nominal group technique are most widely used to generate recommendations through practitioner participation (Black et al., 1999; Fink et al., 1984; Foth et al., 2016; Jünger & Payne, 2020; Redman et al., 1997). While the Delphi method emphasises iterative, anonymous rounds of data collection, the nominal group technique enables real-time interaction and clarification among participants, allowing for immediate identification and ranking of priorities (Jünger & Payne, 2020). Given the limited exploration of family death preparation and the absence of detailed clinical guidance, as discussed in the background chapter, the nominal group technique was considered well-suited to the aims of this study.

3.5.2 Conduct of the nominal group technique

The study followed a structured nominal group technique process involving preparation, sampling, facilitation of group meetings, and data analysis (Jünger & Payne, 2020). A detailed methodological reflection on the use of this technique, including its application in this study, is presented in Paper 4 (Liang, Xiong, & Preston, 2025) (see Chapter Eight). The following section outlines key procedures not included in the published paper.

Sampling

Participants were purposively recruited based on their expertise in specialist palliative care, ensuring a breadth of disciplinary and experiential perspectives to strengthen the quality of the outcomes (Jünger & Payne, 2020). Eligible participants had at least five years of professional experience in specialist palliative care settings (Baker et al., 2006), including inpatient units, consultation teams, or home care services. Physicians, nurses, social workers, psychologists, and chaplains were all eligible to ensure multidisciplinary representation. To support group interaction and allow sufficient time for each participant to contribute, the target group size was set between eight and twelve participants (Jones & Hunter, 1995).

Recruitment

Recruitment was facilitated through gatekeepers such as managers of specialist palliative care teams and professional organisations, including the Taiwan Association of Hospice Palliative Nursing. These gatekeepers assisted in disseminating study information and minimising potential coercion, particularly as the researcher is a Taiwanese specialist palliative care nurse and a member of the same professional community. Interested individuals could contact the researcher directly or, with consent, have their contact details shared. A participant information sheet and consent form were provided to support informed decision-making. Questions or concerns raised during the consent process were addressed using participants' preferred communication methods, including Line, a widely used messaging platform in Taiwan. Participants were informed that the meeting would be digitally recorded to facilitate subsequent analysis of how recommendations were generated and discussed. Written informed consent, including consent for audio recording, was obtained either a few days prior to the meeting (virtually) or on the day of the meeting before it began.

Nominal group meeting

The group meeting followed standard stages of the nominal group technique: introductions, presentation of evidence, recommendation generation and listing, clarification, voting and ranking, and conclusion (Jones & Hunter, 1995; Jünger & Payne, 2020). A pilot meeting was held on 8 June 2023, followed by the main group meeting on

8 July 2023. During the session, participants discussed the research question:

> *What are feasible strategies to improve care for families preparing for the death of a relative, from the perspective of specialist palliative care professionals?*

Recommendations were first generated individually, then shared, clarified, and refined through group discussion. Participants subsequently voted anonymously for their top ten recommendations and ranked them in order of implementation priority. Further details of the meeting process are provided in Paper 4 (Liang, Xiong, & Preston, 2025) (see Chapter Eight). Supporting materials, including the nominal group technique guide and participant characteristics form, are provided in **Appendices 2 and 3**.

3.5.3 Applying framework analysis to refine recommendations

The rationale for applying framework analysis in this study and its implementation are detailed in Paper 4 (Liang, Xiong, & Preston, 2025) (see Chapter Eight). In brief, conversations from the recommendation listing, clarification, and discussion phases of the nominal group meeting were transcribed in Traditional Chinese and analysed inductively using the key five stages of framework analysis: familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation (Ritchie & Spencer, 2002). These segments were selected for in-depth analysis instead of the full meeting transcript, as they contained the richest insights into participants' reasoning and discussions surrounding the recommendations. During the charting stage, selected data extracts were translated into English and incorporated into the thematic framework. This process ensured that the recommendations remained grounded in participants' original meanings while enhancing their clarity, applicability, and transferability to practice.

Through this analytic process, the 42 initial recommendations generated from the meeting were refined and consolidated into four final recommendations, accompanied by two main thematic findings. The findings of the nominal group technique study, including participant characteristics, are presented in Chapter Seven.

3.6 Researcher subjectivity and reflexivity

Positionality, subjectivity, and reflexivity are central to qualitative inquiry because they shape how knowledge is produced throughout the research process. Positionality refers to the researcher’s social, cultural, and professional positioning and the ways in which this shapes interactions with participants, as well as data collection and interpretation (Bourke, 2014). Subjectivity encompasses the perspectives, values, beliefs, and lived experiences that researchers bring to their study, shaped by cultural background, education, professional training, and broader social positioning (Varpio & Ellaway, 2021). Reflexivity is understood as an ongoing, critical engagement with subjectivity and its influence on all stages of the research process (Bourke, 2014; Braun & Clarke, 2022b, 2024). This research is situated within a critical realist paradigm, which assumes that while an independent reality exists, our understanding of it is partial, mediated, and shaped by context (McEvoy & Richards, 2016). This philosophical stance aligns with my beliefs that although “best possible” experiences of preparing for a relative’s death may exist, access to such experiences is shaped by social, cultural, and structural conditions. In this study, subjectivity is not treated as a bias to be minimised but as a resource that requires critical engagement through reflexivity (Braun & Clarke, 2022a, 2022b). This section outlines how my positionality and subjectivity shaped the research process and how I engaged reflexively with that influence.

As the researcher conducting the study, I occupy multiple roles, including being Taiwanese, a family member who has experienced the death of close relatives, a specialist palliative care nurse, and a PhD student trained in the United Kingdom. My cultural upbringing and lived experiences in Taiwanese society have shaped my understanding of death, dying, and bereavement in this context. The death of my grandmother, who received hospice home care and died peacefully at home, deepened my appreciation of the importance of a good death for families’ bereavement. During the process of writing this thesis, my mother died following an unexpected motorcycle accident. She received care in the intensive care unit for several days before her death. This experience further shaped my understanding of the research topic and made me feel that I was, in some ways, connected to the bereaved families I interviewed, as I shared similar experiences and emotions with them. Further reflection on this personal connection is provided in the discussion chapter.

My clinical experience in Taiwanese palliative care has also provided practical insights into end-of-life care, the healthcare system, and the pivotal role of family caregivers. At the same time, my professional and academic training in Taiwan and the United Kingdom has exposed me to theoretical frameworks predominantly grounded in Western approaches to palliative and end-of-life care. This multiple positioning situates me as both an insider, sharing linguistic, cultural and emotional familiarity with participants, and as an outsider, informed by international literature and Western theoretical models. This insider-outsider positioning influenced the study design, my engagement with participants, and the process of data analysis, offering both advantages and challenges (Varpio & Ellaway, 2021). Further reflection on how my subjectivity influenced the interpretation of the findings is provided in the discussion chapter.

During data collection, my familiarity with Taiwanese cultural values, language, and social norms helped me build trust and rapport with participants, which was particularly important when discussing sensitive topics such as death, dying, and bereavement. This shared cultural background appeared to support participants in speaking openly and enabled the collection of rich and nuanced narratives. It also helped me recognise linguistic and cultural meanings embedded in Traditional Chinese or Taiwanese that might have been overlooked by non-native speakers during data analysis. At the same time, I remained aware that my cultural closeness and professional background could shape data collection and my interpretation of participants' accounts, including the risk of reinforcing assumptions or narrowing interpretative possibilities. For example, I might assume I understood participants' meanings without probing further. This multiple positioning, including the clinician-researcher role, highlighted the importance of reflexivity (Salifu, 2025).

In this study, reflexivity involved continual reflection on how my positionality, including my Taiwanese identity, cultural background, personal experience of bereavement and family death preparation, and disciplinary training, shaped my understanding of the research topic. To support reflexive practice, I kept a reflexive journal in my native language to document analytic reflections, emotional responses, and evolving perspectives throughout the research process (Braun & Clarke, 2022a, 2022b). I chose to use my native language when undertaking personal reflection and analytic thinking during data collection and analysis, including thinking through the development of themes and the interpretation of findings (van Nes et al., 2010). This allowed me to reflect in the language shared with participants, supporting deeper understanding of the phenomenon and more comprehensive interpretation of findings. Regular discussions with my two supervisors, one from an English background and the other from a Chinese background, provided valuable opportunities to question assumptions, enhance cultural sensitivity, and deepen reflexive awareness. My supervisors' complementary cultural and linguistic backgrounds supported the research process by offering critical reflections that highlighted the interconnection between language, culture, and family death preparation. These discussions were particularly useful when navigating translation challenges and examining how cultural norms shaped language and meaning in participants' accounts. Reflexivity was also closely connected to the multilingual nature of the research process.

Language and translation were important methodological considerations in this thesis. Data were collected in Traditional Chinese or Taiwanese, while the thesis and publications were written in English. This required careful attention to preserving both the meaning and cultural resonance in participants' accounts. To support this, I remained in the original language as long as possible during the analytic process, including writing my reflexive journal in my native language and translating relevant material into English at later stages of analysis (van Nes et al., 2010). When discussing the analysis with my main supervisor, who does not speak the source language, relevant materials were translated while retaining the original text and avoiding fixed one-word translations (van Nes et al., 2010). When translating, rather than prioritising literal translation, I sought cultural equivalence to preserve the depth and nuance of participants lived experiences. Working across languages also highlighted the broader cross-cultural dynamics of the study, as the research was situated within a Taiwanese context but written and theorised in English. In addition, much of my professional training, as well as the broader practice of palliative care in Taiwan, has been influenced by Western models and evidence. These dynamics underscored the importance of cultural sensitivity and sustained reflexivity throughout the research process.

In sum, consistent with the critical realist paradigm (Bhaskar, 2008), my subjectivity is not viewed as a source of bias to be eliminated but as a lens through which knowledge is generated (Braun & Clarke, 2023). My aim was to engage with participants' situated realities while remaining reflexive about the interpretative processes shaping data collection and analysis. The knowledge generated in this thesis is therefore understood as contextual, situated, and open to reinterpretation.

3.7 Ethical considerations and public engagement

Ethical and public engagement considerations formed an integral part of the research design and conduct of this study. Ethical issues related to the two empirical studies are discussed in Papers 2 and 3 (see Chapters Five and Six) and earlier in this chapter. Copies of the ethical approval documents are provided in the appendices (**Appendix 4**).

Public engagement in health research encompasses various approaches that reflect different levels of involvement. Such engagement may include consulting members of the public about research priorities and implementation strategies, inviting their participation on advisory committees, collaborating with them in developing research proposals, or involving them directly as co-researchers responsible for data collection (Collins & Halliday, 2020). These activities are typically categorised into three main forms: consultation, collaboration, and user-controlled research (Collins & Halliday, 2020). Consultation generally involves a one-off or time-limited interaction in which researchers seek input from individuals with lived experience relevant to the study topic. Collaboration represents a more sustained partnership between researchers and members of the public, with both parties working together toward shared objectives. In contrast, user-controlled research is led by service users who retain primary responsibility for directing and conducting the study. When determining the most appropriate model of public engagement, researchers are encouraged to reflect on their motivations, values, and the intended influence of public involvement on both the research process and outcomes (Collins & Halliday, 2020).

In this PhD study, public engagement followed a consultation approach, with the primary aim of enhancing the relevance of the research topic and the rigour of the study design. The researcher consulted three bereaved family members and three specialist palliative care professionals. These individuals were personally known to the researcher as friends or colleagues with direct experience in preparing for a relative's death. Their contributions informed several key aspects of the study’s development, including the significance of the research topic, strategies for participant recruitment, and approaches to data collection.

The consulted individuals collectively emphasised that preparation for a relative’s death is a critical factor in supporting families through the subsequent bereavement process. They observed that family caregivers often prioritise the needs of the dying relative over their own well-being and highlighted that minimising future regrets is particularly important in this context. They also advised that interviews with bereaved family members should be conducted with particular sensitivity, recommending a flexible approach to accommodate participants’ emotional variability. This feedback directly informed the development of the interview distress protocol for bereaved family caregivers. Finally, they recommended the use of multiple recruitment channels for both bereaved family caregivers and specialist palliative care professionals to increase the likelihood of obtaining a diverse and meaningful dataset, thereby strengthening the depth and applicability of the study’s findings.

The individuals consulted did not take part in the subsequent pilot test of the study. Incorporating public engagement to inform study design is relatively novel within the Taiwanese research context. However, the extent of its influence may have been limited by the researcher being primarily based in the United Kingdom, which reduced opportunities for more in-depth local collaboration.

3.8 Chapter summary

In this chapter, the overarching research question, overarching aim and specific objectives, the philosophical paradigm underpinning the study, and the methods used to address them have been outlined. The rationale for adopting critical realism as the guiding paradigm has been explained, along with how this philosophical stance informed the methodological choices. The methods used in the three studies, a systematic review, a qualitative interview study, and a nominal group technique study, have been described in more detail than in the published papers. Finally, research reflexivity, ethical considerations, and public engagement have been discussed in relation to the overall research process. The next four chapters present the research outputs from the systematic review and the qualitative interview study, comprising three published papers (Chapters Four to Six, i.e., Papers 1, 2, and 3). The empirical findings from the nominal group technique study are presented in Chapter Seven.

CHAPTER 4: TAIWANESE FAMILY MEMBERS' BEREAVEMENT EXPERIENCE FOLLOWING AN EXPECTED DEATH: A NARRATIVE SYNTHESIS REVIEW (PAPER 1)

4.1 Overview

This paper (Liang, Xiong, Remawi, et al., 2024) specifically addresses the first research objective of the thesis:

> *To systematically analyse published literature on the bereavement experiences of Taiwanese family members following an expected death and to identify culturally appropriate bereavement theories relevant to the Taiwanese context.*

A systematic review using a narrative synthesis approach (Popay et al., 2006) was conducted to examine the bereavement experiences of Taiwanese family members following an expected death. The review aimed to gain insight into how families prepare for a relative's death from a post-bereavement perspective, thereby contributing to a broader understanding of family death preparation within the Taiwanese context.

Insights derived from this review provided both theoretical and empirical foundations for the subsequent stages of this thesis. A key finding was that family death preparation influences subsequent bereavement experiences, yet understanding of this process remains limited, particularly outside Western contexts. These findings informed the design of the qualitative interview study (Papers 2 and 3), which explored in greater depth how Taiwanese families prepare for a relative's death within specialist palliative care settings. The review findings also guided the design of the nominal group technique study (Chapter Seven, i.e. Paper 4), serving as evidence presented to participants to support the development of culturally sensitive and practical recommendations for improving support for families during this process.

The published paper is reproduced in the following section.

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RESEARCH **Open Access**

Taiwanese family members' bereavement experience following an expected death: a systematic review and narrative synthesis

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Abstract

Background Bereavement experience is shaped by cultural and social contexts. No systematically constructed reviews were identified to explore the bereavement experience for people who are influenced by Chinese culture valuing filial piety and mutual dependence. This review aimed to systematically review the bereavement experience of Taiwanese family members living in Taiwan following an expected death.

Methods MEDLINE, PsycINFO, CINAHL, China Academic Journal Database, and Chinese Electronic Periodical Services were searched with no date restrictions from inception to 20 October 2022. The methodological rigour of studies was assessed using Hawker's appraisal tool. A narrative synthesis approach using Popay's work was employed to synthesise the findings of the studies. Studies investigating Taiwanese family members' bereavement experiences were included. We excluded papers studying bereavement through the death of a child.

Results Searches retrieved 12,735 articles (after de-duplication), 17 of which met the inclusion criteria and were included for synthesis: English [9] and Chinese [8], published between 2006 and 2021. The studies varied in quality with scores ranging from 22 to 33 out of 36. The studies differed in the relationship between participants and the deceased, the bereaved time frames, and the definitions of bereavement. Most studies focussed on family members of cancer patients receiving specialist palliative care. Three bereavement theories and four tools were used. Risk factors of bereavement outcomes included family members feeling less prepared for death and deaths where palliative sedative therapy was used. Protective factors were higher caregiving burden and longer caregiving periods. Four themes regarding Taiwanese bereavement experience were generated: multiple impacts of death; problem-based coping strategies; importance of maintaining connections; influential religious beliefs and rituals.

Conclusion Continuing the relationship with the deceased is a key element of Taiwanese bereavement experience and it is influenced by religious and cultural beliefs. Suppressing or hiding emotions during bereavement to connect with the deceased and maintain harmonious relationships needs to be acknowledged as culturally acceptable and encouraged by some religions in Taiwan. The findings could be potentially relevant for other Chinese populations, predominantly Buddhist countries or other East Asian societies. The role of preparing for death in bereavement outcomes is little understood and requires further research.

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Keywords Bereavement, Family, Expected death, Taiwan, Narrative synthesis, Mixed-studies review, Chinese

Background

Bereavement care service is an essential part of delivering palliative care [1–3]. Bereavement experience is shaped by cultural and social contexts [4–6]. The bereaved express their grief through social acts and mourning practices appropriate to their cultural context [7]. Hence, the provision of good bereavement support needs to consider the cultural and social context of the bereaved [5, 8], and this would enhance the quality of palliative care services.

Chinese is the largest ethnic group in the world, consisting of about 20% of the global population and numbering around 1.4 billion people worldwide [9]. The Chinese culture has been deeply influenced by Confucianism and collectivism, which values the importance of family, filial piety, mutual dependence [10], and concern for others [11]. Maintaining harmony in a group is also a dominant feature of the Chinese culture [12]. The experience of bereavement in Chinese culture has been explored using different research designs, including quantitative and qualitative. There is a wide range of previous systematic reviews on bereavement experiences such as abnormal grief [13–15], grief measurements [16, 17], interventions for bereavement [18, 19] and bereavement outcomes [20]. However, no systematically constructed reviews were identified to explore such experiences for people who are influenced by Chinese culture. A systematic review to synthesise the current evidence can allow a more comprehensive understanding to inform clinical practice regarding providing culturally sensitive bereavement care. Therefore, a review to synthesise the bereavement experience of Chinese family members should be carried out.

Although many areas of East Asia, such as Taiwan, China, and Hong Kong, share a similar traditional Chinese culture, the palliative health care systems are different. For instance, Taiwan was ranked in third place in the Quality of Death and Dying in 2021; China and Hong Kong were ranked 53rd and 23rd, respectively [21]. Given the differences in healthcare systems, a review to synthesise the bereavement experience of Taiwanese family members living in Taiwan under the context of expected deaths was planned. The review excluded unexpected deaths such as accidents, disasters, and suicides as they are associated with a more difficult bereavement, including greater posttraumatic stress disorder symptoms, enduring depression [22, 23] and abnormal grief [13, 24].

Western-oriented bereavement theories, such as Worden's task model [25, 26] and the Dual Process Model [4, 27], were commonly employed to inform clinical practice in Taiwan. Western cultures tend to promote autonomy and individualism [28], which is very different from Chinese culture, as described earlier. The application of Western-oriented bereavement theories in Taiwan needs adaptation to consider cultural differences [5, 8]. Therefore, this review also aimed to inform which Western-oriented bereavement theories are more culturally appropriate in Taiwan and whether any new theories have been developed and applied in Chinese communities. The aim is these can inform future research and bereavement support practices for Taiwan and other Chinese populations.

Methods

The review question

What is the bereavement experience of Taiwanese family members following an expected death?

The review design

An integrative review approach was used as it can include different designs to gain a wider understanding of the phenomena. The Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement [29] was followed in reporting the review.

The search strategy. Five electronic databases were searched from inception to 20 October 2022: MEDLINE, PsycINFO, CINAHL, China Academic Journal Database (CNKI), and Chinese Electronic Periodical Services (CEPS). A specialist health librarian was consulted for the search strategy. The following key concepts, along with synonyms and tailored subject headings, were used: 'bereavement', 'family', and 'Chinese' (Supplementary Material 1). The reason for using 'Chinese' as a keyword is that the majority of literature tends to define the population in Taiwan as Chinese ('Hua-ren', 華人). Boolean operators (AND, OR) and search commands such as truncation and proximity searches were applied [30]. There were no date restrictions. The MEDLINE database search string (Supplementary Material 2) was adjusted to other databases. Additional search strategies included: using key papers to test the searching strategy, searching Open Grey (grey literature database), screening reference lists of included studies, conducting citation tracking of included papers through Google Scholar, and setting alerts in MEDLINE, PsycINFO, and CINAHL to track potential new articles.

Study eligibility. Table 1 describes the inclusion and exclusion criteria. In the review, Taiwanese family members mean Taiwanese living in Taiwan as this review investigates the bereavement experience which is influenced by cultural and social contexts. Papers about people bereaved through the death of a child were excluded

Table 1 Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Study population	• Taiwanese over 18 years old living in Taiwan • Participants are family members or significant others of the deceased • The relationship to the deceased: spouse, parents, adult children, sibling, significant other, partner	• The bereavement caused by the death of a child
Study topic	• Studies focused on the experience of having lost a relative or significant other from an expected death, trying to adapt to the relative's or significant other's death or the process of grieving and mourning	• Studies focused on developing bereavement measurements or interventions • Unexpected death such as COVID-19, violence, accidents, disaster, suicide, and murder
Type of evidence	• Primary research • Peer-reviewed journal articles	
Language	• English, traditional Chinese	

because it is recognised as a more challenging experience than other types of bereavement [31] and may have a higher risk for suffering in abnormal grief [32]. The main researcher (HJL) screened titles and abstracts of all retrieved articles, while a second reviewer (BNR) screened 10% of them to enhance the rigour of the screening process [29]. Disagreements of four articles (0.3%) were resolved through further discussions about the inclusion criteria among authors.

Quality assessment and data extraction. Hawker et al.'s data extraction form [33] was adapted according to the review's purpose to collect relevant data (Supplementary Material 3). For qualitative research, relevant descriptions of key themes were drawn from the included papers. Quantitative data which answered the review question was transformed into a textual description [34] as this review aims to explore the bereavement experiences such as adaptation after death.

Hawker et al.'s critical appraisal tool with a score ranging from 9 to 36 was chosen as it is suitable for reviewing different designs [33]. Assessment of study quality was conducted by the main researcher (HJL) while extracting data from all identified papers.

Data synthesis. Popay et al.'s approach to narrative synthesis was undertaken in an iterative manner [34]. Tabulation was conducted to summarise details of participants and key findings and to identify patterns and differences across studies. Translating data was applied to systematically identify the main themes that represented research findings. The results of the tabulation were imported into ATLAS.ti to assist with the translating process. Initial free coding was conducted line-by-line inductively across the studies. The researcher (HJL) grouped the codes and developed potential themes (Supplementary Material 4). Initial themes were renamed, and data were moved around to fit the themes throughout this process. These were reviewed and developed in an iterative process through discussion with NP and QX. A conceptual model was developed to visually present the findings through discussion (Supplementary Material 5). Finally, the dominant bereavement theories were used to interpret the review findings.

Results

Searches retrieved 12,735 articles (after de-duplication), 17 of which met the inclusion criteria of the review and were included for synthesis. The Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) flowchart [35] shows details of the studies' identification and selection process (Fig. 1).

Study characteristics

The 17 papers were published between 2006 and 2021. There were ten qualitative studies [36–43, 45, 46], one mixed-methods study [47], and six quantitative surveys [48–53]. Six of the 17 studies employed longitudinal design [39, 43, 48, 49, 52, 53] (Table 2). The main aim of the qualitative studies was to explore family members' bereavement experience, while the quantitative surveys mainly investigated the relationship between grief and specific variables such as family members' demographics and palliative sedation therapy. Most studies ($n=12$) recruited participants from a single hospital [39–43, 45, 46, 48–52], and two qualitative studies included only one family member as the participant [41, 42]. Studies were conducted across Taiwan. For an overview of the characteristics of the included studies see Supplementary Material 7.

The participants in the studies were 2,011 family members; nearly 65% were female. The mean age of family members was 46 years (range: 36–73). The majority of the participants held Buddhist beliefs, with some also practising Taoism/Daoism and Christianity. The included studies differed in the relationship between participants and the deceased and the bereaved time frames. The primary relationships were spouse and parent-adult children [36, 38, 46, 48–53]. The average bereaved time varied with the range between 36 hours and four years, but most studies were from six months to 18 months [37–39, 43, 45, 46, 50–52]. Most studies ($n=16$) investigated terminally ill cancer patients [36–39, 41–43, 45–53] who received specialist inpatient palliative care ($n=10$) [39, 42, 43, 45, 46, 48–51, 53]. No study investigated hospice home care patients. Table 2 describes the characteristics and the key relevant findings of the included studies.

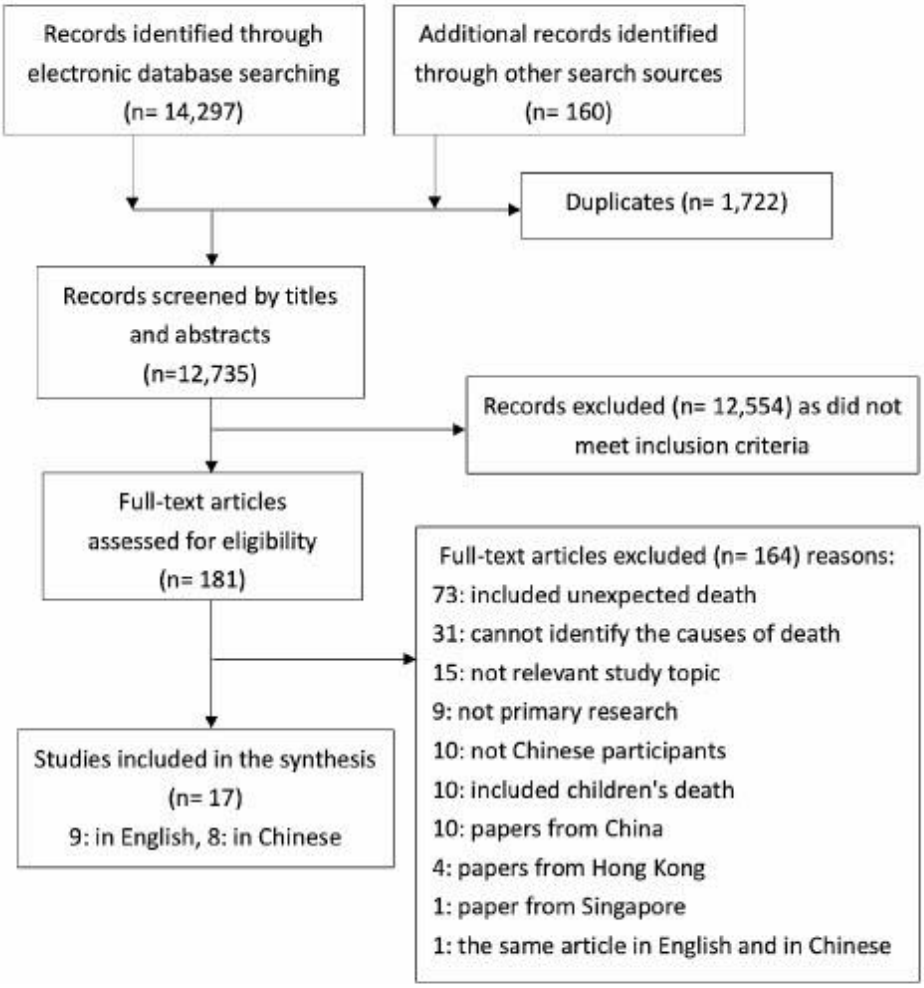

Fig. 1 Search process flowchart (PRISMA flowchart)

The studies varied in quality with scores ranging from 22 to 33 out of 36; most studies (11 out of 17) scored between 26 and 32 [37–40, 43, 45, 47–51] (Supplementary Material 6). Among the nine domains of Hawker's appraisal tool, the included studies were assessed as good or fair in the abstract and title, method and data, and results section. The common reasons for achieving poor or very poor quality in the included studies were related to ethics and bias [36, 37, 39, 49, 50], data analysis [36, 38, 41, 47], and implication and usefulness [36, 37, 39, 42] because of the limited information provided by authors.

Exploration of definitions and theories of bereavement

The definition of bereavement varied among the included studies. Only three studies investigated complicated or prolonged grief [50–52]. Complicated grief was defined as the experience of having separation distress and post-traumatic stress and being unable to cope with the death [50]. Prolonged grief was described as experiencing intense grief reactions which lasted for more than six months [51, 52]. Moreover, Taiwanese researchers Lee et al. developed the term Bei-Dao (悲悼) [43]. Bei (悲) means individual grief; Dao (悼) indicates collective mourning and emphasises the continuing relationship with the deceased [43], which recognises the importance of relationships for the Taiwanese. Other studies also emphasised that reconnection with the deceased was vital for the bereaved [37, 40]. Two studies described bereavement as a family event and would impact the family dynamics [38, 46]; two studies illustrated that bereavement was the experience of making sense of the loss [39, 42]. The other four studies used diverse bereavement definitions: grief reactions with physical, psychosocial, and spiritual dimensions [45]; bereavement was related to the coping mechanisms of the bereaved and their support systems [47]; the bereaved might re-experience grief in a specific time such as the deceased birthday [41]; bereavement might impact the emotional and physical health status of the bereaved [49]. Three studies did not clearly define bereavement [36, 48, 53].

Table 2 Characteristics and key findings of the included studies

Author, year of publication, Region	Participants/ Setting	Method	Key findings	Hawker score
Tsai, 2007, Middle Taiwan [36]	14 bereaved family members of cancer patients, the gender of the participants not mentioned	Grounded theory	1. The benefits of religion for family members' bereavement: providing support, relieving shocks caused by the death of a loved one, religious communities became a supportive system, performing religious rituals which might be beneficial for the deceased, knowing the place afterlife the deceased has gone to, having continuing bonds with the deceased, believing in a reunion with the deceased in the future	22
Tsai, 2009a, Not mentioned [37]	11 bereaved adult children whose parents died from cancer ($n=7$ females), recruited from family support groups or hospitals	Grounded theory	1. The deceased parent became virtual existence and had a new position with different functions in their family. The functions of the new position of the deceased included: communication, decision-making, and having space and affections such as feeling beloved by the deceased parent 2. The methods of continuing bonds between the bereaved children and the deceased parent included: fulfilling the deceased's last wishes, carrying on the deceased's legacy such as recognising the deceased as a role model	26
Tsai, 2009b, Not mentioned [38]	14 bereaved family members of cancer patients ($n=9$ females), were recruited from family support groups or hospitals	Grounded theory	1. Changes in the family relationships of the bereaved after the death of a loved one included: becoming closer in family relationships, repairing conflicts among family members, becoming more isolated in family relationships, arguing with each other more often	26
Lin et al., 2011, Southern Taiwan [39]	10 bereaved caregivers whose spouse died from cancer and received specialist inpatient palliative care ($n=7$ females)	Phenomenological Longitudinal interviews	Themes: the imaginative rumination, such as a sense of the deceased's presence; transformative symbol, such as keeping or throwing away the deceased's belongings; the ethical relationship, such as keeping thinking of the marital relationship and building or refusing new relationships	27
Hung, 2013, , Middle Taiwan [40]	6 bereaved adult family members of patients who died from chronic disease ($n=4$ females)	Ethnography	Effects of performing funeral rituals included: having no time to go through the grief, accepting the truth of the death of a loved one, suppressing individual emotions, facilitating expression of collective emotions, receiving support from other relatives, experiencing reconnection with the deceased	29
Cheng, 2016, Not mentioned [41]	1 middle-aged widow whose husband died from lung cancer	Thematic analysis	Anniversary or holiday reactions of the bereaved included: feeling sad, feeling sorry for the children, going to the tomb, avoiding happy people, easily getting irritated with relatives and friends, spending holidays with friends having a similar experience	25
Jung and Hung, 2017, Not mentioned [42]	1 middle-aged, single female whose father died from cancer and received palliative care service	Narrative inquiry	Themes: the grief reactions such as poor appetite, crying alone, and suppressing emotions in publics, missing a lot about the deceased such as talking to the deceased and watching audio records of the deceased, learning to change such as learning to become independent and cherishing families and friends, accepting the death of the loved one such as the belief in a reunion with the deceased	23
Lee et al, 2017, Southern Taiwan [43]	10 family members whose spouse died from cancer and received specialist inpatient palliative care ($n=7$ females)	Phenomenological Longitudinal interviews Secondary qualitative data analysis [44]	Theme 1: a blurred boundary of life (Yang) and death (Yin): reuniting the deceased through different means such as perceived physical encounters, dreaming of the deceased and performing religious rituals; receiving blessings from the deceased; love never dies and yuan (緣) never ends Theme 2: the transformation of relational bonds between the bereaved and the deceased such as believing in reincarnation; reinventing the ethical bonds among family members such as reassigning roles and responsibilities	31
Liang and Lai, 2020, Southern Taiwan [45]	6 bereaved adult children of cancer patients who received specialist inpatient palliative care ($n=5$ females)	Focus group Content analysis	Themes: physical and mental suffering such as poor sleep, loss of weight, and missing the deceased sorely; bittersweet emotions such as sadness, self-blame, and no regret due to good death; unreal feelings and fighting back tears such as a sense of unreality and crying alone; scene-evoked memories such as seeing the deceased's belongings; self-reflection such as reconsidering life goals	32
Lai et al, 2021, Southern Taiwan [46]	16 family caregivers of cancer patients who received specialist inpatient palliative care ($n=11$ females)	Thematic analysis	Themes: grieving in silence; taboo topics such as avoiding talking about the deceased; emotion hiding such as maintaining a superficial "okay"; asynchronous grief; relational tension such as comparing the intensity of grief to each other family	33

Table 2 (continued)

Author, year of publication, Region	Participants/ Setting	Method	Key findings	Hawker score
Shih et al., 2010, Northern Taiwan [47]	20 older females whose husbands died from chronic disease, recruited from the community administration offices in five districts	Mixed method (survey and critical thematic analysis)	1. Participants with strong religious beliefs reported fewer coping problems 2. Coping problems the participants had, for example, loneliness, being withdrawn, low self-esteem, not wanting to become a burden to their children, low income, lacking help in housekeeping, moving home 3. Coping strategies the participants used, for example, learning self-care, making money, shopping by themselves, living a simple life, paying attention to their own health, receiving support from family members and friends, helping others, becoming optimistic, confident, and calm, praying, chanting, worshipping ancestors, searching for divination resources	29
Liu and Lai, 2006, Northern Taiwan [48]	120 adult family caregivers of terminally ill cancer patients who received specialist inpatient palliative care, 65% female	Longitudinal survey	1. The relationship between anticipatory grief and grief during bereavement remains unclear 2. Age and gender of family caregivers and their relationship to the deceased were not associated with grief during bereavement	28
Hsieh et al., 2007, Northern Taiwan [49]	46 family caregivers of advanced cancer patients who received specialist inpatient palliative care, 56.5% female	Longitudinal survey	1. There was no difference in grief reactions 1 month after death between family caregivers whose patients died at home versus those who died in the hospital 2. Predictor of grief reactions immediately after the death of the patient was the family caregiver's educational level 3. Predictors of grief reactions 1 month after the death of the patient were the patient's age and the perception that the patient had unfinished business	28
Chiu et al., 2010, Southern Taiwan [50]	668 bereaved family caregivers of terminally ill cancer patients who received specialist inpatient or palliative care consultation, 60.6% female	Cross-sectional survey	1. The prevalence of complicated grief was 24.6% ($n=164$) 2. Risk factors of complicated grief: female gender, spouse relationship, parents-children relationship, no religious belief, unavailable family support, history of mood co-morbidity 3. Protective factors of complicated grief: longer duration of caring, caregivers with medical disease history, patients being cared for on the hospice ward	30
Chiu et al., 2011, Southern Taiwan [51]	432 bereaved family caregivers of terminal cancer patients who received specialist inpatient palliative care, 71.1% female	Cross-sectional survey	1. The prevalence of prolonged grief was 9.95% ($n=43$) 2. Risk factors of prolonged grief: older age, female, spousal relationship, parent-child relationship, caregivers suffering medical disease 3. Protective factors of prolonged grief: education, higher income, a longer duration of caring for patients, religious belief, good family support, good social support	32
Tsai et al., 2016, Northern Taiwan [52]	493 family caregivers of terminally ill cancer patients in the general medical inpatient unit, 64.7% female	Longitudinal survey	1. The prevalence of prolonged grief among family caregivers of terminally ill cancer patients decreased through the first years of bereavement with 7.37% (28 out of 380), 1.80% (6 out of 334), 2.49% (7 out of 281), and 1.85% (4 out of 216) at 6, 13, 18, and 24 months after death, respectively 2. Risk factors of prolonged grief: caregivers who suffered from more severe depressive symptoms before the loss, perceived a more difficult dying process and death, and were less prepared for the death 3. Protective factors of prolonged grief: caregivers who reported higher subjective caregiving burden before death and perceived greater concurrent social support	33
Shen et al., 2018, Northern Taiwan [53]	143 family members of advanced cancer patients in a palliative care unit or terminal cases in six intensive care units, 55.2% female	Longitudinal survey	1. Family members of patients in the palliative care unit had lower grief levels than those in the intensive care units 3 days and 1 month after the death 2. For the palliative care unit, family members of patients who received palliative sedation therapy had higher levels of grief than those of patients who did not receive such therapy 3. Risk predictors of higher grief levels: good or very good intimacy relationship with patients, female family members, younger patients	33

Three bereavement theories were mentioned: continuing bonds theory, Worden's task model and meaning reconstruction theory [39, 42, 43, 46]. The continuing bonds theory represents a continuing relationship with the deceased and is a possible adaptive behaviour; Lee et al. considered such a relationship as vital for the Taiwanese [43]. Worden's task model illustrates four grief tasks, such as acceptance of the loss, that should be achieved while going through bereavement. However, Lai et al. argued that the task of experiencing the pain of grief might not be suitable for the bereaved Taiwanese who tended to suppress and hide their emotions [46]. Two studies emphasised that finding meaning in loss is key, which was the important point of the meaning reconstruction theory [39, 42], but they did not provide further comments.

Measurement tools

Four tools were used in six surveys (Table 3) [48–53]: the Chinese variation of the Inventory of Complicated Grief [50, 51] and the Prolonged Grief-13 [52] were used to detect abnormal grief; the Chinese version of the Texas Revised Inventory of Grief [49, 53] and the Chinese Perinatal Grief Scale [48] were used to assess the level of grief. The quality of the four tools was mentioned in all six surveys. Two studies explained that the Chinese variation of the Inventory of Complicated Grief was suitable for their research sample, supported by the literature [50, 51]. The Chinese version of the Texas Revised Inventory of Grief for family members of inpatient palliative care patients also demonstrated good psychometric characteristics [49]. However, this scale was then employed for terminal patients in intensive care units in the research of Shen et al. [53]. Finally, the Perinatal Grief Scale, initially developed for perinatal loss, was applied to family members of adult cancer patients in the work of Lit and Lai after the rigorous translation and validating procedures, including modifying to suitable wording and measuring internal consistency reliability for adult populations [48].

Predictors of bereavement outcomes

Six surveys investigated predictors of bereavement outcomes [48–53] (Table 4). All six studies included terminally ill cancer patients' family members as participants; one of them also included family members of terminally ill patients in intensive care units [53]. Only one study included patients not in receipt of specialist palliative care [52].

Some factors appeared modifiable through health care interventions before the death, including family members who felt that their loved one had unfinished business [49], felt less prepared for the death and perceived a difficult dying process and death [52]. Receiving specialist inpatient palliative care [50, 53] and Taiwanese family members having a faith were potentially beneficial for bereavement outcomes [47, 50, 51]. Furthermore, some

Table 3 Measurement tools of bereavement

Tool	Purpose	Scale items	Content subscales	Response format	Used in the included studies	
					Authors	Timing after death
Chinese variation of the Inventory of Complicated Grief	Detect complicated grief	19	No subscales Content: frequency of emotional, cognitive, and behavioural symptoms, E.g., anger over the death, avoidance of reminders of the deceased [54]	5-point Likert	Chiu et al, 2010 [50]	6–14 months Average: 8.9 months
					Chiu et al, 2011 [51]	6-14.2 months Average: 9.1 months
Chinese version of the Texas Revised Inventory of Grief	Assess reactions and levels of grief	26	3 subscales: 1) Past behaviours 2) Present feelings 3) An assortment of facts related to death	5-point Likert, True or false	Hsieh et al., 2007 [49]	1 month
		21	2 subscales: 1) Past behaviours 2) Present feelings	5-point Likert	Shen et al, 2018 [53]	3 days and 1 month
Prolonged Grief-13	Diagnose prolonged grief	Not applicable	No subscales The criteria include: 1) Experience of yearning 2) At least five of nine symptoms of functional impairment are caused by the death: E.g., feeling emotionally numb, stunned, that life is meaningless 3) Symptoms present more than at least six months after the death	Not applicable	Tsai et al., 2016 [52]	6, 13, 18, and 24 months
Chinese Perinatal Grief Scale	Assess grief during bereavement	33	3 subscales: 1) Active grief 2) Difficulty coping 3) Despair	5-point Likert	Liu and Lai, 2006 [48]	Approximately 2 months

Table 4 Protective and risk factors of bereavement outcomes

Protective factors	
Family members related	• Personal medical disease history [50] • Religious belief [51] • Education [51] • Reporting higher subjective caregiving burden just before patient death [52] • Longer duration of caring for patients [50, 51]
Patients related	• Being cared for on the hospice ward [50, 53]
Social related	• Higher income [51] • Good family support [51] • Perceived good social support [51, 52]
Risk factors	
Family members related	• Female [50, 51, 53] • Older age [51] • Educational level [49] • No religious belief [50] • Suffering their own medical disease [51] • Having a history of mood co-morbidity [50] • Suffering severe depressive symptoms before the death [52] • Good or very good intimacy relationship with patients [53] • The perception that the patient had unfinished business [49] • Perceived a more difficult dying process and death [52] • Less prepared for death [52]
Patients related	• Younger age [53] • Receiving palliative sedation therapy [53]
Other	• Spouse or parents-children relationship [50, 51] • Unavailable family support [50]

predictors were somewhat counterintuitive. Higher caregiving burden [52] and longer caregiving periods [50, 51] could positively impact the bereavement experience. By contrast, receiving palliative sedation therapy was associated with higher levels of grief [53].

Although being female [50, 51, 53], of older age [51], and spouse or parents of children [50, 51] were the risk predictors for worse bereavement outcomes, one study by Liu and Lai showed that gender and the age of adult family caregivers and their relationship with the deceased were unrelated to the bereavement [48]. The two studies did not state whether lower or higher education was important [49, 51]. Overall, the quality of the six surveys was good; all scored over 28. A minority of participants in three surveys experienced complicated grief [50–52].

Key themes

Through the systematic comparison and exploration of the included studies, four themes about the bereavement experience of Taiwanese family members following an expected death were generated: multiple impacts of the death, problem-based coping strategies, importance of maintaining connections, and influential religious beliefs and rituals (Fig. 2).

Theme 1: multiple impacts of the death

The bereaved Taiwanese encounter multiple impacts caused by an expected death, including physical, daily life, psychosocial, and spiritual dimensions. The bereaved suffered from physical problems such as poor appetite [42] and poor sleep [45] which led to challenges in daily life, including lack of help in housekeeping and low income [47]. They also experienced considerable psychosocial impacts during bereavement, such as self-blame [40, 45], sadness [41, 45], missing the deceased [42, 45], worry about becoming a burden to others [47], and being irritated with other people [41]. However, the loss might offer them an opportunity to adjust their personal values and life goals by thinking of meaning in life [45].

Theme 2: Problem-based coping strategies

The bereaved Taiwanese tended to employ problem-based coping strategies to adjust to their life without the deceased, including the behavioural strategy - taking actions and the cognitive strategy - thinking positively. Taking actions indicated they learned new ways and changed their behaviours to cope, including learning self-care [47], engaging in personal religious communities, performing religious rituals [36, 40, 47], changing their caring focus to their children [39, 43], and reassigning roles and responsibilities amongst the family [43]. Additionally, thinking positively was a cognitive coping strategy the bereaved Taiwanese used which included trying to be confident, calm, and optimistic [47], cherishing families and friends [42], feeling happy because of having shared memories with the deceased, and having no regret due to good death of the loved one [45].

Theme 3: Importance of maintaining connections

'Importance of maintaining connections' was the broader theme including two subthemes: continuing the relationship with the deceased and maintaining relationships with others.

Continuing the relationship with the deceased. Continuing the relationship with the deceased family member was particularly important. This was achieved through two means: 'the belief' and 'the doing'. Regarding 'the belief', the bereaved Taiwanese believed a reunion with the deceased would happen in the future because of their religious belief [36, 42, 43]. Christians believed in meeting the deceased in Heaven [36, 42]. Buddhists believed in reuniting with the deceased following reincarnation. For instance, the deceased might be reborn as a new-born in their family [43]. The bereaved Taiwanese also believed in encountering the deceased in the future because of the concept of yuan (緣), a Chinese culture-specific belief which means the relationship is endless [43].

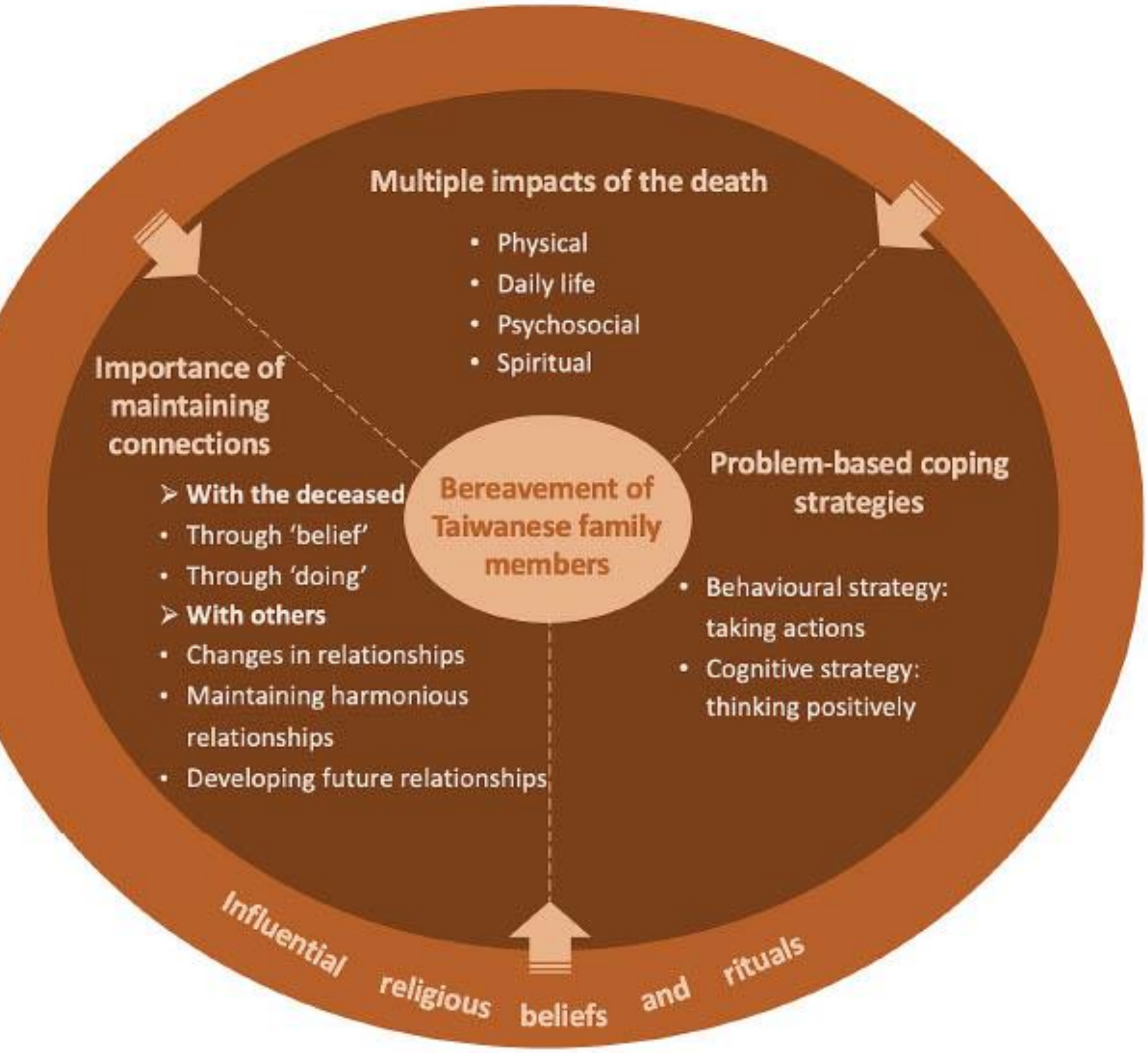

Fig. 2 Themes of the bereavement experience of Taiwanese family members

'The doing' was the second way of connecting with the deceased. Notably, the bereaved Taiwanese felt they did something beneficial for the deceased by conducting religious rituals such as chanting [36, 40], praying [36], and offering sacrifice [37, 41, 43] and not crying, because crying for the deceased would threaten the well-being of their soul [40, 46]. Maintaining or inheriting non-material resources related to the deceased was another vital connection. For instance, maintaining the deceased family member's bloodline, life values, religious beliefs, and preferences such as singing songs they liked and also inheriting their roles and responsibilities in the family [37, 41, 42]. Additionally, there were several other ways of 'doing': physical encounters with the deceased such as seeing or hearing them, dreaming about the deceased [39, 43], keeping thinking of a time related to the deceased such as shared memories with them [39, 41, 45], talking to the deceased [37, 42]; and keeping and seeing physical materials which reminded them of the deceased such as their belongings, room, photos, and films [37, 39, 42, 43, 45].

Maintaining relationships with others. Maintaining relationships with others who were still living was vital too, including changes in relationships, maintaining harmonious relationships, and developing future relationships. Changes in relationships with others, because of the expected death, comprised positive and negative components. The bereaved Taiwanese might resolve conflicts with their family and become closer than before the death [38]. However, they might argue with each other more often and become more isolated with conflicted family relationships [38, 46]. This was because the death revealed or exacerbated existing family problems [38], or the bereaved could not understand and support their other family members [46].

Maintaining harmonious relationships was important for the bereaved Taiwanese but it required avoiding mentioning the deceased [46] and behaving well in public such as suppressing and hiding their emotions and crying alone [42, 45, 46]. Regarding future relationships, they might rebuild or refuse new relationships [39]; for instance, the bereaved spouse may decide to live in widowhood for their entire life [43].

Theme 4: Influential religious beliefs and rituals

The final theme of the Taiwanese bereavement experience is influential religious beliefs and rituals. Religion was an important protective factor for bereavement outcomes [47, 50, 51]. The bereaved Taiwanese felt supported by their belief that they had a continuing relationship with the deceased [36, 40, 43]. Additionally, they felt comfortable knowing the place the deceased went after death such as Heaven (Abrahamic religions) [36, 42] and the Western Pure Land (Buddhism), where there is a world without suffering [40]. Performing funeral rituals according to religious beliefs also helped them accept the death, such as guiding the soul of the deceased family member to the paper spirit tablet which includes written the name of the deceased and symbolises the deceased's soul [40]. However, they would suppress emotions and have no time to focus on their grief when conducting rituals and being with other people [40].

Discussion

This review explores the bereavement experience of Taiwanese family members following an expected death. The results show that continuing the relationship with the deceased and suppressing or hiding emotions during bereavement deeply reflects the specific Taiwanese culture and the experience of family members. Importantly, the results show that the experience of family members before the death plays a vital role in their bereavement. Among the included studies, family members of cancer patients were the most common, possibly because cancer has been the leading cause of death in Taiwan for over four decades [55]. Cancer patients in Taiwan are more likely to receive specialist palliative care than people with noncancer. In 2017, 60.95% of cancer patients and 14.21% of noncancer patients received such care during their last year [56]. It is almost certain that specialist palliative care was the research context for most of the included studies.

Continuing the relationship

This review suggests that continuing the relationship with the deceased family member is a vital and specific phenomenon in Taiwan. The idea of detaching from the deceased dominated the understanding of bereavement during most of the twentieth century, and this influential idea shifted about thirty years ago [57]. The review shows that the bereaved Taiwanese strongly believe they will reunite with the deceased in the future due to their religious and cultural belief, such as reincarnation and the concept of yuan (緣) [43]. The concept of yuan (緣), the belief that relationships are endless no matter death, is an influential opinion in Chinese society and a key notion of Buddhism as well. A likely explanation is that Buddhism is a powerful religion in Taiwan [58] although the participants' religions in the review varied including Buddhists, Taoists, and Christians. Importantly, the review shows that the bereaved Taiwanese also believe they can help the deceased go to a better after-world through religious rituals [36, 37, 40, 41, 43]. Similarly, a study in Hong Kong showed that conducting rituals, such as burning paper, was believed to help the deceased have a better afterlife [59]. Indeed, caring about the afterlife of the deceased is a traditional Chinese value, as the bereaved believe the well-being of the deceased could influence their own life [60]. Such elements of the Taiwanese bereavement experience are very different from some Western experiences. Two studies in the United States investigating afterlife beliefs, religion, and bereavement adjustment did not show similar findings to this review [61, 62], including belief in reincarnation and improving the well-being of the deceased through rituals. Hence, the findings of the review may be appropriate for other Chinese populations or predominantly Buddhist societies.

The review found that ancestor worship is a culturally meaningful way to connect to the deceased in Taiwan [37, 41, 43]. The purpose of ancestor worship is to express filial piety, respect, and gratitude to the deceased senior family members [60]. This ritual has been widely performed by having tablets on a shrine in homes or communal ancestral halls across Taiwan [63] and many areas of East Asia due to the philosophy of Confucianism [60, 64]. Therefore, this review's finding could also be potentially relevant to other East Asian societies and continuing the relationship should be understood in social and cultural contexts [65, 66].

The review shows that continuing the relationship may positively impact the bereavement by having 'hope' because of a belief in a future reunion with the deceased [36, 42, 43], and feeling comfortable knowing the deceased no longer suffers in their afterlife [36, 40, 42]. However, a study in Hong Kong showed some participants have negative feelings due to fear that the deceased went to hell [59]. Two studies from Western countries showed that continuing the relationship was associated with poor bereavement adjustments, such as depression [67, 68] and a higher level of grief [67], however, both employed different items to measure this variable [67, 68]. Consequently, whether continuing the relationship is beneficial or disadvantageous in coping with bereavement is still debated [26, 69, 70], possibly because its definition is complex and highly related to social and cultural contexts [65].

Culturally acceptable and religious behaviour

The review shows that the bereaved Taiwanese avoid expressing emotions and tend to use behavioural and cognitive strategies to adjust to death. They suppress or hide emotions to avoid becoming a burden to others [46], thus, choosing 'Bao xi bu bao you' (報喜不報憂), which means to only report good or pleasant news, not bad news. Unlike the value of Western societies highlighting autonomy and individualism, Taiwan and other East Asian countries value mutual dependence and social relationships due to Confucianism [10, 60]. Hence, controlling negative emotions is key to maintaining harmonious relationships [71]. Suppressing or hiding emotions might also be helpful to maintain dignity which is highly valued in Chinese culture [5, 72, 73]. If a person cannot suppress or hide emotions properly, it may cause embarrassment that is knowns as 'shi tai' (失態) and 'diu lian' (丟臉) [74], which means making a 'gaffe' and 'losing face', respectively.

The term Jie a.i. (節哀) is often used to express condolences for the bereaved in Chinese society. This expression comes from Confucianism, the book of Li Ji (禮記), which is a collective work by Confucian philosophers over two thousand years ago. The purpose of Jie a.i. (節哀) is to encourage the bereaved to restrain their grief, accept the death and move on with life because the death cannot be changed. From the perspective of Confucianism, expressing emotions is not an adaptative way to cope with bereavement compared to cognitive and behavioural strategies. It explains why the bereaved Taiwanese tend to employ problem-based coping strategies to adjust to death, as found in the review.

Moreover, suppressing or hiding emotions may be related to the religious beliefs of the bereaved Taiwanese. The review shows the bereaved chose not to cry for the deceased. This may be related to the predominant religion of Buddhism in Taiwan because Buddhists believe crying for the deceased would negatively influence their process of rebirthing to a better world and threaten their well-being in the after-world [58]. Similarly, a study in Hong Kong showed that family members tried not to cry at the moment of death as they worried it would affect the reincarnation of the deceased [75]. Consequently, the findings of the review seem to be suitable for other Chinese populations, predominantly Buddhist countries or other East Asian societies.

From the view of Western-oriented bereavement theories, it is widely believed that expressing emotions is a highly adaptive means of coping with bereavement [26, 76, 77]. Nonetheless, the review shows that it is unclear whether suppressing or hiding emotions negatively impacts Taiwanese bereavement. Two studies from outside of East Asian countries found that emotional expression was not beneficial for bereavement adjustments such as improvement in depressive symptoms [78]. Therefore, it may not be appropriate to simply emphasise the importance of expressing emotions in working through bereavement.

'Emotional expressive flexibility' may be more suitable for understanding the expression of emotions during bereavement. The concept means the ability to flexibly enhance or suppress emotional expression according to situational demands [79, 80]. As discussed before, the purpose of suppressing or hiding emotions for the bereaved Taiwanese is to maintain harmonious relationships [10, 60, 71] and avoid becoming a burden to others [11]. It highlights they value their interpersonal relationships when expressing emotions during bereavement. Studies from the United States show that expressing emotions according to individual and contextual needs was associated with better bereavement adjustment, such as fewer depressive symptoms [81] and less suffering from grief symptoms including self-blame and difficult acceptance of the death [82]. The role of emotional expressive flexibility in bereavement adjustment should be addressed in future bereavement research, especially in the context of Chinese culture.

Reflections on Western-oriented bereavement theories

The continuing bonds theory may be more appropriate for understanding Taiwanese bereavement because continuing the relationship is very important. This theory was developed in the United States while working with bereaved parents and inspired by ancestor worship in Japanese culture [66, 83]. Nonetheless, ancestor worship has a very specific cultural meaning for showing respect to the deceased senior family members. Hence, this ritual is not an appropriate way of connecting with the junior deceased generations such as a child, as discussed before.

The continuing bonds theory proposes that the ongoing relationship with the deceased is normal and widespread, might be beneficial for bereavement adjustment, and should be understood in social and cultural contexts [57, 66]. The critical point of this theory is similar to the term Bei Dao (悲悼), developed by Taiwanese researchers [43]. The review shows that continuing the relationship deeply reflects Taiwanese cultural values and religious beliefs, including belief in reincarnation and yuan(緣), helping the deceased have a better afterlife, and not crying for the deceased. It supports the importance of assessing the religious beliefs of patients and their family members at the end of life. However, more work is needed to explore the application of this theory, especially in the context of Taiwan and other East Asia countries.

Other Western-oriented bereavement theories emphasising the importance of detachment from the deceased might not be appropriate for the Taiwanese who want to maintain the bond. For instance, John Bowlby's popular attachment theory theorises that the development of affectional relationships early in life influences responses to the loss of a loved one. He proposed that the bereaved should detach from the deceased to recover from the loss [84].

Although some Western-oriented bereavement theories looked at bereavement from the view of continuing relationships or developing bonds, they seem to not be culturally appropriate for the Taiwanese. Worden's task model, a widely used theory in clinical practice, proposes that finding a way to remember the deceased should be achieved [26]. The Dual Process Model, reporting the bereaved person oscillating between loss and restoration orientation coping behaviours to come to terms with the loss of a loved one, also emphasises maintaining an emotional bond with the deceased [4, 27]. However, both fail to mention that such a continuing relationship is related to cultural and social contexts, which is highly important for the bereaved Taiwanese based on the findings of the review. Worden's task model suggests that working with the pain caused by the loss, such as sadness and anger, is one of the mourning tasks. Nonetheless, the review shows that the bereaved Taiwanese tend to suppress or hide emotions during bereavement to connect with the deceased and maintain harmonious relationships with others.

Experiences at the end of life and bereavement

This review highlights the experience of family members at the end of life, including 'Two P' elements: patient care-related experience and preparedness-related experience, which could influence bereavement.

Patient care-related experience. The patient care-related experience includes (a) family members' perceived quality of care leading up to the death of patients and (b) the caregiving experience of family members.

Firstly, this review shows that the bereaved Taiwanese may suffer from a higher level of grief if they perceive the patient had unfinished business [49] and a more difficult dying process and death [45, 52]. A study in the United States reported that better quality of death of cancer patients predicted better bereavement of family caregivers [85]. Nonetheless, palliative sedation therapy, a treatment for managing severe symptoms during end-of-life care, may negatively impact the Taiwanese's bereavement [53]. Most family members participating in the study strongly agreed or agreed that there might be other means of relieving symptoms. A likely explanation is that they may worry that the most appropriate means to relieve patients' suffering had not been used. It may also be related to Buddhism, as Buddhists believe that maintaining awareness during the process of dying is the key to rebirthing to a better world [58, 60]. To summarise, good quality of care leading up to the death of patients, especially good symptom management which maintains awareness, through appropriate interventions, may positively impact bereavement.

This review shows caregiving experience of family members at the end of life could also impact bereavement. The bereaved Taiwanese who had a higher subjective caregiving burden [52] and a longer caregiving period, may have better bereavement adjustment [50, 51]. This interesting finding reflects the Taiwanese culture emphasising a tendency for concern for those close to oneself [11]. Similarly, a systematic synthesis showed that family caregivers tend to ignore their own needs and feelings and do their best to relieve the patients' suffering; they would be more satisfied with their caregiving experience because of a sense of fulfilling duty and showing love through care [86]. However, a qualitative study in China showed that family members perceived adverse caregiving, such as feeling exhausted, negatively impacted bereavement [87].

Preparedness-related experience. Preparedness-related experience of family members at the end of life, which would influence their bereavement, includes the experience of preparing for the death of a loved one. This review shows the bereaved Taiwanese could suffer from complicated grief due to less preparation for the death [52]. Similarly, two review articles from Europe showed that low levels of preparation for death were associated with abnormal grief [88, 89]. A Delphi study of developing a consensus on bereavement care in palliative care services in Europe highlights the importance of helping family members prepare for death and understand when death is impending [6]. Preparing for the death of family members seems beneficial for bereavement. Thus, 'preparing for death and bereavement' may be more appropriate for describing such an experience and it would be an essential issue in palliative care and end-of-life care. However, this topic is not well understood such as which components of preparing for the impending death impact the bereavement experience.

Strengths and limitations

This is the first review to explore the bereavement experience of Taiwanese family members following an expected death. A systematic and comprehensive searching approach was used to gain a deeper and broader understanding, including using articles in English and Chinese and including different study designs (quantitative, mixed methods, and qualitative research). However, there are several limitations. Two qualitative studies included only one family member as the participant [41, 42]. Most included studies recruited participants from a single hospital ($n=12$), investigated family members of cancer patients ($n=16$), and explored the context of specialist palliative care ($n=10$). Consequently, those may undermine the transferability of this review [90]. Although the review involved a second reviewer, the data extraction, quality appraisal and synthesis were conducted by only one reviewer, which might undermine this study's rigour. However, some measures were taken to improve quality through discussions between authors throughout the study. Despite the limitations discussed here, the synthesis answers the review question, which reflects the specific bereavement experience of the bereaved Taiwanese.

Future research

An alternative approach to exploring the topic of bereavement is necessary. There is an urgent need to investigate the experience of preparing for death and bereavement for family members and how this impacts bereavement. Future research should also focus on barriers to implementation for preparing family members for death and bereavement from the perspectives of healthcare providers. Moreover, for the bereavement theory development, continuing the relationship with the deceased is a relatively new notion and should be explored in social and cultural contexts. More work is needed to examine whether continuing the relationship with the deceased is beneficial for bereavement adjustment and to explore the continuing bonds theory, particularly in the context of Chinese culture. For instance, investigating the belief in reincarnation, which is a vital feature of continuing the relationship with the deceased in Taiwan and predominantly Buddhist societies, in coping with bereavement. The role of emotional expressive flexibility in bereavement adjustment should also be addressed in future bereavement research.

Conclusions

The review suggests that continuing the relationship with the deceased is a key element of the bereavement experience for the bereaved Taiwanese and it is influenced by religious beliefs and cultural values, including the belief in reincarnation and yuan (緣), helping the deceased have a better afterlife by performing rituals and connecting to the senior deceased family members through ancestor worship. The continuing bonds theory could be useful for understanding the Taiwanese bereavement experience and potentially for people who are influenced by Chinese culture. Moreover, suppressing or hiding emotions during bereavement to connect with the deceased and maintain harmonious relationships needs to be acknowledged as culturally acceptable and encouraged by some religions in Taiwan. The review findings could be potentially relevant for other Chinese populations, predominantly Buddhist societies or other East Asian countries. More importantly, preparing for death and bereavement for family members would be critical at the end of life but it is not well understood, leading to a major obstacle to good palliative care and end-of-life care. Studies exploring the role of preparing for death in bereavement outcomes are required, aiming to improve bereavement care services [6].

Abbreviations

CEPS	Chinese Electronic Periodical Services
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CNKI	China Academic Journal Database
ENTREQ	Enhancing transparency in reporting the synthesis of qualitative research
MEDLINE	Medical Literature Analysis and Retrieval System Online
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analysis

Supplementary Information

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Supplementary Material 1: Search terms

Supplementary Material 2: Example of electronic database searching (MEDLINE)

Supplementary Material 3: Data extraction form

Supplementary Material 4: Codes and initial themes

Supplementary Material 5: Drafts of a conceptual model

Supplementary Material 6: Result of quality assessment for the included studies

Supplementary Material 7: Overview of characteristics of the included studies

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Author contributions
HJL designed the study, carried out this review and the narrative synthesis and wrote the manuscript. NP and QX participated in the design of the study, provided guidance in the synthesis, and reviewed the manuscript. BNR participated in the title and abstract screening. All authors listed have revised and approved the submitted version manuscript.

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Data availability
All data generated or analysed during the study are included in this article. Additional data, including the search strategy, data extraction, quality appraisal and data synthesis, can be found in the Supplementary File and are also available from the corresponding author (h.liang3@lancasrer.ac.uk).

Declarations

Ethical approval and consent to participate
Not applicable. Ethical approval and consent to participate were not required in conducting the narrative synthesis review.

Consent for publication
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Competing interests
Nancy Preston is a section editor at BMC Palliative Care. Hui-Ju Liang, Qian Xiong, and Bader Nael Remawi declare that they have no competing interests.

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References
1. Ferrell BR, Twaddle ML, Melnick A, Meier DE. National consensus project clinical practice guidelines for quality palliative care guidelines, 4th edition. J Palliat Med. 2018;21(12):1684–9.
2. World Health Organization. National cancer control programmes: policies and managerial guidelines. World Health Organization; 2002.
3. Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, et al. Redefining palliative care-a new consensus-based definition. J Pain Symptom Manage. 2020;60(4):754–64.
4. Stroebe M, Schut H. The dual process model of coping with bereavement: a decade on. OMEGA-Journal of Death and Dying. 2010;61(4):273–89.
5. Koo BWS, Tin AF, Koo EWK, Lee SM. When east meets west: implications for bereavement counseling. In: Chan CLW, Chow AYM, editors. Death, dying and bereavement: a Hong Kong Chinese experience. Hong Kong: Hong Kong University Press; 2006. pp. 261–71.
6. Keegan O, Murphy I, Benkel I, Limonero JT, Relf M, Guldin M-B. Using the Delphi technique to achieve consensus on bereavement care in palliative care in Europe: an EAPC White Paper. Palliat Med. 2021;35(10):1908–22.
7. Stroebe M, Schut H. Culture and grief. Bereave Care. 1998;17(1):7–11.
8. Chen L, Fu F, Sha W, Chan CLW, Chow AYM. Mothers coping with bereavement in the 2008 China earthquake: a dual process model analysis. Omega. 2019;80(1):69–86.
9. Parker G, Gladstone G, Chee KT. Depression in the planet's largest ethnic group: the Chinese. Am J Psychiatry. 2001;158(6):857–64.
10. Yum JO. The impact of confucianism on interpersonal relationships and communication patterns in East Asia. Commun Monogr. 1988;55(4):374–88.
11. Hui CH, Triandis HC. Individualism-collectivism: a study of cross-cultural researchers. J Cross-Cult Psychol. 1986;17(2):225–48.
12. Brewer MB, Chen Y-R. Where (who) are collectives in collectivism? Toward conceptual clarification of individualism and collectivism. Psychol Rev. 2007;114(1):133.
13. Djelantik AAAMJ, Smid GE, Mroz A, Kleber RJ, Boelen PA. The prevalence of prolonged grief disorder in bereaved individuals following unnatural losses: systematic review and meta regression analysis. J Affect Disord. 2020;265:146–56.
14. Eisma MC, Stroebe MS. Emotion regulatory strategies in complicated grief: a systematic review. Behav Ther. 2021;52(1):234–49.
15. Thiemann P, Street AN, Heath SE, Quince T, Kuhn I, Barclay S. Prolonged grief disorder prevalence in adults 65 years and over: a systematic review. BMJ Supportive and Palliative Care. 2021.
16. Treml J, Kaiser J, Plexnies A, Kersting A. Assessing prolonged grief disorder: a systematic review of assessment instruments. J Affect Disord. 2020;274:420–34.
17. Setubal MS, Bolibio R, Jesus RC, Benute GG, Gibelli MA, Bertolassi N, et al. A systematic review of instruments measuring grief after perinatal loss and factors associated with grief reactions. Palliat Supportive Care. 2021;19(2):246–56.
18. Williams J, Shorter GW, Howlett N, Zakrzewski-Fruer J, Chater AM. Can physical activity support grief outcomes in individuals who have been bereaved? A systematic review. Sports Med - Open. 2021;7(1).
19. Laranjeira C, Moura D, Salci MA, Carreira L, Covre E, Jaques A et al. A scoping review of interventions for family bereavement care during the COVID-19 pandemic. Behav Sci. 2022;12(5).
20. Wu-Chung EL, Leal SL, Denny BT, Cheng SL, Fagundes CP. Spousal caregiving, widowhood, and cognition: a systematic review and a biopsychosocial framework for understanding the relationship between interpersonal losses and dementia risk in older adulthood. Neurosci Biobehav Rev. 2022;134.
21. Finkelstein EA, Bhadelia A, Goh C, Baid D, Singh R, Bhatnagar S, et al. Cross country comparison of expert assessments of the quality of death and dying 2021. J Pain Symptom Manag. 2022;63(4):e419–e29.
22. Kaltman S, Bonanno GA. Trauma and bereavement. J Anxiety Disord. 2003;17(2):131–47.
23. Kristensen P, Weisaeth L, Heir T. Bereavement and mental health after sudden and violent losses: a review. Psychiatry. 2012;75(1):76–97.
24. Krychiw JK, James R, Ward-Ciesielski EF. Suddenness of death as a determinant of differential grief experiences. Bereave Care. 2018;37(3):92–100.
25. Worden JW. Grief counseling and grief therapy: A handbook for the mental health practitioner. 2009.
26. Worden JW. Grief counseling and grief therapy: a handbook for the mental health practitioner. Springer Publishing Company; 2018.
27. Stroebe M, Schut H. The dual process model of coping with bereavement: rationale and description. Death Stud. 1999;23(3):197–224.
28. Inglehart RF. Changing values among western publics from 1970 to 2006. West Eur Politics. 2008;31(1–2):130–46.
29. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Med Res Methodol. 2012;12(1):1–8.
30. Aveyard H, Payne S, Preston N. A postgraduate's guide to doing a literature review in health and social care. 2021.
31. Middleton W, Raphael B, Burnett P, Martinek N. A longitudinal study comparing bereavement phenomena in recently bereaved spouses, adult children and parents. Aust N Z J Psychiatry. 1998;32(2):235–41.
32. Kersting A, Brähler E, Glaesmer H, Wagner B. Prevalence of complicated grief in a representative population-based sample. J Affect Disord. 2011;131(1–3):339–43.
33. Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: reviewing disparate data systematically. Qual Health Res. 2002;12(9):1284–99.
34. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. Guidance on the conduct of narrative synthesis in systematic reviews. Prod ESRC Methods Programme Version. 2006;1(1):b92.
35. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ. 2009;339(7716):e78–336.
36. Tsai PJ. The religion and grief healing. Taiwan J Hospice Palliat Care. 2007;12(4):385–94.
37. Tsai PJ. In my heart forever: a study of Taiwanese people's continuing bonds with their deceased paretns. Formosa J Mental Health. 2009;22(4):411–33.
38. Tsai PJ. A study of the changes in the familial relationship in bereaved families. J Life-and-Death Stud. 2009;10:159–98.
39. Lin YS, Hou YC, Hsu MT. The plurality and diversity of the bereavement process: exploring the psychological reaction experiences to the cancer death events of the new widows/widowers. J Life-and-Death Stud. 2011(11):1–40.
40. Hung YC. The analysis of mourning experiences in traditional funeral rituals: from death to encoffining ceremony. Chin J Guidance Couns. 2013(37):55–88.
41. Cheng TY. Anniversary reactions in a middle-aged widow. J Guidance Couns. 2016;38(1):83–100.
42. Jung YY, Hung CH. The grief process of middle-adulthood which facing father's death of cancer. Guidance Q. 2017;53(1):25–34.
43. Lee WL, Hou YC, Lin YS. Revisiting the continuing bonds theory: the cultural uniqueness of the Bei Dao phenomenon in Taiwanese widows/widowers. Qual Health Res. 2017;27(12):1892–904.
44. Hou YC. The plurality and diversity of the bereave- ment process: exploring the psychological reaction expe- riences to the cancer death events of the new widows/ widowers. Taiwan: Kaohsiung Medical University; 2006.

45. Liang HJ, Lai WS. A focus group study to explore grief experiences among bereaved families. Taiwan J Hospice Palliat Care. 2020;24(3):193–208.
46. Lai WS, Li WW, Chiu WH. Grieving in silence: experiences of bereaved Taiwanese family members whose loved ones died from cancer. Eur J Oncol Nursing: Official J Eur Oncol Nurs Soc. 2021;52:101967.
47. Shih SN, Turale S, Shih FJ, Tsai JC. Religiosity influences on bereavement adjustments of older widows in Taiwan. J Clin Nurs. 2010;19(5):856–66.
48. Liu NC, Lai EYL. Find a way out: bereavement support in Taiwan hospice. Supportive care in cancer: Official Journal of the Multinational Association of Supportive Care in Cancer. 2006;14(1):4–10.
49. Hsieh M, Huang M, Lai Y, Lin C. Grief reactions in family caregivers of advanced cancer patients in Taiwan: relationship to place of death. Cancer Nurs. 2007;30(4):278–84.
50. Chiu YW, Huang CT, Yin SM, Huang YC, Chien CH, Chuang HY. Determinants of complicated grief in caregivers who cared for terminal cancer patients. Supportive care in cancer: Official Journal of the Multinational Association of Supportive Care in Cancer. 2010;18(10):1321–7.
51. Chiu YW, Yin SM, Hsieh HY, Wu WC, Chuang HY, Huang CT. Bereaved females are more likely to suffer from mood problems even if they do not meet the criteria for prolonged grief. Psycho-oncology. 2011;20(10):1061–8.
52. Tsai WI, Prigerson HG, Li CY, Chou WC, Kuo SC, Tang ST. Longitudinal changes and predictors of prolonged grief for bereaved family caregivers over the first 2 years after the terminally ill cancer patient's death. Palliat Med. 2016;30(5):495–503.
53. Shen HS, Chen SY, Cheung DST, Wang SY, Lee JJ, Lin CC. Differential family experience of palliative sedation therapy in specialized palliative or critical care units. J Pain Symptom Manag. 2018;55(6):1531–9.
54. Prigerson HG, Maciejewski PK, Reynolds CF, Bierhals AJ, Newsom JT, Fasiczka A, et al. Inventory of complicated grief: a scale to measure maladaptive symptoms of loss. Psychiatry Res. 1995;59:65–79.
55. Ministry of Health and Welfare of the Republic of China/Taiwan. Statistics of death of population in Taiwan 2021 [Available from: https://dep.mohw.gov.tw/dos/lp-5069-113.html
56. Control Yuan of Republic of China/Taiwan. The report of the challenges of providing palliative care in Taiwan 2019 [updated November 22. Available from: https://www.cy.gov.tw/News_Content.aspx?n=528&s=14922
57. Klass D, Silverman PR. Introduction: what's the problem? In: Klass D, Silverman PR, Nickman SL, editors. Continuing bonds: new understandings of grief. USA: Taylor & Francis; 1996. pp. 3–27.
58. Shih HK. Exploration for dying and death from the perspective of Buddhsim. Humanistic Buddhism Journal Arts and Culture. 2020(28):62–83.
59. Chan CLW, Chow AYM, Ho SMY, Tsui YKY, Tin AF, Koo BWK, et al. The experience of Chinese bereaved persons: a preliminary study of meaning making and continuing bonds. Death Stud. 2005;29(10):923–47.
60. Hsu CY, O'Connor M, Lee S. Understandings of death and dying for people of Chinese origin. Death Stud. 2009;33(2):153–74.
61. Carr D, Sharp S. Do afterlife beliefs affect psychological adjustment to late-life spousal loss? J Gerontol B Psychol Sci Soc Sci. 2014;69(1):103–12.
62. Clarke S, Religiosity. Afterlife beliefs, and bereavement adjustment in adulthood. J Religious Gerontol. 2003;14(2/3):207–24.
63. Weller RP. Identity and social change in Taiwanese religion. Taiwan: Routledge; 2020. pp. 339–65.
64. Yao X, Yao H. -c. An introduction to confucianism. Cambridge University Press; 2000.
65. Root BL, Exline JJ. The role of continuing bonds in coping with grief: overview and future directions. Death Stud. 2014;38(1–5):1–8.
66. Steffen EM, Klass D. Culture, contexts and connections: a conversation with Dennis Klass about his life and work as a bereavement scholar. Mortality. 2018;23(3):203–14.
67. Boelen PA, Stroebe MS, Schut HA, Zijerveld AM. Continuing bonds and grief: a prospective analysis. Death Stud. 2006;30(8):767–76.
68. Field NP, Friedrichs M. Continuing bonds in coping with the death of a husband. Death Stud. 2004;28(7):597–620.
69. Benore ER, Park CL. INVITED ESSAY: death-specific religious beliefs and bereavement: belief in an afterlife and continued attachment. Int J Psychol Relig. 2004;14(1):1–22.
70. Stroebe M, Schut H, Boerner K. Continuing bonds in adaptation to bereavement: toward theoretical integration. Clin Psychol Rev. 2010;30(2):259–68.
71. Bond MH. Emotions and their expression in Chinese culture. J Nonverbal Behav. 1993;17(4):245–62.
72. Penson RT. Bereavement across cultures. In: Moore RJ, Spiegel D, editors. Cultures cancer, culture, and communication. New York: Kluwer Academic/Plenum Publishers; 2004. pp. 241–79.
73. Yick AG, Gupta R. Chinese cultural dimensions of death, dying, and bereavement: focus group findings. J Cult Divers. 2002;9(2):32–42.
74. Ho DY-f. On the concept of face. Am J Sociol. 1976;81(4):867–84.
75. Chow AYM, Chan CLW, Ho SMY, Tse DMW, Suen MHP, Yuen KFK. Qualitative study of Chinese widows in Hong Kong: insights for psycho-social care in hospice settings. Palliat Med. 2006;20(5):513–20.
76. Lindemann E. Symptomatology and management of acute grief. Pastoral Psychol. 1963;14(6):8–18.
77. Parkes CM, Bereavement. Br J Psychiatry. 1985;146(1):11–7.
78. Stroebe M, Stroebe W, Schut H, Zech E, van den Bout J. Does disclosure of emotions facilitate recovery from bereavement? Evidence from two prospective studies. J Consult Clin Psychol. 2002;70(1):169–78.
79. Bonanno GA, Papa A, Lalande K, Westphal M, Coifman K. The importance of being flexible: the ability to both enhance and suppress emotional expression predicts long-term adjustment. Psychol Sci. 2004;15(7):482–7.
80. Westphal M, Seivert NH, Bonanno GA. Expressive flexibility. Emotion. 2010;10(1):92–100.
81. Coifman KG, Bonanno GA. When distress does not become depression: emotion context sensitivity and adjustment to bereavement. J Abnorm Psychol. 2010;119(3):479–90.
82. Gupta S, Bonanno GA. Complicated grief and deficits in emotional expressive flexibility. J Abnorm Psychol. 2011;120(3):635–43.
83. Klass D, Silverman PR, Nickman SL. Continuing bonds: new understandings of grief. Taylor & Francis; 1996.
84. Bowlby J. The making and breaking of affectional bonds: I. Aetiology and psychopathology in the light of attachment theory. Br J Psychiatry. 1977;130(3):201–10.
85. Garrido MM, Prigerson HG. The end-of-life experience: modifiable predictors of caregivers' bereavement adjustment. Cancer. 2014;120(6):918–25.
86. Lowers J, Scardaville M, Hughes S, Preston NJ. Comparison of the experience of caregiving at end of life or in hastened death: a narrative synthesis review. BMC Palliat Care. 2020;19(1):154.
87. Tang Y. Caregiver burden and bereavement among family caregivers who lost terminally ill cancer patients. Palliat Support Care. 2019;17(5):515–22.
88. Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin MB. Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. Clin Psychol Rev. 2016;44:75–93.
89. Treml J, Schmidt V, Nagl M, Kersting A. Pre-loss grief and preparedness for death among caregivers of terminally ill cancer patients: a systematic review. Soc Sci Med. 2021;284:114240.
90. Krefting L. Rigor in qualitative research: the assessment of trustworthiness. Am J Occup Therapy. 1991;45(3):214–22.

Publisher's Note

4.2 Chapter summary

In this chapter, a systematic review (Paper 1) using a narrative synthesis approach (Popay et al., 2006) synthesising what is known about the bereavement experiences of Taiwanese family members following an expected death has been presented. The review included 17 studies and showed that how prepared families feel and how they experience the dying process can shape subsequent bereavement outcomes (Liang, Xiong, Remawi, et al., 2024). At the same time, the evidence did not clearly explain what families actually do to prepare, or which aspects of preparation matter most for later adjustment. These findings informed a qualitative interview study exploring family death preparation in depth. The qualitative interview study has been published in peer-reviewed journals (Papers 2 and 3) and is presented in the following two chapters.

CHAPTER 5: ‘*REGRETS BECOME A LASTING SOURCE OF PAIN*’: A QUALITATIVE STUDY ON FAMILY CAREGIVERS’ EXPERIENCES LEADING UP TO A RELATIVE’S DEATH (PAPER 2)

5.1 Overview

Both Papers 2 and 3 are developed based on the same dataset, but focus on different dimensions of family death preparation. They present findings from the qualitative interview study analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2022b), which addressed the following two objectives of the thesis:

> *To explore Taiwanese family caregivers’ experiences of preparing for a relative’s death within specialist palliative care settings.*
>
> *To examine how Taiwanese families’ approaches to death preparation are influenced by cultural context and how such preparations shape their subsequent bereavement experiences.*

This second paper (Liang, Xiong, Lin, et al., 2025) reports findings specifically related to families’ preparations and actions before the death and explores how these processes influenced their later bereavement experiences. The findings highlight the pivotal role of healthcare professionals in supporting family death preparation, particularly regarding end-of-life decision-making and caregiving. However, as discussed in the background chapter, existing clinical guidelines remain limited and vague. These insights informed the design of the subsequent nominal group technique study (Chapter Seven and Paper 4), which aimed to develop practical recommendations for improving support for families preparing for a relative’s death.

The published paper is reproduced in the following section.

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'Regrets become a lasting source of pain': A qualitative study on family caregivers' experiences leading up to a relative's death

Hui-Ju Liang[1], Qian Xiong[2], Peng-Chan Lin[3,4], Jui-Hung Tsai[3,4] and Nancy Preston[5]

Abstract

Background: Death preparations can benefit families both before and during bereavement. While these preparations are culturally influenced, evidence from non-Western cultures, like Eastern Asia, is limited.

Aim: To explore how family caregivers prepare for a relative's death in Taiwan.

Design: A qualitative interview study analysed with reflexive thematic analysis.

Setting/participants: Twenty-two primary family caregivers following a death involving specialist palliative care were interviewed.

Results: An overarching theme was 'getting everything right to have no regrets between the dead and the living'. Within this, two themes focussed upon improving the dying relative's outcomes and the families' subsequent bereavement: (1) 'making the right end-of-life decisions is crucial but complex', exploring preparations to involve (or not) the dying relative in making choices to minimise regrets. Participants often felt they understood the dying relative's wishes so respected their preferences while maintaining family harmony through consensus-building and professional guidance. (2) 'becoming a competent caregiver is the priority', addressing preparations for fulfilling responsibilities, making sacrifices and developing caregiving competence to ensure the dying relative's comfort. This would help reduce feelings of regret about not having done enough.

Conclusion: Preparing for end-of-life decisions and caregiving is important for participants to reduce regret, benefiting subsequent bereavement. Of particular importance is family involvement and consensus-building in end-of-life decisions, reflecting Taiwan's family-led culture. These findings can inform clinical practices in family-centric decision-making cultures where healthcare workers should be aware of the need to build consensus, sometimes without involving the dying person. Future research should include patients' and healthcare professionals' perspectives.

Keywords

Death preparation, decision making, caregiving, bereavement, end-of-life care, family involvement, regret, Taiwan

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What is already known about the topic?

- Preparing families for a relative's death in palliative and end-of-life care is important, involving medical, psychosocial, spiritual and practical tasks to enhance cognitive, behavioural and emotional readiness.
- Adequate death preparation benefits families' experiences before death and during bereavement and is shaped by cultural contexts.
- Research on family caregivers' death preparation primarily focusses on Western societies, overlooking insights from non-Western cultures like Eastern Asia, which could hinder culturally appropriate care.

What this paper adds?

- Preparing for 'right' end-of-life decisions and caregiving was important for participants' death preparation, which aimed at reducing future regrets and benefiting subsequent bereavement.
- Protecting the dying relative through varying levels of involvement, respecting their preferences, maintaining family harmony through consensus-building and being supported by professionals' expertise increased the potential for the best end-of-life decisions.
- Preparations to reduce regret about not having done enough involved fulfilling care responsibilities, developing caregiving competence to ensure the dying relative's comfort, making sacrifices and fulfilling their last wishes.

Implications for practice, theory or policy

- The findings provide culturally appropriate guidance for preparations before death to help families feel they have minimised regrets, including assisting them in making the best possible end-of-life decisions, fulfilling care responsibilities, ensuring they feel they have done their best and preparing them to provide competent caregiving to ensure the dying relative's comfort.
- Clinicians should discuss end-of-life care plans with family members, recognise the importance of building family consensus and recommend including the patient in these discussions where possible when caring for patients from family-centric cultures.
- Further research is needed to explore the role of autonomy in end-of-life decision-making and death preparation from patients' and healthcare professionals' perspectives.

Introduction

Family preparation for death involves completing medical, psychosocial, spiritual and practical tasks[1,2] for improving cognitive, behavioural and emotional readiness for the death,[3] which shapes families' end-of-life care experiences and subsequent bereavement.[4–6] Adequate preparation alleviates fear of death, enables families to be present at the end of life and makes the impending death more acceptable while also easing the bereavement experience.[5–7] Inadequate preparation is linked to poor bereavement adjustment,[4,8,9] leading to complicated grief and distress, depression and anxiety.[3,10] Feelings of regret or guilt of not doing enough for the deceased before death are common among bereaved individuals.[11–14] However, existing evidence fails to identify which aspects of preparation influence bereavement.

Informal caregivers, often family members, are key in palliative and end-of-life care[15] due to their increased responsibilities as death nears.[16,17] They usually coordinate with healthcare professionals, make end-of-life decisions,[18] and deliver direct care. Families become aware of the impending death through caregiving[19] to meet complex care demands and prepare for death.[20] Most research on family caregivers' death preparation is conducted in Western societies,[5–7,20–25] limiting its cross-culture transferability.[26] Research from non-Western world, such as Eastern Asia,[27–31] is limited. Such studies often focus on identifying the relationship between death preparation and caregiving burden using a quantitative approach with standardised measurements.[29] For example, a survey in Taiwan showed that 60% of family caregivers felt insufficiently prepared for a relative's death,[30] but it offers limited insights into why people have these experiences and the key components of preparation.

Taiwan's palliative care services are funded through National Health Insurance and are well-developed to cover people with cancer and non-cancer diagnoses.[32] Ensuring patients' autonomy during advance care planning consultations is a legal responsibility stipulated by The Patient Right to Autonomy Act (2016).[33] Advance care planning in the West enhances family caregivers' death preparedness,[7,21,34] understanding of end-of-life processes,[21] and coping with impending death.[34] Taiwan's palliative care framework offers a valuable context for investigating families' death preparation. This paper draws upon data collected for a PhD project[35] and focusses on family caregivers' experiences of death preparation before their relative dies and how the preparation affects subsequent bereavement using qualitative methods.

Methods

Design

A qualitative interview study was conducted, followed by Braun and Clarke's reflexive thematic analysis[36] that allows for exploring experiences to develop meaningful patterns of death preparations for generating a better understanding in a broad context.[36,37] It is underpinned by critical realism acknowledging that good experiences of death preparations exist but are contextually influenced.[36,38] Reflexive Thematic Analysis Reporting Guidelines ensured study quality and thorough reporting.[36,39–41]

Setting

The study aimed at families whose relatives had experienced specialist palliative care in Taiwan. Taiwan's specialist palliative care services include multidisciplinary teams with advanced training, offering hospice inpatient, consultation and home care services.

Participants

Participants were family members who were primary caregivers of a relative who received specialist palliative care before death, aged 20 years or older (recognised as an adult in Taiwan before January 2023[42]), fluent in Mandarin or Taiwanese. They had bereaved 6–18 months,[19,23] an appropriate timeframe allowing for grieving[43] and recall of experiences. Individuals bereaved for deaths of children (under 20 years old) were excluded due to significant differences from adult deaths.[44]

Sampling and recruitment

Purposive and snowball sampling methods were employed for recruitment. Specialist palliative care teams holding records of deceased patients for bereavement support were initially contacted to help recruit potential participants. The consent process encouraged questions and discussion, and written informed consent was obtained before all interviews.

Data collection

Following a pilot interview in September 2022, H-JL conducted semi-structured interviews with a literature-informed topic guide (Supplemental Appendices 1)[5,19,21,23,24] from October 2022 to March 2023, either in-person at participants' convenient places or online complying with the COVID-19 policies. Demographic data were collected (Supplemental Appendices 2). Interviews were audio-recorded and had flexible durations. A distress protocol was developed[45] to ensure safety (Supplemental Appendices 3).

H-JL's background as a palliative care nurse might affect interviews and data interpretation. Thus, she kept a reflexive journal to challenge assumptions in real-time and reflect on personal feelings and thoughts.[36]

Recruitment was concluded based on information power that continually assessed data richness to ensure the research questions were sufficiently addressed.[36,46]

Ethical approval

Ethics approval was received from the Hospital (A-ER-111-193) and Lancaster University (FHM-2022-0972-ExRev-1) Research Ethics Committees.

Data analysis

H-JL conducted data analysis recursively following the six phases of reflexive thematic analysis: familiarising with the dataset, coding, generating initial themes, developing and refining themes and writing up.[36] Interview recordings were transcribed in Traditional Chinese and managed with NVivo. Coding was conducted in Traditional Chinese for close engagement with the data and to improve analysis quality.[47] Selected code labels and relevant data were translated into English for team discussions, including NP being an English speaker, to enhance understanding, interpretation of the data and researcher reflexivity throughout the analysis process.[36]

H-JL critically engaged with the dataset, conducted two rounds of inductive coding and translated final codes into English with certain Traditional Chinese terms retained. H-JL then generated, reviewed and refined themes by clustering related codes, creating thematic maps (Supplemental Appendices 4), defining each theme and developing a coherent narrative.

Findings

Participants characteristics

Twenty-two primary family caregivers from seven hospitals with specialist palliative care units were interviewed (Table 1). The hospitals included four medical centres, two regional hospitals and one district hospital across Southern ($n = 3$), Central ($n = 2$), Northern ($n = 1$) and Eastern ($n = 1$) Taiwan. Participants' mean age was 55.3 years (range = 23–78 years), including 8 men and 14 women, mainly adult children of people who died, employed full-time and followed Taiwanese folk religion. The average bereavement period was 10.7 months (range = 6–17 months). The 21 deceased patients, averaging 70.9 years old (range 44–93 years), were mostly women and mainly diagnosed with cancer. Nearly half died at home, while the rest were in hospice or non-hospice inpatient units. Interviews averaged 115 min (range = 70–186 min).

Table 1. Descriptive characteristics of family members and deceased patients.

Bereaved family members (*N* = 22)		Deceased patients (*N* = 21)	
Age		Age at death	
20–40	2	41–65	7
41–65	15	66–80	9
66+	5	81+	5
Gender		Gender	
Man	8	Man	4
Woman	14	Woman	17
Employment status		Primary medical diagnosis	
Full time	12	Cancer	14
Retired	8	Non-cancer	7
Unemployed	2	Specialist palliative care received before death	
Religious beliefs		Inpatient, consultation and home care	7
Taiwanese folk religion	8	Inpatient and consultation care	4
Buddhism	3	Inpatient and home care	3
Taoism/Daoism or Yiguandao	3	Inpatient care	2
Christianity/Catholic	6	Home care	5
No affiliation	2	Death of place	
Relationship with deceased patients		Home	10
Adult children	14	Hospice inpatient unit	9
Spouse	5	Non–hospice inpatient unit	2
Sibling	2		
Parents of adult child	1		
Bereaved time before recruitment (months)			
6–12	18		
13–18	4		

Themes

An overarching theme of 'getting everything right – to have no regrets between the dead and the living' was developed as a vital goal in death preparation. Participants aimed at doing their best in death preparation to minimise future regrets, reduce the dying relative's regrets and ensure their comfort:

> *It's necessary to ensure that the person who's about to leave [referring to dying] has no regrets but also making sure that those close to them don't carry regrets in their hearts. (Daughter, FC4)*

> *'Having no regrets between both sides [referring to the dying relative and families]' (Daughter, FC18)* was emphasised. Participants noted that *'regrets become a lasting source of pain' (Father, FC13)* and that *'there will be no chance to do it again' (Daughter, FC4)*, leading to *'self-blame' (Daughter, FC18)* and *'guilt' (Daughter, FC3)*, which complicated bereavement. As described, *'To have less grief means not feeling regrets' (Father, FC13)*. While phrases like *'having no regrets' (Daughter, FC18)* and *'not feeling regrets' (Father, FC13)* may seem unrealistic, participants used them to stress the need to reduce regrets when preparing for a relative's death, recognising their impact on bereavement.

This overarching theme was broken down into two themes focussed upon improving the dying relative's well-being leading up to the death: (1) 'making the right end-of-life decisions is crucial but complex' and (2) 'becoming a competent caregiver is the priority'. These themes highlight families' preparations and actions before the death, specifically regarding regrets and their impacts on subsequent bereavement (Figure 1).

Theme 1: Making the right end-of-life decisions is crucial but complex. This theme explores the complexity and importance of preparing for the 'right' end-of-life decisions, including how and why families make these choices and what they mean to them.

Preparing to address worries about making wrong choices. Preparing to address worries about making wrong choices as death approached was emphasised. Participants expressed anxieties such as *'Did I make any wrong decisions?' (Daughter, FC10)* and *'I worried that this choice for my mother was wrong' (Daughter, FC12)*. They were afraid that decisions could lead to *'increased suffering' (Husband, FC19)*, *'unnecessary treatments' (Daughter, FC17)* or shorten the relative's life, causing *'unforgivable guilt' (Father, FC13)*. These concerns often revolved around decisions regarding withholding or withdrawing life-prolonging treatments like *'removing a nasogastric tube' (Daughter, FC12)* and *'Do-Not-Resuscitate' (Daughter, FC9)*:

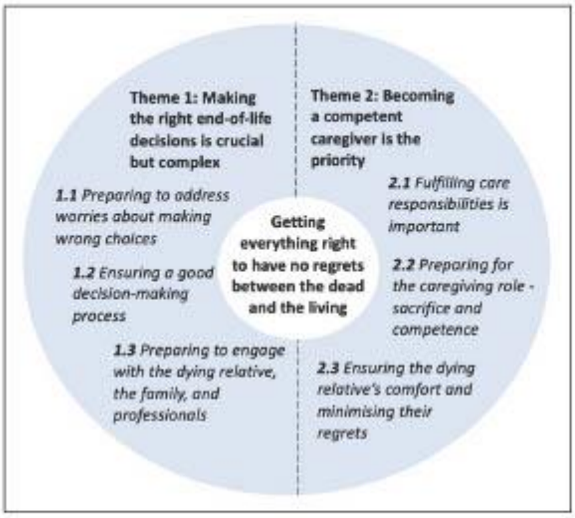

Figure 1. Families' preparations and actions before the relative's death.

> *To be honest, when faced with signing a Do Not Resuscitate form, I really couldn't bring myself to do it. Overcoming that barrier was extremely challenging. It was very, very difficult. That feeling was truly frightening. I mean, once I signed, it felt like my mother was going to pass away soon. (Daughter, FC17)*

Participants addressed these concerns by striving to get choices 'right', making the best possible end-of-life decisions through a good decision-making process and involving all essential parties, as detailed below.

Ensuring a good decision-making process. Preparing for a good decision-making process was part of making the best possible end-of-life decisions. This included easing the dying relative's burdens and shielding them from negative emotions like *'fear' (Sister, FC5)*. As expressed, *'We didn't want to make my mum feel like her life was coming to an end' (Daughter, FC7)*. Participants thus found it essential to determine whether, when and how to involve the dying relative, leading to varying inclusion levels. Exclusion happened if the dying relative showed disinterest or if decisions were guided by families' knowledge about them and topic sensitivity. Selective involvement aimed to protect the dying relative, while inclusion was necessary if they preferred to decide independently, highlighting the importance of aligning the process with their preferences:

> *In the past, my mum always made decisions for herself. So, I also hoped that in the final moments of her life, she could follow her own wishes and make her own decisions. (Daughter, FC18)*

Protecting the dying relative during decision-making also influenced how distressing information was disclosed. Participants felt *'guilt' (Daughter, FC2)* if inappropriate disclosure caused suffering. Concerns included *'potential impacts on the illness condition' (Husband, FC20)*, *'collapse' (Daughter, FC2)*, emotional distress like *'shocking, overwhelming' (Daughter, FC9)* or *'disrupted joy in life' (Husband, FC19)*. This information included medical details like *'life expectancy' (Daughter, FC9)* and non-medical issues such as other family members dying or becoming unwell. Consequently, participants often withheld full disclosure or provided only vague details:

> *I asked the physician how much time my young sister had left, and he said approximately three months. However, I only told her that her treatment was no longer effective and did not reveal the specific time remaining. [The patient did not ask about her lifespan] (Sister, FC5)*

Preparing to engage with the dying relative, the family and professionals. Preparing to engage with the dying relative, family and professionals was important to make the best possible end-of-life decisions. While direct involvement of the dying relative was not always essential, respecting their preferences was vital. As expressed, *'It's so important to respect my mother's preferences' (Daughter, FC18)*. Therefore, planning to understand the dying relative's end-of-life preferences through discussions like *'advance care planning consultation' (Son, FC16)* was necessary. Preferences varied from general principles like *'don't make me suffer' (Daughter, FC17)* to specific ones like *'Do Not Resuscitate' (Daughter, FC9)*. Without explicit instructions, participants needed to infer potential preferences based on their understanding of the dying relative:

> *Knowing my husband's personality, I was aware that he wouldn't want to continue lying in bed and be cared for by others. So, I made the decision about removing a nasogastric tube for him. (Wife, FC14)*

Preparing to *'maintain family harmony' (Daughter, FC18)* by reaching consensus in end-of-life decision-making was essential. As expressed, *'I feared my sisters might oppose our mother's advance directive and see it as me acting unilaterally' (Son, FC16) 'caregiving matters' (Daughter, FC18)*. This emphasised the need for family consensus on decisions, including, to avoid conflicts:

> *If one of my siblings didn't agree with the decisions I made for my mother, the outcome couldn't be satisfied like it is now. So, I believe that it's important to have a consensus among the family. (Daughter, FC17)*

Preparing to engage with healthcare professionals was important for making the best possible end-of-life decisions. Participants, often *'non-professionals' (Daughter, FC3)*, found it challenging to act as intermediaries in *‘the professional decision-making process’ (Daughter, FC12)*. Gaining knowledge in advance through ways like *‘searching for information’ (Sister, FC5)* improved their communication with professionals. As expressed, *‘I would know how to ask medical staff questions after doing some research’ (Daughter, FC7)*. Additionally, obtaining professionals’ expertise and medical information about the dying relative through *‘family meetings’ (Wife, FC1)* was essential in enhancing participants’ confidence and moving them beyond relying solely on personal opinions:

> *The family meeting process gave me the feeling that the decision [referring to removing a nasogastric tube] we made for my mother was reviewed and supported by the medical team, not just made on our own, but I had a team to support it. (Daughter, FC12)*

Preparing for the ‘right’ (the best possible) end-of-life decisions to minimise regrets included ensuring a process that shielded the dying relative from stress, aligned with their preferences, maintained family harmony through consensus-building and relied on professionals’ expertise.

Theme 2: Becoming a competent caregiver is the priority. Why and how family members prepare to become competent caregivers and actions taken to maximise the dying relative's comfort, the primary goal of death preparation, are explored in this theme.

Fulfilling care responsibilities is important. Fulfilling care responsibilities before the death helped minimise regrets afterwards. Familial duty and affection motivated participants to care for their dying relatives. As expressed, *‘I had to fulfil the responsibility as a husband’ (Husband, FC19)*. Adult children saw *‘caring for sick parents’ (Son, FC22)* as a way to honour *‘filial piety’ (Daughter, FC18)* and repay their nurturing, regardless of past relationship quality. For instance, *‘Caring for my mother was a way of paying her back for raising me’ (Son, FC22)*. This approach helped avoid the regret of *‘wanting to care for parents, but they are no longer around’ (referring to their death) (子欲養而親不在, Zi yù yǎng ér qīn bùzài) (Daughter, FC4)*. Showing gratitude for the dying relative’s past contributions to the family through caregiving was also important:

> *My wife hasn’t experienced much happiness since we got married. We’ve faced challenges from the beginning, and she’s stood by me through it all. That’s why I’ve made it a priority to accompany and care for her to the best of my ability. (Husband, FC15)*

Fulfilling caregiving responsibilities to minimise regret was perceived as essential, necessitating thorough preparation for this role, as described below.

Preparing for the caregiving role – Sacrifice and competence. Preparing for caregiving involved making sacrifices and developing competence. These sacrifices prioritised the dying relative’s needs over their own and gave participants a sense of having *‘fulfilled the utmost responsibility and done everything possible’ (Husband, FC19)* and helped *‘minimise regrets’ (Daughter, FC12)* after death. Sacrifices included adjusting personal lives to *‘move back to live with my mother to care for her’ (Daughter, 18)* and *‘focus almost entirely on my young sister apart from work’ (Sister, FC5)*, as well as neglecting personal physical, social and emotional needs at times, such as *‘enduring a painful knee from frequently climbing stairs while caregiving’ (Husband, FC19)*, ‘giving up *all volunteering activities’ (Daughter, FC18)* and *‘making a lot of efforts to maintain emotional stability while caring for my mother’ (Daughter, FC12)*.

Witnessing the dying relative’s suffering was described as *‘unbearable’ (Son, FC11)*, causing mental pain like *‘helplessness, self-blame’ (Daughter, FC3)*, *‘guilt’ (Daughter, FC4)*, feeling *‘heartbroken’ (Daughter, FC6)* and *‘deep pain in heart’ (Husband, FC19)*. Participants feared they could not ease or might worsen the suffering through inadequate caregiving. Despite this, caregiving also evoked positive feelings of being *‘relieved’* and *‘more at ease’ (Sister, FC5)*. Participants developed their caregiving competence by *‘acquiring a lot of knowledge’ (Son, FC22)* and learning new skills through *‘guidance from healthcare professionals’ (Husband, FC15)*, *‘training courses’ (Son, FC22)* and *‘online resources’ (Sister, FC5)*.

Ensuring the dying relative’s comfort and minimising their regrets. Preparations to ensure the dying relative’s comfort and reduce regrets before death included competent caregiving and selecting an appropriate care location. Preferences varied between hospitals with *‘palliative care inpatient units’ (Wife, FC1)*, valued for their *‘medical staff’s expertise’ (Husband, FC15)* and *‘assisted bathing equipment’ (Daughter, FC10)* and care at home, which offered *‘a sense of security’ (安全感, ān quán gǎn) (Daughter, FC17)* in a familiar environment. Home care required preparing for symptom management like learning to administer *‘subcutaneous morphine’ (Husband, FC15)* and adjusting the home environment to meet the relative’s needs, including space and necessary medical devices:

> *My brother’s room was transformed into my father’s room. We moved some furniture out and put a medical bed into the room. (Daughter, FC4)*

Preparing to provide personal care, including *‘changing nappies, adjusting positions’ (Daughter, FC12)* and *‘preparing meals’ (Daughter, FC4)*, was essential for the dying relative’s cleanliness and comfort. Participants viewed food preparation as a way of *‘expressing care’ (Daughter,* *FC2)* and regarded food as vital for physical strength. They worried about their dying relative *'being hungry' (Son, FC11)* if they did not eat enough, motivating them to prepare meals to *'supplement nutrition' (Daughter, FC7).* Therefore, preparing to understand and accept the dying relative's reduced appetite and decreased need for food through *'past experiences, reading materials' (Daughter, FC2)*, and *'professional explanations' (Son, FC11)* was necessary.

Ensuring the dying relative's *'happiness' (Wife, FC1), 'feeling loved' (Husband, FC19)* and *'inner peace' (Daughter, FC12)* as they *'approached the last moment of life' (Wife, FC1)* was important. Preparation involved helping them *'feel happy and joyful until the end' (Husband, FC19)* by safeguarding their decision-making process, as discussed in Theme 1. This also included providing family companionship through *'being surrounded by family members' (Father, FC13)* and respecting their preferences for enjoyable activities, like *'not making my husband do things he didn't want to do' (Wife, FC1).* Adjusting interactions, including *'greeting and talking to my wife even when she could no longer communicate verbally' (Husband, FC19)*, was essential for showing love. Additionally, preparing religious practices based on shared beliefs, such as *'singing hymns' (Daughter, FC12), 'discussing religious texts' (Son, FC21)* and performing rituals like *'lighting a lantern' (a practice from Yiguandao, which blends teachings from Confucianism, Taoism, Buddhism, Christianity and Islam) (Son, FC22)*, enhanced the dying relative's inner peace and mental strength.

Preparing the dying relative to minimise regrets before death was vital. As expressed, *'I told my husband, I didn't want you to leave (referring to die) with regrets' (Wife, FC1).* This included help them review their life, asking questions like *'Have you been happy in your entire life' (Daughter, FC18*), and creating opportunities for *'reconciliation' (Son, FC11)* and heartfelt expressions between the dying relative and family members. Actions included *'showing gratitude and saying sorry' (Daughter, FC10), 'offering comforting words' (Daughter, FC3*) and *'resolving past conflicts' (Daughter, FC4).* Understanding and fulfilling the dying relative's unfinished business or wishes was also important:

> *About a month before my younger sister passed away, she was in the hospital and expressed her wish to see our father's spirit tablet [a tablet with the deceased's name, symbolising the soul of the deceased] and worship him. We sought permission from the hospital and brought her home to fulfil her wish. (Sister, FC5)*

Preparing to be competent caregivers was the priority, aiming to minimise future regrets by fulfilling caregiving responsibilities, making sacrifices and ensuring the dying relative's comfort.

Discussion

Main findings of the study

Preparing for the 'right' end-of-life decisions and caregiving was important for Taiwanese families in the study during death preparation, aimed at minimising future regrets and benefiting subsequent bereavement. The best possible decisions included protecting the dying relative by deciding whether to involve them in discussions, maintaining family harmony through consensus-building and relying on professional expertise. Preparations to reduce regret about not doing enough involved fulfilling care responsibilities, making sacrifices, developing caregiving competence to ensure the dying relative's comfort and addressing their last wishes to minimise regrets.

What this study adds?

The study demonstrates how the cultural context shapes families' end-of-life decision-making and caregiving for the dying relative during death preparation. Participants' end-of-life decision-making reflects Taiwan's family-led culture, which may conflict with the Western-centric model underpinning Taiwan's palliative care practices. The time participants spent caring for a dying relative aligns with findings from Western studies,[20,24] but our study reveals the deeper cultural significance of caregiving in Taiwan.

This study highlights that it was sometimes necessary to shield patients from direct participation in end-of-life discussions, with their level of involvement determined by families who aimed to ensure the best possible decisions. Patients were excluded if they showed no interest or based on families' prior knowledge of the patients and the sensitivity of topics. These complex interactions between patients and families shaped their awareness of the impending death over time[48] and influenced death preparation.[49] However, the families' exclusionary approach may conflict with Western perspectives on patient autonomy, prioritising individualism and opposing paternalism,[50] and these views often influence medical practices in Taiwan.[51] Instead, relational autonomy, which respects individual choice within social and cultural contexts, is more suitable for end-of-life situations across cultures,[50] including family-centric societies.[52] Our findings show families played a key role in decision-making[53] that is viewed as a collective family responsibility in Taiwanese culture.[52] In Taiwan, the Natural Death Act (2000)[54] and the Patient Right to Autonomy Act (2016)[33] mandate family participation in medical decisions, including their right to sign Do-Not-Resuscitate forms considering patients' preferences[54] and involving at least one family member in advance care planning.[33] These laws acknowledge family roles in medical decision-making but may struggle to address the need for building family consensus in end-of-life decisions, aiming to avoid conflicts and maintain family harmony, as this study highlights. This reflects the central Taiwanese cultural emphasis on Confucian values of family-centredness[52,55] and harmonious relationships.[55] From the perspective of relational autonomy, patients' preferences should take precedence over contextual factors, including family wishes, when they conflict.[50] Thus, this approach is less applicable in the Taiwanese context, where family consensus is important despite potential misalignment with patients' end-of-life care preferences.[56] Our findings provide new insights into relational autonomy in end-of-life decision-making from the family perspective. Future research should investigate this concept from the viewpoints of patients and professionals.

Align with previous research, this study finds that families' death preparation impacted their bereavement.[4,5,8] Our study further highlights that getting end-of-life decision-making and caregiving 'right' was perceived as beneficial for subsequent bereavement by minimising regret. Regret, involving self-appraisal of past behaviours, often leads to painful emotions such as guilt, self-blame and a wish to change those actions if dissatisfied.[57,58] Regret or guilt about not doing enough for the deceased before death is common among the bereaved,[11–14] and such feelings can intensify grief, making bereavement more challenging.[59–61] While bereavement theories typically focus on post-death experiences,[62,63] our study offers preventative insights into reducing regrets beforehand to ease bereavement. However, this approach may not apply to sudden or unexpected deaths.

End-of-life decision regrets among families are underexplored,[64] with limited evidence on their extent and contributing factors.[65] For instance, a Taiwanese study found substantial decision regrets among family caregivers before and after the death,[66] while a U.S. study linked life-prolonging treatment to increased regrets among African American families.[67] These regrets likely stem from the complex decision-making process involving dying patients, families and healthcare professionals, as underscored in our study. Attempting to make the best possible end-of-life decisions was seen as beneficial in this study by mitigating regret from perceived wrong choices. This involved protecting the dying relative from too close involvement at times, maintaining family harmony and relying on professional expertise to avoid unnecessary suffering and treatments.

Evidence on the impact of end-of-life caregiving on bereavement is mixed.[9,61,68] For example, a U.S. study found that positive caregiving aspects, such as feeling useful, were linked to higher grief levels.[68] However, our study shows that being useful through fulfilling care responsibilities,[24,69] making sacrifices,[70] and ensuring the dying relative's comfort[70,71] were perceived as beneficial for bereavement. Families in our study also experienced emotional distress from witnessing suffering and feeling unable to help, leading to self-blame and guilt,[72] complicating the bereavement. Our findings underscore self-sacrifice being important in caregiving, shaped by Taiwan's collectivist culture prioritising others over individuals[73] and Confucius values emphasising filial piety[55,74] and the fulfilment of family care duties.[74,75] This cultural significance of caregiving may help explain the positive impact of end-of-life caregiving on bereavement among Taiwanese families.[70]

Healthcare professionals were pivotal in families' death preparation, including end-of-life decision-making and caregiving.[1,2,21,76] However, families' needs often remained unmet, even in palliative care settings.[77] Future research should explore healthcare professionals' perspectives on strategies for supporting family preparation. Suggestions for preventing challenging bereavement before death include assisting families in making the best possible decisions, fulfilling care responsibilities, ensuring they feel they have done their best and preparing them to provide competent caregiving to ensure the dying relative's comfort. Additionally, clinical practices should prioritise family involvement and consensus-building in end-of-life decision-making through family meetings,[78] in contexts where family-centric approaches are valued or when caring for patients and families from other cultural backgrounds in Western societies. Patients' wishes and families' knowledge about the patient can help clinicians decide whether to exclude the patient from end-of-life care discussions. When the patient is excluded, it is vital to guide families in respecting the patients' expressed preferences or inferring potential preferences based on their understanding of the patient, especially when no explicit instructions have been provided.

Reflections, strengths and limitations of the study

Families' death preparation is contextual, including interactions with the dying relative, other family members, healthcare professionals, healthcare system and the broader social and cultural context. The main researcher (H-JL), a senior Taiwanese palliative care nurse, acted as a clinician-researcher, which might have influenced data generation and analysis[79] due to her personal cultural background and preconceived views on death preparation. However, researcher reflexivity was fully considered.[36,79] H-JL maintained a reflexive journal and had ongoing discussions with NP and QX to receive critical feedback, enhancing data interpretation and reflexivity.[36] For example, the interviews did not explore participants' views on what constituted 'right', 'good' or 'best' end-of-life decisions. Instead, H-JL reflected this point on the Taiwanese collectivist values, emphasising self-improvement through self-criticism.[73] In Taiwanese society, criticism of poor decision-making is common, which may explain the focus on making 'right' decisions. In this study, 'right' was interpreted as 'the best possible'.

The study's strength is the diverse participant residences across Taiwan, achieved through purposive sampling, which enriched the data, allowed for a thorough exploration of research questions and enhanced its transferability to countries with family-centred decision-making.[36] To preserve cultural meaning, findings were translated from Traditional Chinese to English later in the analysis, retaining certain Traditional Chinese words.[47] Additionally, H-JL and QX, who spoke Chinese and English, facilitated exploring language nuances in both languages.

The study has some limitations, including potential issues with transferability to non-specialist palliative care settings and non-primary family caregivers. The predominance of adult children of deceased patients, mainly women, and the focus on people with cancer could also affect transferability.[80] While we believe that participants' experience of the entire death preparation process provided valuable insights, we acknowledge that the 6- to 18-month bereavement timeframe might have influenced the study's findings, particularly the emphasis on preparation to reduce regret about not doing enough, a sentiment commonly felt by bereaved individuals.[11] Future research should explore this topic in non-specialist palliative care contexts, focus on the period before the patient's death, examine a wider range of relationships with the deceased, address various diagnoses and incorporate patients' perspectives. Additionally, although both in-person and virtual interviews might affect data quality, previous research shows they yield similar rapport and depth of information,[81] consistent with our study's comparable interview durations.

Conclusion

Preparing for end-of-life decisions and caregiving is important for Taiwanese families in the study to minimise regrets, benefiting subsequent bereavement. Family involvement and consensus-building in these decisions are essential in Taiwan, reflecting its family-led culture. These findings can inform clinical practices in family-centric decision-making contexts. Suggestions for preventing difficult bereavement before death include fulfilling caregiving responsibilities, providing competent care and relieving the dying relative's suffering. Future research should include the perspectives of patients and healthcare professionals.

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Author contributions

H-JL, NP and QX contributed to the conception and design. H-JL, P-CL and J-HT managed ethical approval and participant recruitment. H-JL conducted the interviews and thematic analysis. H-JL, NP and QX presented the data analysis and interpretation. NP and QX supervised the study. H-JL drafted the manuscript. All authors reviewed and approved the final version for submission.

Data management and sharing

Additional data are available in the Supplementary File and from the corresponding author (h.liang3@lancaster.ac.uk).

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The study was approved by the National Cheng Kung University Hospital Institutional Review Board (Ref: A-ER-111-193) and Lancaster University Faculty of Health and Medicine Research Ethics Committee (Ref: FHM-2022-0972-ExRev-1). Details of the consent process are included in the article.

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Supplemental material

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References

1. Loke AY, Li Q and Man LS. Preparing family members for the death of their loved one with cancer: a review of literature and direction for future research. *J Hosp Palliat Nurs* 2013; 15: E1–E11.
2. Hebert RS, Prigerson HG, Schulz R, et al. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. *J Palliat Med* 2006; 9: 1164–1171.
3. Nielsen MK, Neergaard MA, Jensen AB, et al. Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clin Psychol Rev* 2016; 44: 75–93.
4. Caserta M, Utz R, Lund D, et al. Cancer caregivers' preparedness for loss and bereavement outcomes: do preloss caregiver attributes matter? *Omega* 2019; 80: 224–244.
5. Hovland-Scafe CA and Kramer BJ. Preparedness for death: how caregivers of elders with dementia define and perceive its value. *Gerontologist* 2017; 57: 1093–1102.
6. Kim Y, Carver CS, Spiegel D, et al. Role of family caregivers' self-perceived preparedness for the death of the cancer

patient in long-term adjustment to bereavement. *Psycho-oncology* 2017; 26: 484–492.
7. Schulz R, Boerner K, Klinger J, et al. Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *J Palliat Med* 2015; 18: 127–133.
8. Barry LC, Kasl SV and Prigerson HG. Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *Am J Geriatr Psychiatry* 2002; 10: 447–457.
9. Tsai W-I, Prigerson HG, Li C-Y, et al. Longitudinal changes and predictors of prolonged grief for bereaved family caregivers over the first 2 years after the terminally ill cancer patient's death. *Palliat Med* 2016; 30: 495–503.
10. Treml J, Schmidt V, Nagl M, et al. Pre-loss grief and preparedness for death among caregivers of terminally ill cancer patients: a systematic review. *Soc Sci Med* 2021; 284: 114240.
11. Tey MQ and Lee GL. Understanding bereavement experiences and coping among bereaved family caregivers in Singapore: positive meaning reconstruction in the dual process model. *Omega*. Epub ahead of print 12 October 2022. DOI:10.1177/00302228221133584.
12. Milberg A, Olsson E-C, Jakobsson M, et al. Family members' perceived needs for bereavement follow-up. *J Pain Symptom Manag* 2008; 35: 58–69.
13. Holtslander L, Baxter S, Mills K, et al. Honoring the voices of bereaved caregivers: a Metasummary of qualitative research. *BMC Palliat Care* 2017; 16: 48.
14. Ishida M, Onishi H, Matsubara M, et al. Psychological distress of the bereaved seeking medical counseling at a cancer center. *Jpn J Clin Oncol* 2012; 42: 506–512.
15. Tishelman C and Payne S. White paper on improving support for family carers in palliative care: Part 1: recommendations from the European association for palliative care (EAPC) task force on family carers. *Eur J Palliat Care* 2010; 17: 238–245.
16. Jo S, Brazil K, Lohfeld L, et al. Caregiving at the end of life: perspectives from spousal caregivers and care recipients. *Palliat Support Care* 2007; 5: 11–17.
17. Ham L, Fransen HP, de Graeff A, et al. Relatives' unmet needs in the last year of life of patients with advanced cancer: results of a Dutch prospective, longitudinal study (eQuiPe). *J Palliat Care* 2025; 40(1): 41–50.
18. Reigada C, Pais-Ribeiro JL, Novella A, et al. The caregiver role in palliative care: a systematic review of the literature. *Health Care Curr Rev* 2015; 3: 2.
19. Hovland CA and Kramer BJ. Barriers and facilitators to preparedness for death: experiences of family caregivers of elders with dementia. *J Soc Work End-of-Life Palliat Care* 2019; 15: 55–74.
20. Breen LJ, Aoun SM, O'Connor M, et al. Family caregivers' preparations for death: a qualitative analysis. *J Pain Symptom Manag* 2018; 55: 1473–1479.
21. Hebert RS, Schulz R, Copeland VC, et al. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *J Pain Symptom Manag* 2009; 37: 3–12.
22. Hebert RS, Dang Q and Schulz R. Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: findings from the REACH study. *J Palliat Med* 2006; 9: 683–693.
23. Supiano KP, Luptak M, Andersen T, et al. If we knew then what we know now: the preparedness experience of pre-loss and post-loss dementia caregivers. *Death Stud* 2022; 46(2): 369–380.
24. Durepos P, Ploeg J, Sussman T, et al. "A crazy roller coaster at the end": a qualitative study of death preparedness with caregivers of persons with dementia. *SAGE Open Nurs* 2020; 6: 1–11.
25. Nielsen MK, Neergaard MA, Jensen AB, et al. Preloss grief in family caregivers during end-of-life cancer care: a nationwide population-based cohort study. *Psycho-Oncology* 2017; 26: 2048–2056.
26. Gire J. How death imitates life: cultural influences on conceptions of death and dying. *Online Read Psychol Cult* 2014; 6: 3.
27. Tang ST, Chang WC, Chou WC, et al. Family caregivers' emotional preparedness for death is distinct from their cognitive prognostic awareness for cancer patients. *J Palliat Med* 2021; 24: 405–412.
28. Wen FH, Chou WC, Hou MM, et al. Associations of death-preparedness states with bereavement outcomes for family caregivers of terminally ill cancer patients. *Psycho-Oncology* 2022; 31: 450–459.
29. Wen FH, Chou WC, Hou MM, et al. Caregivers' death-preparedness states impact caregiving outcomes and patients' end-of-life care. *J Pain Symptom Manag* 2022; 63: 199–209.
30. Wen FH, Chou WC, Hsieh CH, et al. Distinct death-preparedness states by combining cognitive and emotional preparedness for death and their evolution for family caregivers of terminally ill cancer patients over their last 6 months of life. *J Pain Symptom Manag* 2021; 62: 503–511.
31. Tang ST, Hsieh CH, Chou WC, et al. Course of changes in emotional preparedness for death and its associations with caregiving outcomes for family caregivers of terminally ill cancer patients over their last year of life. *J Pain Symptom Manag* 2021; 61: 974–982.
32. Finkelstein EA, Bhadelia A, Goh C, et al. Cross country comparison of expert assessments of the quality of death and dying 2021. *J Pain Symptom Manag* 2022; 63: e419–e429.
33. Laws and Regulations Database of The Republic of China (Taiwan). Patient Right to Autonomy Act, https://law.moj.gov.tw/ENG/LawClass/LawAll.aspx?pcode=L0020189 (2016, accessed 1 August 2024).
34. Sellars M, Chung O, Nolte L, et al. Perspectives of people with dementia and carers on advance care planning and end-of-life care: a systematic review and thematic synthesis of qualitative studies. *Palliat Med* 2019; 33: 274–290.
35. Liang H-J, Xiong Q, Lin P-C, et al. 'A good ending but not the end': exploring family preparations surrounding a relative's death and the Afterlife–a qualitative study. *Palliat Med* 2024; 38(10): 1184–1193.
36. Braun V and Clarke V. *Thematic analysis: a practical guide*. 1st ed. Thousand Oaks: Sage, 2022.
37. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
38. McEvoy P and Richards D. A critical realist rationale for using a combination of quantitative and qualitative methods. *J Res Nurs* 2016; 11: 66–78.
39. Braun V and Clarke V. Supporting best practice in reflexive thematic analysis reporting in Palliative Medicine: a review

of published research and introduction to the Reflexive Thematic Analysis Reporting Guidelines (RTARG). *Palliat Med* 2024; 38(6): 608–616.

40. Braun V and Clarke V. Conceptual and design thinking for thematic analysis. *Qual Psychol* 2022; 9: 3.
41. Braun V and Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual Res Psychol* 2021; 18: 328–352.
42. Judicial Yuan T. The legal age of adulthood will be lowered to 18 years old, effective January 1, 2023, https://www.judicial.gov.tw/tw/cp-1454-359073-62da4-1.html# (2021, accessed 02 August 2024).
43. Miller MD. Complicated grief in late life. *Dialogues Clin Neurosci* 2012; 14: 195–202.
44. Bogetz JF, Revette A, Rosenberg AR, et al. "I could never prepare for something like the death of my own child": parental perspectives on preparedness at end of life for children with complex chronic conditions. *J Pain Symptom Manag* 2020; 60: 1154–1162.e1151.
45. Draucker CB, Martsolf DS and Poole C. Developing distress protocols for research on sensitive topics. *Arch Psychiatr Nurs* 2009; 23: 343–350.
46. Braun V and Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exerc Health* 2021; 13: 201–216.
47. Abfalter D, Mueller-Seeger J and Raich M. Translation decisions in qualitative research: a systematic framework. *Int J Soc Res Methodol* 2020; 24: 469–486.
48. Glaser BG and Strauss AL. *Awareness of Dying*. 1st ed. Somerset: Taylor & Francis Group, 1965.
49. Durepos P, Sussman T, Ploeg J, et al. What does death preparedness mean for family caregivers of persons with dementia? *Am J Hosp Palliat Med* 2019; 36: 436–446.
50. Gómez-Vírseda C, De Maeseneer Y and Gastmans C. Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC Med Ethics* 2019; 20: 1–15.
51. Cheng S-Y, Hu W-Y, Liu W-J, et al. Good death study of elderly patients with terminal cancer in Taiwan. *Palliat Med* 2008; 22: 626–632.
52. Tan Kiak Min M. Beyond a Western bioethics in Asia and its implication on autonomy. *New Bioethics* 2017; 23: 154–164.
53. Kwak J and Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist* 2005; 45: 634–641.
54. Laws and Regulations Database of The Republic of China (Taiwan). Natural Death Act (Hospice Palliative Care Act), https://law.moj.gov.tw/ENG/LawClass/LawAll.aspx?pcode=L0020066 (2000, accessed 1 August 2024).
55. Yum JO. The impact of Confucianism on interpersonal relationships and communication patterns in East Asia. *Commun Monogr* 1988; 55: 374–388.
56. Lee S-C, Shih C-Y, Chen S-T, et al. Factors contributing to non-concordance between end-of-life care and advance care planning. *J Pain Symptom Manag* 2024; 67: 544–553.
57. Sugden R. Regret, recrimination and rationality. *Theor Decis* 1985; 19: 77–99.
58. Landman J. Regret: a theoretical and conceptual analysis. *J Theor Soc Behav* 1987; 17(2): 135–160.
59. Holland JM, Thompson KL, Rozalski V, et al. Bereavement-related regret trajectories among widowed older adults. *J Gerontol Ser B: Psychol Sci Soc Sci* 2014; 69: 40–47.
60. Stroebe M, Stroebe W, Van De Schoot R, et al. Guilt in bereavement: the role of self-blame and regret in coping with loss. *PLoS ONE* 2014; 9: e96606.
61. Tang Y. Caregiver burden and bereavement among family caregivers who lost terminally ill cancer patients. *Palliat Support Care* 2019; 17: 515–522.
62. Worden JW. *Grief counseling and grief therapy: a handbook for the mental health practitioner*. Cham: Springer Publishing Company, 2018.
63. Stroebe M and Schut H. The dual process model of coping with bereavement: a decade on. *Omega (Westport)* 2010; 61: 273–289.
64. Elidor H, Adekpedjou R, Zomahoun HTV, et al. Extent and predictors of decision regret among informal caregivers making decisions for a loved one: a systematic review. *Med Decis Making* 2020; 40: 946–958.
65. Okimura A and Hayashi N. Relationships between bereaved families' decision-making regret about end-of-life care place for patients with cancer and relevant factors. *Asia Pac J Oncol Nurs* 2023; 10: 100167.
66. Wen F-H, Hsieh C-H, Hou M-M, et al. Decisional-regret trajectories from end-of-life decision making through bereavement. *J Pain Symptom Manag* 2023; 66: 44-53.e41.
67. Smith-Howell ER, Hickman SE, Meghani SH, et al. End-of-life decision making and communication of bereaved family members of African Americans with serious illness. *J Palliat Med* 2016; 19: 174–182.
68. Boerner K, Schulz R and Horowitz A. Positive aspects of caregiving and adaptation to bereavement. *Psychol Aging* 2004; 19: 668.
69. Lowers J, Scardaville M, Hughes S, et al. Comparison of the experience of caregiving at end of life or in hastened death: a narrative synthesis review. *BMC Palliat Care* 2020; 19: 154.
70. Liang H-J, Xiong Q, Remawi BN, et al. Taiwanese family members' bereavement experience following an expected death: a systematic review and narrative synthesis. *BMC Palliat Care* 2024; 23: 14.
71. Garrido MM and Prigerson HG. The end-of-life experience: modifiable predictors of caregivers' bereavement adjustment. *Cancer* 2014; 120: 918–925.
72. Stetz KM. Caregiving demands during advanced cancer: the spouse's needs. *Cancer Nurs* 1987; 10: 260–268.
73. Markus HR and Kitayama S. Culture and the self: implications for cognition, emotion, and motivation. *Psychol Rev* 1991; 98: 224–253.
74. Fang ML, Malcoe LH, Sixsmith J, et al. Exploring traditional end-of-life beliefs, values, expectations, and practices among Chinese women living in England: informing culturally safe care. *Palliat Support Care* 2015; 13: 1261–1274.
75. Hui CH and Triandis HC. Individualism-collectivism: a study of cross-cultural researchers. *J Cross-Cult Psychol* 1986; 17: 225-248.

76. Hauksdottir A, Valdimarsdottir U, Fürst C, et al. Health care-related predictors of husbands' preparedness for the death of a wife to cancer: a population-based follow-up. *Ann Oncol* 2010; 21: 354–361.
77. Gallagher R and Krawczyk M. Family members' perceptions of end-of-life care across diverse locations of care. *BMC Palliat Care* 2013; 12: 1–9.
78. Glajchen M, Goehring A, Johns H, et al. Family meetings in palliative care: benefits and barriers. *Curr Treat Options Oncol* 2022; 23: 658–667.
79. Hay-Smith EJC, Brown M, Anderson L, et al. Once a clinician, always a clinician: a systematic review to develop a typology of clinician-researcher dual-role experiences in health research with patient-participants. *BMC Med Res Methodol* 2016; 16: 1–17.
80. Krefting L. Rigor in qualitative research: the assessment of trustworthiness. *Am J Occup Ther* 1991; 45: 214–222.
81. Jenner BM and Myers KC. Intimacy, rapport, and exceptional disclosure: a comparison of in-person and mediated interview contexts. *Int J Soc Res Methodol* 2019; 22: 165–177.

5.2 Chapter summary

Paper 2 focuses on family caregivers' preparation before a relative's death and how these actions and efforts shaped bereavement outcomes. Key elements of pre-death preparation involved making the best possible end-of-life decisions and providing competent caregiving to ensure the dying relative's comfort (Liang, Xiong, Lin, et al., 2025). These efforts helped families feel that they had fulfilled their responsibility and done their best for the dying relative, which in turn minimised regret and eased bereavement. Taiwanese family caregivers' preparation for the time surrounding a relative's death and the post-death period was published in a peer-reviewed journal (Paper 3) and is presented in the next chapter.

CHAPTER 6: ‘*A GOOD ENDING BUT NOT THE END*’- EXPLORING FAMILY PREPARATIONS SURROUNDING A RELATIVE’S DEATH AND THE AFTERLIFE: A QUALITATIVE STUDY (PAPER 3)

6.1 Overview

Building on the previous paper (Liang, Xiong, Lin, et al., 2025), this third paper (Liang, Xiong, Lin, et al., 2024) presents further findings from the qualitative interview study analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2022b).

This paper examines families’ preparations surrounding the time of death, the funeral, and the afterlife. These findings demonstrate that beliefs and practices related to the afterlife hold distinctive cultural significance in shaping how Taiwanese families approach and make sense of death preparation. The study provides deeper insight into how cultural and religious contexts influence family caregivers’ experiences during this process, particularly how these beliefs shape families’ notions of a good death, their continuing bonds with the deceased relative, and the expression of emotional restraint.

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'A good ending but not the end': Exploring family preparations surrounding a relative's death and the Afterlife – A qualitative study

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Abstract

Background: Adequate death preparation positively influences families' experience before death and during bereavement. However, how to prepare families in non-Western cultures has received scant attention.

Aim: To explore family caregivers' experiences in preparing for a relative's death in specialist palliative care in Taiwan.

Design: A qualitative study employing reflexive thematic analysis of data collected from semi-structured interviews was conducted.

Setting/participants: Twenty-two family caregivers from seven hospitals participated.

Results: The overarching theme was 'getting everything right to have no regrets between the dead and the living'. We developed two themes to explain preparations for the time surrounding and after the death, including the deceased' afterlife: (1) 'having a good ending but not the end of the relationship', which addresses preparations for the death itself, the funeral, the afterlife and maintaining connections and (2) 'using religious beliefs and cultural norms to guide preparation', which explores perceptions of a good death, including refrain from strong emotions before and after the death.

Conclusion: Funeral arrangements, enhancing the deceased's afterlife and maintaining connections to the deceased are crucial for families' experiences which can be impacted by actions they take as they prepare for the death. A culturally appropriate death is beneficial for the dying relative which includes preparing to not show strong emotions during and after the death. These insights inform the importance of the cultural context in death preparation in Taiwan and provide perspectives for palliative care beyond Western culture, potentially benefiting Chinese populations, predominantly East Asian and Buddhist societies.

Keywords

Palliative care, death, family, religion, culture, funeral ceremony, qualitative research

What is already known about the topic?

- Preparation for a relative's death is crucial in palliative and end-of-life care, greatly influencing the experience of family members both before the death and during subsequent bereavement.
- Preparedness, including cognitive, behavioural and emotional readiness, is a multifaceted concept requiring accomplishment through medical, psychosocial, spiritual and practical tasks.
- Research on death preparation, predominantly conducted in Western countries, may limit its universal applicability, hindering the provision of culturally appropriate palliative and end-of-life care.

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What this paper adds?

- Preparing for the time after death is crucial in Taiwanese families, including appropriate conduct at the moment of death, organising a meaningful funeral, enhancing the deceased's afterlife and preparing for ongoing relationships.
- Taiwanese families' preparation for death emphasises achieving a culturally appropriate death for the dying relative, with a focus on a dignified appearance (clean and well-dressed body, eyes closed, mouth shut) at the moment of death and ensuring a better afterlife, aiming to prevent regrets for both the deceased and the living.
- Preparing to refrain from strong emotions around the dying relative, both during and after their death, is important and culturally appropriate and believed to benefit their well-being.

Implications for practice, theory or policy

- Understanding and respecting families' religious beliefs (e.g. regarding the afterlife) and conforming to cultural norms are essential when assisting them in preparing for a relative's death.
- Our study contributes to a deeper understanding of what constitutes a good death from family perspectives within Taiwan's cultural context, which may apply to other Chinese societies.
- Further research could explore culturally appropriate emotional support strategies for Taiwanese individuals and develop effective approaches to establishing continuing relationships before a relative's death that positively impact bereavement adjustments, thereby informing proactive bereavement support.

Introduction

Preparedness for a relative's death involves cognitive, behavioural and emotional readiness[1–3] and requires managing medical, psychosocial, spiritual and practical tasks.[2–4] Assisting families in this is crucial in palliative and end-of-life care,[5,6] with evidence showing positive impacts on families, including emotional support, acceptance of death[7] and better bereavement outcomes such as lower levels of grief[8] and reduced complicated grief.[1,8–10] Despite its importance, there is a need to improve this aspect of care as studies indicate that family caregivers often lack essential information about the dying process and are unsure about the appropriate actions to take at the time of death,[11] with approximately 60% (*N* = 393) feeling inadequately prepared.[12]

Research on families' death preparation remains understudied, with most focussing on Western countries like the United States,[2,7,13,14] Canada[15] and Australia.[16] Culture influences how people approach death, respond to related issues and define a good or bad death.[17] Differences in culture suggests that findings from Western studies may not universally apply, potentially hindering culturally appropriate palliative and end-of-life care for other groups. Therefore, research specific to non-Western cultures, like East Asian contexts, is essential to address this gap.

Although some studies in East Asian cultures have explored preparedness for death, they often do not fully capture the comprehensive actions taken by families. For example, research in Taiwan has examined how family caregivers' preparedness relates to variables like depressive symptoms,[18–20] quality of life,[18] prolonged grief symptoms,[20] and subjective caregiving burden.[19] In Japan, insufficient preparedness has been linked to factors like unawareness of patients' medical conditions.[21] Given the influence of Confucianism and Collectivism in East Asian cultures, which emphasise familial support, filial piety (children showing respect, obedience and care for parents), mutual dependence,[22] and concern for others,[23] means culturally contextualised studies are needed to better understand death preparation in the region.

Taiwan ranks the third among the 81 countries in the 2021 Quality of Death and Dying study,[24] offering a well-developed palliative care system to evaluate death preparation in non-Western cultures. With constitutionally protected freedom of religion, Taiwan's diverse religious landscape, including Buddhism, Taoism, Christianity and Taiwanese folk religion (a blend of Buddhism, Taoism and Confucianism),[25] offers insights into the role of religion in death preparation. This study explores how cultural context influences family caregivers' experiences of preparing for a relative's death in specialist palliative care in Taiwan.

Methods

Design

The study employed Braun and Clarke's reflexive thematic analysis with a Big Q approach grounded in critical realism,[26] highlighting the acknowledgement that reality exists but is subject to contextual influences.[27] This method was chosen for its theoretical flexibility and alignment with the study's critical realism philosophy,[26] aiding in understating participants' experiences within a broader context by developing meaningful patterns across the dataset.[26,28] The inductive nature informs both data collection and analysis. Reporting of the study followed the Reflexive Thematic Analysis Reporting Guidelines.[26,29–31]

Setting

In Taiwan, government-funded palliative care services are integrated into the healthcare system to support patients with a cancer or non-cancer diagnosis. Specialist palliative care is provided by multidisciplinary teams with advanced training, operating across hospice inpatient units, consultation teams and home care services,[32] which is the context of this study.

Participants

Eligible participants were bereaved family members of patients who received specialist palliative care services before their death. They were aged 20 years or older, fluent in Mandarin or Taiwanese, and served as unpaid caregivers. The bereaved timeframe ranged from 6 to 18 months before recruitment, following previous studies on preparedness.[13,14] Six months post-death allowed for the grieving process,[33] while the 18-month limit facilitated recall of experiences. Those bereaved by a child's death (under 20 years old) were excluded due to their unique experiences, as indicated by previous research.[34]

Sampling and recruitment

Purposive and snowballing sampling methods were employed to recruit participants. Specialist palliative care teams, who maintain records of deceased patients to support bereaved families, were contacted to assist recruitment. Each potential participant received an information sheet and consent form (Supplemental Appendix 1). Interested individuals contacted the research team or had their information forwarded if preferred. The consent process included clarifications and additional details as requested. Written informed consent was obtained before the interview in-person or electronically.

Data collection

Semi-structured interviews were conducted from October 2022 to March 2023 using a literature-informed topic guide,[2,7,13–15] covering awareness of impending death, challenges, facilitators, tasks and emotions related to death preparation (Supplemental Appendix 2). Minor adjustments were made following a pilot interview in September 2022, including adding a question about actions that enhance preparedness and those to avoid.

H-JL conducted individual interviews in person or virtually, based on participants' preferences and COVID-19 policies. In-person interviews occurred at participants' homes or in private public spaces like cafes. An interview distress protocol[35] (Supplemental Appendix 3) was developed. H-JL maintained a reflexive journal, reflecting on assumptions, emotions and thoughts.[26]

Following the study's philosophical assumptions, when recruitment ended was guided by information power, ensuring data sufficiency for addressing the research questions. The assessment was ongoing through data collection and analysis.[26,36]

Ethical approval

Approval was obtained from the Hospital (A-ER-111-193) and University (FHM-2022-0972-ExRev-1) Research Ethics Committee.

Data analysis

The six-phase recursive process of reflexive thematic analysis was employed.[26] H-JL transcribed interview audio recordings in Chinese, managing with NVivo software. Coding was conducted in Chinese for linguistic convenience and data proximity but with some initial translation for discussion with the wider team as NP did not speak Chinese.[37] H-JL conducted two rounds of inductive coding, generating distinct code labels without predetermined frames. The list of code labels was translated into English, keeping certain original Chinese words by the end of coding. H-JL developed initial themes by clustering related codes, refining them through review and thematic maps (Supplemental Appendix 4). Continuous discussions with NP and QX aimed to enhance understanding, interpretation and researcher reflexivity.[26]

Findings

Participants characteristics

Twenty-two participants (8 men and 14 women) were interviewed from seven hospitals (Table 1), comprising four medical centres, two regional hospitals and one district hospital across Southern ($n = 3$), Central ($n = 2$), Northern ($n = 1$) and Eastern ($n = 1$) Taiwan. Participants' average age was 55.3 years (range = 23–78 years). Most were women, working full time, adult children of deceased patients and practicing Taiwanese folk religion. On average, they were bereaved for 10.7 months (range = 6–17 months). A total of 21 deceased patients averaged 70.9 years old (range = 44–93 years), mostly women, diagnosed mainly with cancer, with about half dying at home. Interviews lasted between 70 and 186 min, averaging 115 min.

Themes

The overarching theme was 'getting everything right to have no regrets between the dead and the living', a primary goal in Taiwanese families' death preparation. Families strived to ensure a culturally appropriate death

Table 1. Descriptive characteristics of family members and deceased patients.

Family member participant characteristics	*N* = 22
Age (years)	
20–40	2
41–65	15
66+	5
Gender	
Man	8
Woman	14
Employment status	
Full time	12
Retired	8
Unemployed	2
Religious beliefs	
Taiwanese folk religion	8
Buddhism	3
Taoism/Daoism or Yiguandao	3
Christianity/Catholic	6
No affiliation	2
Relationship with deceased patients	
Adult children	14
Spouse	5
Sibling	2
Parents of adult child	1
Bereaved time before recruitment (months)	
6–12	18
13–18	4
Deceased patient characteristics	***N* = 21**
Age at death (years)	
41–65	7
66–80	9
81+	5
Gender	
Man	4
Woman	17
Primary medical diagnosis	
Cancer	14
Non-caner	7
Specialist palliative care received before death	
Inpatient, consultation and home care	7
Inpatient and consultation care	4
Inpatient and home care	3
Inpatient care	2
Home care	5
Death of place	
Home	10
Hospital	11

for their dying relative, aiming to avoid regrets. We developed two themes to explain families' preparations for the time surrounding and after the death, including the deceased' afterlife: 'having a good ending but not the end of the relationship' and 'using religious beliefs and cultural norms to guide preparation' (Figure 1). These preparations and beliefs about the afterlife hold specific cultural importance in Taiwanese families' approach to a relative's death, which is discussed below.

Figure 1. Families' preparations for the time surrounding and after a relative's death.

Theme 1: Having a good ending but not the end of the relationship. Taiwanese families' death preparation extended beyond the moment of death, including actions from the dying process through to the funeral. These preparations aimed to ensure a good ending, involving appropriate conduct at the moment of death, arranging a meaningful funeral and enhancing a better afterlife. Emphasis was also placed on preparing to maintain connections with the deceased.

Ensuring everything is right surrounding the death. Families ensured appropriate conduct at the moment of death by being physically present and ensuring the dying relative had a clean, neatly dressed body to uphold their dignity. Preparing to be physically present at the death involved learning to recognise dying signs, planning arrival times, deciding on attendees and considering alternative methods if unable to be present. This presence fostered closeness, allowing final interactions and farewells and ensuring the relative did not die alone, with immediate and extended family typically present:

> *In total, more than 30 relatives, including my aunts and sisters, came to see my mother for the final time, to say the last goodbye. (Son, FC16)*

Video calls often served as an alternative for this final interaction, especially during the pandemic when physical presence was hindered by quarantine policies. However, despite offering comfort, this method cannot fully replace physical presence, which might be more helpful in later bereavement.

Preparing a clean, neatly dressed body and offering comforting words were crucial for ensuring the dying relative could '*depart with dignity' (Daughter, FC2)*. This involved preparing clothing and necessary items, understanding body handling procedures at death, including managing tubes like '*urinary catheters' (Husband, FC15)* for home deaths, and learning how to clean the relative's body and dress them, often with coordination from nurses or funeral staff:

> *At the last moment, when we were changing his clothes, my son helped shave his beard and tidy up his hair. The hospice nurse assisted us with this. (Wife, FC1)*

Preparing for organising a meaningful funeral. Getting the funeral 'right' was essential and required advance planning. In Taiwanese culture, it is a crucial life event symbolising life's conclusion. A well-conducted funeral offered the deceased a dignified ending and insights into their life. For instance, a large funeral could symbolise societal contributions and convey love, echoing the Taiwanese saying, '*As the coffin is closed, the fate is sealed*' *(蓋棺論定, Gài guān lùn dìng) (Daughter, FC18)*, which reflects beliefs that judgments on one's life are made after death. Families also expressed gratitude and love through funeral activities, contributing to overall preparation. A common and unique practice involved collaborating with funeral staff to prepare the deceased's body before the ceremony:

> *The funeral staff asked me if I would like to come and watch as they gave my mum a spa treatment. I agreed. During this process, he guided me to give my mum a massage, massaging her hands and feet. He also guided me to kiss her and say goodbye. In that process, I could still express to my mum; I love you [chopped up and teary-eyed], and say goodbye while talking to her. (Daughter, FC7)*

Funeral preparations were intricate, involving decisions on whether, who, what and how to discuss arrangements with the dying relative. Some families chose open engagement, while others opted to shield the dying relative. Selecting the 'right' individuals, like those perceived as '*better at communication*' *(Daughter, FC4)* and possessing '*more rational and positive thinking*' *(Sister, FC5)*, was crucial. Discussions varied from discussing key principles to planning detailed tasks such as organising elaborate *'burial clothes' (Daughter, FC2)* and *'posthumous photos' (Wife, FC1)*, choosing a *'funeral venue' (Daughter, FC4)* and *'resting place' (Husband, FC15)*, arranging *'religious rituals' (Daughter, FC3)*, preparing offerings like *'flowers' (Daughter, FC2)* and *'white envelopes' (白包, Bái bāo, a Taiwanese tradition involving monetary gifts) (Son, FC21)*. An invitation list was compiled based on the preferences of the family and their dying relative. Using appropriate language and alternative expressions to address sensitive topics was vital during these discussions. For instance, asking questions like '*Where would you like to live afterwards?' (Daughter, FC18)* instead of directly discussing burial places helped navigate the conversation thoughtfully.

Supporting the dying relative in transitioning to a better afterlife. Preparing for a better afterlife was integral to a good ending, influenced by religious beliefs and cultural customs. This included guiding the dying relative towards their destination after death, facilitating a smooth transition and alleviating suffering in the afterlife.

Preparing the dying relative for their destination after death involved discussing shared religious beliefs about the afterlife. Religious expressions like encouraging them to *'follow the Bodhisattva' (菩薩, Púsà, referring to a being committed to the path of a Buddhahood) (Daughter, FC6)* or assuring them with statements such as *'God loves you, you do not have to be afraid and follow the light' (Daughter, FC9)* were commonly used in their final moments.

Preparing for a smooth transition from life to death involved contacting religious practitioners like *'the head monk of the temples' (Daughter, FC17)* or *'a minister in Christianity' (Daughter, FC9)* in advance. For Buddhists and followers of Taiwanese folk religion, who believed *'the soul experienced great pain during separation from the body' (Son, FC16)*, the *'support-chanting' (助念, Zhù niàn) (Son, FC11)* ritual was arranged. This ritual, conducted from dying until hours after death, involved *'chanting Buddhist names' (Son, FC16)* and *'avoiding moving the body' (Son, FC11)*. Preparations included *'organising contact details for chanting groups' (Son, FC21)*, preparing the *'Rebirth Blanket' (a Buddhist item for alleviating suffering, bringing blessings and guiding the deceased to rebirth in the Pure Land) (Husband, FC20)* and discussing the location and duration of the chanting session.

Ritual preparations from the deathbed to the funeral aimed to enhance the deceased's afterlife, ensuring essentials like *'money in the afterworld' (Wife, FC1)*. Rooted in Taiwanese folk religion, common practices included burning *'paper gold ingots, paper lotus flowers' (Wife, FC1)*, and *'symbolic daily necessities like paper watches' (Daughter, FC2)*. Influenced by Confucianism, there was a tradition of preparing the deceased's favourite food as sacrificial offerings:

> *During the funeral period, we needed to worship him three times a day, ensuring that he could have a meal with each of them. (Daughter, FC4)*

Preparing to maintain connections with the dying relative. Ongoing care for the afterlife reflected families' belief in a lasting connection. Before death, it was important to prepare for a continuing relationship with the deceased. Non-religious methods included *'leaving behind some memories*' *(Daughter, FC9)* and preparing physical items like *'photos' (Daughter, FC17), 'videos' (Wife, FC1), 'gifts' (Daughter, FC9)* and creative works such as *'handprint models' (Daughter, FC12)*. Viewing mementoes provided a sense of the deceased's enduring presence; as one participant described, 'It *made me feel like our mother was still accompanying us' (Daughter, FC9)*. However, allocating sufficient time and emotional energy for this viewing mementoes after death was essential:

> *I actually don't dare to look at my deceased father's photos and videos. I recorded a lot of them, but I dared not watch them after he left [referring to dying]. This week, I happened to reset my mobile phone, so basically, everything I recorded was gone. I backed them up on my laptop, but they were completely detached from my mobile phone. I'm not ready to watch them. (Son, FC11)*

Anticipating a future reunion brought comfort, providing a sense of being *'a bit better and relaxed' (Daughter, FC12)* during the death preparation. Rooted in religious beliefs, Buddhists anticipated reunion in the *'Western Pure Land' (Daughter, FC17)*, while Christians in *'Heaven' (Sister, FC8)*. Discussing the future reunion with the dying relative before death was helpful in preparing for a continuing relationship afterwards:

> *I knew my elder sister told her, you've gone, and we will follow. In the next life, we'll meet again. Go in peace, and we'll be sisters again in the next life [choking up and shedding tears]. (Sister, FC5)*

Religious beliefs and cultural norms influenced families' preparations and actions from the dying process to the funeral, focussing on ensuring a better afterlife and maintaining connections with the deceased, as discussed above. The following theme further explores this influence.

Theme 2: Using religious beliefs and cultural norms to guide preparation. Religious beliefs and cultural norms guided Taiwanese families in preparing for a relative's death. This theme explores how these beliefs shaped families' perceptions of a good death and influenced their emotional expressions before and after the death.

A good death ('好走', Hǎo zǒu) is culturally appropriate. Achieving a culturally appropriate death ('好走', Hǎo zǒu) was crucial in families' death preparations, ensuring no regrets between the deceased and the living. Families emphasised following religious and cultural beliefs to allow the dying relative to die naturally, such as *'allowing nature to take its course' (順其自然, shùn qí zì rán) (Wife, FC1), 'obeying destiny' (聽天命, tìng tiān mìng) (Sister, FC5)* and accepting that *'the lifespan of human beings has been predestined' (Son, FC22)* by the Creator/God/gods. These beliefs helped families accept imminent death and enhanced their emotional readiness:

> *It's just that the determination of time is in God's arrangement. . . . So, what I meant was, when my wife left [referring to dying], it was also her time, and she departed. It's the same for everyone. This was also to prepare my sons psychologically. (Husband, FC19)*

Some specific indicators at the moment of death shaped a culturally appropriate death, reflecting careful preparations discussed in Theme 1. Physical presence of relatives at the moment of death, influenced by the cultural tradition of 'Suí shì zài cè' (隨侍在側, signifying descendants being at the bedside), was crucial, especially for senior relatives:

> *I felt that my mother had a peaceful departure because all her children were by her side at her dying, which I believed was very comforting. People often talk about having a good death, where your descendants surround you during your dying, and you can peacefully rest. For me, my mother's dying was like this – a good and peaceful ending. (Daughter, FC7)*

Emphasis was also placed on a dignified appearance at the moment of death, which included a clean and well-dressed body, a peaceful expression resembling sleep with *'no pain' (Son, FC21), 'no discomfort' (Wife, FC14)* and *'eyes closed and mouth shut' (Daughter, FC18)*. These aspects echoed the cultural belief of 'sǐ yě míng mù (死也瞑目), symbolising a peaceful death free from worries and attachments, articulated as *'no attachments left' (Son, FC21)* and *'wasn't afraid' (Daughter, FC17)*.

A better, suffering-free afterlife was integral to a culturally appropriate death. Families believed the deceased transitioned to this favourable afterlife, often recognised it when the deceased's body remained *'still soft' (Daughter, FC7)*, influenced by their religious beliefs:

> *My mother appeared lively, not like a dead person; her hands could be lifted, and her body was soft as cotton after being taken out of the freezer. I felt she had departed from the sea of suffering [苦海, Kǔhǎi, referring to the life of a human being is filled with various hardships and pains]. She ascended to the Boundless Pure Land [referring to an after-world advocated by Yiguandao – a religion which combines the five teachings, including Confucianism, Taoism, Buddhism, Christianity and Islam], commonly known as heaven. Isn't that wonderful? She is happier there, free from troubles and worries. (Son, FC22)*

Influenced by the cultural belief of *'leaves falling back to the roots' (落葉歸根, luò yè guī gēn) (Son, FC16)*, dying at home was considered a good death. When this was not possible, families performed a ritual of *'covering the deceased with an oxygen mask and waiting to remove it until returning home' (Son, FC16)*. This required coordination with funeral staff and advance preparation. However, some perceived home deaths unfavourably, fearing a negative impact on the well-being of surviving family members:

> *My mother deeply believed that people should not pass away at home. She thought that leaving in such a way would be unfavourable for the people at home, for the family. She believed it would not be good for the younger generations and would be detrimental to the household. (Daughter, FC4)*

Not showing strong emotions is beneficial for the dying relative's well-being. Religious beliefs and cultural norms guided families to control emotional expression for their dying relative's well-being. Avoiding strong emotions like crying loudly around the dying relative during the dying process and funeral was believed to facilitate a smoother transition and enhance the afterlife, contributing to a good death. However, expressing sorrow through weeping or tears was acceptable. Rooted in Buddhist beliefs, loud crying might hinder the transition:

> *I only hoped that she could peacefully and smoothly reach Amitabha Buddha. My belief was so clear. So I didn't cry. I couldn't cry. If I cried, what if she fell down? It's because my religion tells me not to cry. If I cried, it would hinder her. (Daughter, FC17)*

Guided by the collectivist value of concern for others, families practiced emotional restraint to prioritise the dying relative's needs, aiming to protect them from emotional burdens like feeling *'uneasy and uncomfortable' (Husband, FC20)* and to ensure a dignified funeral and a better afterlife:

> *Was my mother happy to see me sad? Consider whether my mum would have wanted to see me sad and discouraged because of her leaving [referring to dying]. Was it helpful for my mum if I were sad for her? It might make her feel distressed if she sees me sad from above [referring to an after-world the deceased has reached]. She would worry about me instead. (Son, FC22)*

Religious beliefs and cultural norms shaped views of a good death, promoting emotional restraint before and after death for the well-being of the dying relative.

Discussion

Main findings of the study

Preparing for post-death arrangements was crucial for families in Taiwan, aligning with religious beliefs and cultural norms. This involved ensuring appropriate conduct at the moment of death, organising a meaningful funeral, enhancing the deceased's afterlife and maintaining connections with the deceased. These components comprised a culturally appropriate death. Preparing to not show strong emotions around the dying relative during and after death was necessary to benefit their well-being.

What this study adds

Our study's main findings differ from the existing literature, which primarily focusses on death preparation in Western cultures.[2,7,13–16] In Taiwan, preparing for the funeral was key.[2,16] Rooted in the Confucian cultural principle of 'carefully handling the conclusion of life' (慎終, shèn zhōng), the funeral held diverse meanings, providing closure and insights to the deceased, with a particular emphasis on conducting appropriate funeral ceremonies, especially for parents. Our study underscores the complexity of funeral preparations, involving decisions about the dying relative's involvement, selecting 'right' family members for discussions, determining preparation content and using appropriate language. It challenges the common avoidance of death conversations in Chinese culture, often deemed taboo due to its association with bad luck.[38] Thus, acknowledging and respecting family culture when addressing death-related topics becomes imperative, demanding a sensitive approach.[2,4] Recognising funeral preparations is crucial in Taiwan, providing insights into culturally appropriate palliative and end-of-life care, potentially applicable to Confucian-influenced societies like Chinese populations and East Asian countries.[39]

The study underscores the importance of achieving a culturally appropriate death in Taiwanese families' preparations, focussing on natural death[40] and freedom from pain,[41–45] which is consistent with previous evidence. Significant Cultural aspects included ensuring a dignified appearance at death (clean and well-dressed body, eyes closed, mouth shut) and enhancing the afterlife, reflecting Taiwanese religious beliefs and traditional Chinese values of posthumous care.[38] Despite Taiwan developing a Good Death scale based on Western literature and expert opinions in palliative care, it overlooks these religious beliefs and familial concerns about the afterlife.[46] Additionally, previous studies have debated whether dying at home effectively indicates a good death.[42,44,47] with our findings revealing variability based on patient needs and family beliefs. This research sheds light on what constitutes a good death from Taiwanese family perspectives, with implications for similar practices in other Chinese societies. Considering the place of death is crucial in supporting families during death preparation. Further research could investigate whether home deaths reliably reflect good deaths and evaluate the quality of palliative and end-of-life care in Taiwanese populations.[48]

Our study highlights how religious beliefs and cultural norms shaped Taiwanese families' approach to death preparation, though distinguishing their individual influences was challenging. For instance, refraining from loud crying before and after death was seen as both religiously and culturally appropriate. Some participants engaged in rituals like support-chanting more due to cultural norms than personal religious beliefs.[49] Moreover, many Taiwanese people follow multiple religions, such as identifying as Buddhists or Taoists while also incorporating beliefs of Taiwanese folk religion.[25] These intertwined practices and beliefs complicate clear distinctions. Despite this complexity, it remains crucial to understand families' religious beliefs and respect their cultural norms when assisting with death preparation.

The need to prepare for an ongoing relationship after death is linked to the continuing bonds theory within Western-oriented bereavement theory.[50,51] The theory, inspired by Japanese ancestor rituals, stresses maintaining connections with the deceased is normal and prevalent.[52] Despite literature often overlooking this aspect before death,[53,54] our study reveals how such bonds were formed through actions like creating positive memories[13] and preparing mementoes with the deceased.[55] Anticipating and discussing a future reunion with the dying relative, influenced by participants' beliefs about the afterlife, aided family preparedness, highlighting the importance of aligning strategies with religious beliefs and cultural norms.[53] Research highlights the importance of maintaining connections in Taiwanese family members' bereavement experiences,[56] but the impact of these connections on bereavement adjustment remains debated.[56–61] Consequently, further research could investigate strategies for maintaining a continuing relationship before death that positively impacts bereavement outcomes, enhancing death preparation and proactive bereavement support. Understanding families' religious beliefs, particularly about the afterlife, is essential for maintaining connections through religion and improving their preparedness.

Our study highlights the importance of preparing to refrain from strong emotions around the dying relative during and after the death, mainly influenced by Buddhism and the cultural value of collectivism.[23] A review confirms that hiding emotions is culturally appropriate and linked to religious beliefs during bereavement in Taiwan.[56] However, expressing emotions is generally seen as adaptive in Western literature during grieving.[60,62,63] Further research could explore culturally appropriate emotional support strategies for Taiwanese people, Chinese populations and individuals following Buddhism.

Reflections, strengths and limitations of the study

The main researcher (H-JL), a senior palliative care nurse from Taiwan, with extensive experience in assisting families with death preparation, might think they understood the participants' stories which could limit deeper exploration during interviews and analysis. Ongoing discussions with NP and QX enhanced researcher reflexivity through challenging assumptions.[26] A reflexive journal was used to enhance the analysis.[26]

Moreover, the study highlights the importance of cultural context in death preparation, including preparations for the funeral and the deceased's afterlife. These aspects are often overlooked in clinical practices, which tend to be dominated by Western-centric palliative care knowledge.

A notable strength is the diverse participant pool from seven hospitals across Taiwan, representing various religious beliefs. This diversity enriched the data, facilitating a comprehensive exploration of research questions and improving the transferability of study findings to Taiwan and potentially to Chinese populations, predominantly East Asian societies or Buddhist countries.[26]

Limitations include the study may not fully capture preparedness in contexts involving non-specialist palliative care. The predominance of female participants and adult children of deceased patients, alongside the inclusion of both cancer and non-cancer diagnoses, could impact the study's transferability.[64] Further research could explore death preparation among male participants, other family relationships (e.g. spouses) and persons living with chronic conditions before death (e.g. dementia). Including patients' perspectives in future studies would enhance a more comprehensive understanding of death preparation.

Another potential limitation is the translation of findings from Chinese into English, which may have lost some cultural meaning. However, H-JL and QX spoke both languages, enabling the exploration of language nuances. This was further enhanced by initially coding the data in Chinese and translating it into English later while retaining certain Chinese words.[37]

Conclusion

Taiwanese family members' death preparation, influenced by religious beliefs and cultural norms, extends to the time after the death, aiming for a culturally appropriate death. It involves funeral preparations, enhancing the afterlife and maintaining connections. Not showing strong emotions is culturally appropriate and beneficial for the dying relative. These insights inform death preparation in Taiwan and provide perspectives for palliative and end-of-life care beyond Western culture, potentially benefiting Chinese populations, predominantly East Asian societies or Buddhist countries. Future research exploring culturally appropriate strategies for emotional support and maintaining connections before death is needed.

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Author contributions

H-JL, NP and QX contributed to the conception and design. H-JL, P-CL and J-HT contributed to the ethical approval and participant recruitment. H-JL carried out the interviews and thematic analysis. H-JL, NP and QX presented the data analysis and interpretation. NP and QX provided supervision for the study. H-JL drafted the manuscript. All authors reviewed the manuscript and approved the final version for submission.

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Ethics approval

The study received approval from the National Cheng Kung University Hospital Institutional Review Board (Ref: A-ER-111-193) and Lancaster University Faculty of Health and Medicine Research Ethics Committee (Ref: FHM-2022-0972-ExRev-1). Details of the consent process are provided in this article.

Data management and sharing

Additional data are available in the Supplementary File and from the corresponding author (h.liang3@lancaster.ac.uk).

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Supplemental material

Supplemental material for this article is available online.

References

1. Nielsen MK, Neergaard MA, Jensen AB, et al. Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clin Psychol Rev* 2016; 44: 75–93.
2. Hebert RS, Schulz R, Copeland VC, et al. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *J Pain Symptom Manag* 2009; 37: 3–12.
3. Durepos P, Sussman T, Ploeg J, et al. What does death preparedness mean for family caregivers of persons with dementia? *Am J Hosp Palliat Med* 2019; 36: 436–446.
4. Hebert RS, Prigerson HG, Schulz R, et al. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. *J Palliat Med* 2006; 9: 1164–1171.
5. Keegan O, Murphy I, Benkel I, et al. Using the Delphi technique to achieve consensus on bereavement care in palliative care in Europe: an EAPC White Paper. *Palliat Med* 2021; 35: 1908–1922.
6. Hudson P, Remedios C, Zordan R, et al. Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *J Palliat Med* 2012; 15: 696–702.
7. Hovland-Scafe CA and Kramer BJ. Preparedness for death: how caregivers of elders with dementia define and perceive its value. *Gerontologist* 2017; 57: 1093–1102.
8. Kim Y, Carver CS, Spiegel D, et al. Role of family caregivers' self-perceived preparedness for the death of the cancer patient in long-term adjustment to bereavement. *Psychooncology* 2017; 26: 484–492.
9. Schulz R, Boerner K, Klinger J, et al. Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *J Palliat Med* 2015; 18: 127–133.
10. Treml J, Schmidt V, Nagl M, et al. Pre-loss grief and preparedness for death among caregivers of terminally ill cancer patients: a systematic review. *Soc Sci Med* 2021; 284: 114240.
11. Gallagher R and Krawczyk M. Family members' perceptions of end-of-life care across diverse locations of care. *BMC Palliat Care* 2013; 12: 25.
12. Wen FH, Chou WC, Hsieh CH, et al. Distinct death-preparedness states by combining cognitive and emotional preparedness for death and their evolution for family caregivers of terminally ill cancer patients over their last 6 months of life. *J Pain Symptom Manag* 2021; 62: 503–511.
13. Supiano KP, Luptak M, Andersen T, et al. If we knew then what we know now: the preparedness experience of pre-loss and post-loss dementia caregivers. *Death Stud* 2022; 46(2): 369–380.
14. Hovland CA and Kramer BJ. Barriers and facilitators to preparedness for death: experiences of family caregivers of elders with dementia. *J Soc Work End Life Palliat Care* 2019; 15: 55–74.
15. Durepos P, Ploeg J, Sussman T, et al. "A crazy roller coaster at the end": a qualitative study of death preparedness with caregivers of persons with dementia. *SAGE Open Nurs* 2020; 6: 1–11.
16. Breen LJ, Aoun SM, O'Connor M, et al. Family caregivers' preparations for death: a qualitative analysis. *J Pain Symptom Manag* 2018; 55: 1473–1479.
17. Gire J. How death imitates life: cultural influences on conceptions of death and dying. *Online Read Psychol Cult* 2014; 6: 3.
18. Tang ST, Hsieh CH, Chou WC, et al. Course of changes in emotional preparedness for death and its associations with caregiving outcomes for family caregivers of terminally ill cancer patients over their last year of life. *J Pain Symptom Manag* 2021; 61: 974–982.
19. Wen FH, Chou WC, Hou MM, et al. Caregivers' death-preparedness states impact caregiving outcomes and patients' end-of-life care. *J Pain Symptom Manag* 2022; 63: 199–209.
20. Wen FH, Chou WC, Hou MM, et al. Associations of death-preparedness states with bereavement outcomes for family caregivers of terminally ill cancer patients. *Psychooncology* 2022; 31: 450–459.
21. Matsuzaka S, Ohba A, Masukawa K, et al. Factors associated with the preparedness for bereavement in families of patients with cancer: a secondary analysis of a nationwide bereaved family survey. *Psychooncology* 2024; 33: e6276.
22. Yum JO. The impact of confucianism on interpersonal relationships and communication patterns in East Asia. *Commun Monogr* 1988; 55: 374–388.
23. Hui CH and Triandis HC. Individualism-collectivism: a study of cross-cultural researchers. *J Cross Cult Psychol* 1986; 17: 225–248.
24. Finkelstein EA, Bhadelia A, Goh C, et al. Cross country comparison of expert assessments of the quality of death and dying 2021. *J Pain Symptom Manag* 2022; 63: e419–e429.
25. Wikipedia contributors. Religion in Taiwan, https://en.wikipedia.org/w/index.php?title=Religion_in_Taiwan&oldid=1217025478 (2024, accessed April 3 2024).
26. Braun V and Clarke V. *Thematic analysis: a practical guide*. 1st ed. Thousand Oaks: Sage, 2022.

27. McEvoy P and Richards D. A critical realist rationale for using a combination of quantitative and qualitative methods. *J Res Nurs* 2016; 11: 66–78.
28. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
29. Braun V and Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual Res Psychol* 2021; 18: 328–352.
30. Braun V and Clarke V. Conceptual and design thinking for thematic analysis. *Qual Psychol* 2022; 9: 3.
31. Braun V and Clarke V. Supporting best practice in reflexive thematic analysis reporting in Palliative Medicine: a review of published research and introduction to the Reflexive Thematic Analysis Reporting Guidelines (RTARG). *Palliat Med* 2024; 38(6): 608–616.
32. National Health Insurance Administration. The palliative care services in Taiwan, https://www.nhi.gov.tw/Content_List.aspx?n=D8386FD9AD1B49D3&topn=D39E2B72B0BDFA15 (2021, accessed February 03 2022).
33. Miller MD. Complicated grief in late life. *Dialogues in clinical neuroscience* 2012; 14: 195–202.
34. Bogetz JF, Revette A, Rosenberg AR, et al. "I could never prepare for something like the death of my own child": parental perspectives on preparedness at end of life for children with complex chronic conditions. *J Pain Symptom Manag* 2020; 60: 1154–1162. e1151.
35. Draucker CB, Martsolf DS and Poole C. Developing distress protocols for research on sensitive topics. *Arch Psychiatr Nurs* 2009; 23: 343–350.
36. Braun V and Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exerc Health* 2021; 13: 201–216.
37. Abfalter D, Mueller-Seeger J and Raich M. Translation decisions in qualitative research: a systematic framework. *Int J Soc Res Methodol* 2020; 24: 469–486.
38. Hsu CY, O'Connor M and Lee S. Understandings of death and dying for people of Chinese origin. *Death Stud* 2009; 33: 153–174.
39. Jung Y, Yeom H-E and Lee N-R. The effects of counseling about death and dying on perceptions, preparedness, and anxiety regarding death among family caregivers caring for hospice patients: a pilot study. *Korean J Hosp Palliat Care* 2021; 24: 46–55.
40. Miyashita M, Morita T, Sato K, et al. Factors contributing to evaluation of a good death from the bereaved family member's perspective. *Psychooncology* 2008; 17: 612–620.
41. Meier EA, Gallegos JV, Thomas LPM, et al. Defining a good death (successful dying): literature review and a call for research and public dialogue. *Am J Geriatr Psychiatry* 2016; 24: 261–271.
42. Miyashita M, Morita T, Sato K, et al. Good death inventory: a measure for evaluating good death from the bereaved family member's perspective. *J Pain Symptom Manag* 2008; 35: 486–498.
43. Wilson DM and Hewitt JA. A scoping research literature review to assess the state of existing evidence on the "bad" death. *Palliat Support Care* 2018; 16: 90–106.
44. Miyashita M, Sanjo M, Morita T, et al. Good death in cancer care: a nationwide quantitative study. *Ann Oncol* 2007; 18: 1090–1097.
45. Steinhauser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. *Ann Intern Med* 2000; 132: 825–832.
46. Cheng S-Y, Hu W-Y, Liu W-J, et al. Good death study of elderly patients with terminal cancer in Taiwan. *Palliat Med* 2008; 22: 626–632.
47. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476–2482.
48. Pasman HRW, Brandt HE, Deliens L, et al. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manag* 2009; 38: 145–156. e121.
49. Shih S-Y. Religious behavior and religious phenomena (Part I). *Chin Buddhism Monthly* 1982; 26: 3–10.
50. Steffen EM and Klass D. Culture, contexts and connections: a conversation with Dennis Klass about his life and work as a bereavement scholar. *Mortality* 2018; 23: 203–214.
51. Klass D and Silverman PR. Introduction: what's the problem? In: Klass D, Silverman PR and Nickman SL (eds) *Continuing bonds: new understandings of grief*. USA: Taylor & Francis, 1996, pp.3–27.
52. Klass D. Grief in an Eastern culture: Japanese ancestor worship. In: Klass D, Silverman PR and Nickman SL (eds) *Continuing bonds: new understandings of grief*. USA: Taylor & Francis, 1996, pp.59–70.
53. Root BL and Exline JJ. The role of continuing bonds in coping with grief: overview and future directions. *Death Stud* 2014; 38: 1–8.
54. Hedtke L and Winslade J. *Remembering lives: Conversations with the dying and the bereaved*. Milton: Taylor & Francis Group, 2004.
55. Riegel M, Buckley T and Randall S. Family's experience of memory making in adult intensive care and its use in early bereavement: a descriptive qualitative study. *J Clin Nurs* 2023; 32: 6648–6661.
56. Liang H-J, Xiong Q, Remawi BN, et al. Taiwanese family members' bereavement experience following an expected death: a systematic review and narrative synthesis. *BMC Palliat Care* 2024; 23: 14.
57. Benore ER and Park CL. INVITED ESSAY: death-specific religious beliefs and bereavement: belief in an afterlife and continued attachment. *Int J Psychol Relig* 2004; 14: 1–22.
58. Boelen PA, Stroebe MS, Schut HA, et al. Continuing bonds and grief: a prospective analysis. *Death Stud* 2006; 30: 767–776.
59. Field NP and Friedrichs M. Continuing bonds in coping with the death of a husband. *Death Stud* 2004; 28: 597–620.
60. Worden JW. *Grief counseling and grief therapy: a handbook for the mental health practitioner*. New York: Springer, 2018.
61. Stroebe M, Schut H and Boerner K. Continuing bonds in adaptation to bereavement: toward theoretical integration. *Clin Psychol Rev* 2010; 30: 259–268.
62. Lindemann E. Symptomatology and management of acute grief. *Pastor Psychol* 1963; 14: 8–18.
63. Parkes CM. Bereavement. *Br J Psychiatry* 1985; 146: 11–17.
64. Krefting L. Rigor in qualitative research: the assessment of trustworthiness. *Am J Occup Ther* 1991; 45: 214–222.

6.2 Chapter summary

Paper 3 demonstrates that family death preparation in Taiwan extends beyond the point of death (Liang, Xiong, Lin, et al., 2024). Families described preparing for the moment of death itself, arranging for a meaningful funeral, maintaining continuing relationships, and supporting the dying relative's peaceful transition and afterlife. These accounts reflect the central role of religious beliefs, ritual practices and cultural norms in guiding preparation. They also shaped understandings of a good death and encouraged emotional restraint before and after death as culturally and religiously appropriate.

The interview study indicated that healthcare professionals can play a vital role in supporting family death preparation, but practical guidance on how healthcare professionals can do so remains limited. Building on the findings of the qualitative interview study (Papers 2 and 3), a nominal group technique study with specialist palliative care professionals in Taiwan was conducted. The aim was to develop recommendations to better support families' death preparation, and the findings are presented in the next chapter. A critique of the methods used is presented in the subsequent chapter.

CHAPTER 7: FINDINGS OF THE NOMINAL GROUP TECHNIQUE STUDY

The preceding chapters presented findings from the systematic review (Paper 1, Chapter Four) and the qualitative interview study (Papers 2 and 3, i.e., Chapters Five and Six), which explored family experiences of death preparation in Taiwan. Building on this foundation, the current chapter reports the findings of the nominal group technique study. The methods for this study were reported in Chapter Three and Paper 4 (Chapter Eight). This study aimed to generate recommendations for how healthcare professionals can better support families in preparing for a relative's death in Taiwan and to identify priorities for implementation. The study involved specialist palliative care professionals and employed the nominal group technique (Jünger & Payne, 2020) to reach consensus.

7.1 Characteristics of specialist palliative care professionals

Ten specialist palliative care professionals participated in the nominal group technique meeting. The group included two physicians, six nurses, one psychologist, and one chaplain. Their demographic and professional characteristics are summarised in **Table 7**. The mean age was 52.2 years (range, 33–74), and the mean length of specialist palliative care experience was 16.3 years (range, 6–26). Most participants were women (n = 7), with men accounting for three. Geographically, the majority were based in northern Taiwan (n = 7), followed by two from the south and one from central Taiwan.

Table 7: Characteristics of specialist palliative care professionals (n=10).

Age		**Type of specialist palliative care**	
30-50	4	Inpatient care	1
51-65	5	Consultation care	3
66+	1	Home care	1
Gender		Inpatient and home care	1
Man	3	Inpatient, consultation, and home care	4
Woman	7	**Years of experience in specialist palliative care**	
Profession		5-10	2
Physician	2	11-20	5
Nurse	6	21-30	3

Psychologist/chaplain	2	**Region of specialist palliative care team**	
		Northern	7
		Middle	1
		Southern	2

7.2 Initial results from the nominal group meeting

The initial outcomes of the nominal group technique meeting, including the number of recommendations generated, a summary of their content, and the associated voting and ranking results, are presented in this section.

A total of 42 recommendations were generated by participants on how healthcare professionals could better support families in preparing for a relative's death. Participants were then asked to select ten recommendations from the list of 42, based on their perceived importance and priority for implementation. The ten most frequently selected recommendations were identified through this voting process. These were subsequently ranked on a scale from 1 (highest priority) to 10 (lowest priority) to determine their implementation order, with lower aggregated scores indicating higher overall priority. The process is illustrated in **Figure 2**.

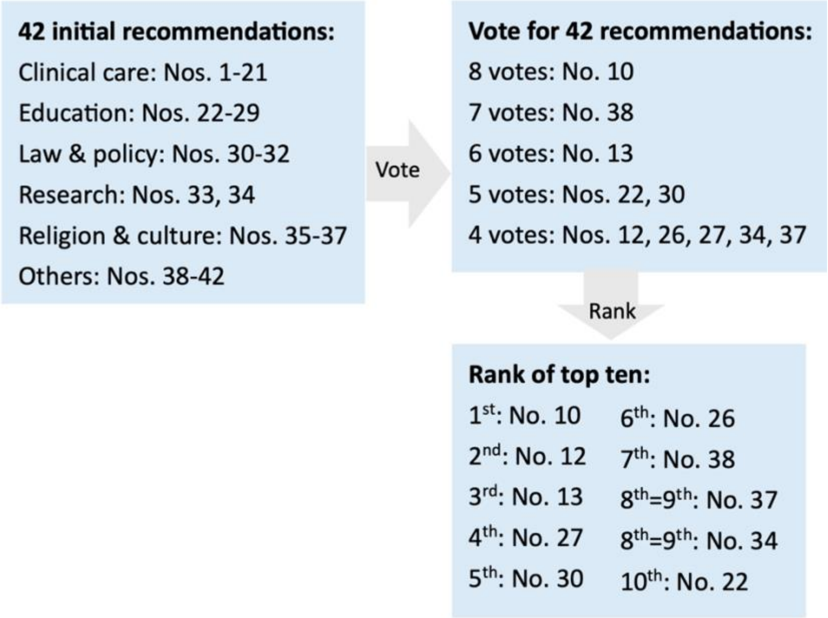

Figure 2: The process of voting and ranking during the group meeting.

All 42 recommendations were categorised into six predefined thematic areas: clinical care (21 recommendations), education (8), law and policy (3), research (2), religion and culture (3), and other considerations (5), as summarised in **Table 8**. Clinical care was the most frequently represented theme, underscoring its central role in supporting families through death preparation. Participants also highlighted the importance of education on death and dying for both healthcare professionals and students, alongside the need for supportive government policies and further research.

The top ten priority recommendations spanned all six predefined thematic areas: clinical care (Recommendations 10, 12, 13), education (Recommendations 22, 26, 27), law and policy (Recommendation 30), research (Recommendation 34), religion and culture (Recommendation 37), and other considerations (Recommendation 38). Clinical care and education were the most frequently represented. As one participant reflected: *"In my view, it is very important that these top ten recommendations cover various aspects" (Participant A)*. Collectively, the top ten emphasised the need for healthcare professionals to recognise signs of dying and to provide appropriate end-of-life care (Recommendation 10). This included involving families in decision-making (Recommendation 12) and facilitating consensus between patients and families on end-of-life matters, such as funeral arrangements (Recommendation 37). Effective communication (Recommendation 13), supported by adequate education and training (Recommendations 26 and 27), was regarded as essential. In addition, raising public awareness about death-related issues (Recommendations 22 and 38), advocating for supportive government policies (Recommendation 30), and conducting further research in this area (Recommendation 34) were identified as vital to improving family death preparation.

During the voting process, eight recommendations received four votes. However, three of these (Recommendations 1, 3, and 4) were mistakenly excluded from the final top ten list. All three were related to clinical care, including predicting life expectancy, an important element of end-of-life preparation. This oversight was addressed later during the framework analysis (Parkinson et al., 2016; Ritchie & Spencer, 2002), as discussed in the section on the finalised recommendations.

Table 8: Initial recommendations, voting and ranking result.

Rank order	No. & description of initial recommendation from the nominal group meeting [a]	Stage 1: Vote for 42 recommendations	Stage 2: Rank of top 10 [b]
1st	10. Healthcare professionals have the ability to recognise dying signs and deliver appropriate care	8	35
2nd	12. Healthcare professionals could encourage family members to participate in end-of-life care decision-making through various means (e.g., shared decision making)	4	41
3rd	13. Healthcare professionals have the ability to communicate with patients, families and other healthcare staff during end-of-life care	6	45
4th	27. The need to include end-of-life care in healthcare professional education programmes	4	48
5th	30. Making top-down policies is crucial	5	53
6th	26. Using bedside teaching and real case studies in end-of-life care education	4	60
7th	38. The need to promote death preparation as a social issue through various ways (e.g., death festivals, using social media)	7	63
8th=9th	37. Healthcare professionals have the ability to help patients and their families reach a consensus on funeral arrangements	4	68
8th=9th	34. Research is needed to understand the end-of-life needs of patients in community settings (e.g., how Taiwanese died in community settings)	4	68
10th	22. The need to provide education about death and dying to individuals in community settings or long-term care institutions	5	69
n/a	1. Healthcare professionals could identify the needs of family members facing the impending death of a relative	4 [c]	
	3. Healthcare professionals have the capability to predict the life expectancy of their patients	4 [c]	
	4. Healthcare professionals could deliver appropriate care to patients, tailored to the various stages of their life expectancy	4 [c]	
	14. Healthcare professionals could help family members fulfil the patient’s last wishes and complete their unfinished business	3	

23. The need to create and distribute films that educate the public about death preparation	3
2. Healthcare professionals could address the needs of family members facing the impending death of a relative	2
6. The need to provide integrated and continuous palliative care across disciplines in hospitals and extend outreach to the community	2
7. Healthcare professionals could facilitate family meetings with family members to help them prepare for a relative’s death	2
8. Healthcare professionals could guide family members to participate in the physical care of the patient	2
11. Healthcare professionals could facilitate communication between patients and their families	2
18. Healthcare professionals could provide anticipatory grief support to significant others of the patient, reaching beyond their families	2
25. Death education should be compulsory in general education curricula	2
29. Improve death literacy as well as health literacy, particularly at end of life among the public	2
33. Developing and optimising prognostic tools for accurately estimating survival time is needed	2
36. Religious-related groups/organisations could actively provide the public with death education and consultation services	2
39. Healthcare professionals in community settings could initiate advance care planning discussions with patients and the public in the community	2
41. Non-profit organisations should establish multiple channels for medical consultation both in person and online	2
9. Staff in long-term care institutions have the capability to identify patients with palliative care needs	1
15. The need to conduct family-centred groups that focus on the family as a unit to address psychosocial and spiritual concerns among the family	1
16. Healthcare professionals could ask patients two questions during end-of-life care: “How would	1

you describe your life in a sentence?” & “Do you have any unfinished wishes?”	
24. The need to provide death education to the public through diverse channels (e.g., Death Café)	1
28. Healthcare professionals in intensive care units should improve their skills in providing end-of-life care	1
35. Healthcare professionals could have knowledge about the religious and cultural customs that are associated with funeral arrangements and rituals	1
42. National clinical audits should assess whether hospitals provide appropriate integrated palliative and end-of-life care	1
5. Healthcare professionals could assist patients in creating a legacy to connect with their families after death	0
17. Healthcare professionals should possess both moral sensitivity and legal knowledge to provide appropriate end-of-life care for individuals who have unspeakable relationships with the patient	0
19. Healthcare professionals could offer anticipatory grief support for family members coping with a foetus diagnosed with life-limiting conditions	0
20. The need to deliver appropriate end-of-life care for family members who are Taiwanese new immigrants	0
21. The need to provide appropriate end-of-life care for family members or significant others facing death caused various life-limiting conditions at all ages	0
31. Government agencies could offer funding for research	0
32. Making an unpaid leave policy to encourage family members to attend family meetings or family-centred groups	0
40. The provision of appropriate end-of-life care is needed in primary care networks	0

[a] Predefined theme of recommendations: Clinical care, Nos. 1-21; Education, Nos. 22-29; Law & policy, Nos. 30-32; Research, Nos. 33 & 34; Religion & culture, Nos. 35-37; Others, Nos. 38-42

[b] lower score higher ranking

[c] Three of the eight recommendations received the same number of votes, but three were mistakenly excluded from the final top ten.

n/a: not applicable

When comparing the number of votes with the final priority rankings of the top ten recommendations, both areas of alignment and divergence were evident. For instance, the clinical care recommendation on recognising signs of dying (Recommendation 10) received the highest number of votes and was also ranked as the top priority. Similarly, the recommendation to enhance healthcare professionals' communication skills (Recommendation 13) was third in both votes and ranking.

In contrast, some recommendations showed a mismatch between votes and ranking. The recommendation on involving families in end-of-life care decision-making (Recommendation 12) received the fewest votes among the top ten but was ranked second in priority. Conversely, the recommendation to promote death preparation as a societal concern (Recommendation 38) received the second-highest number of votes but was placed seventh in the final ranking.

Notably, all three clinical care recommendations included in the top ten were ultimately ranked among the highest-priority items. This reflected participants' emphasis on the centrality of clinical practice in supporting families, as one participant explained: *"Because I am working on the front of clinical practice, I believe that we need to focus back on the aspect of clinical care" (Participant D)*. The alignment and divergence between voting and ranking are illustrated in **Figure 3**.

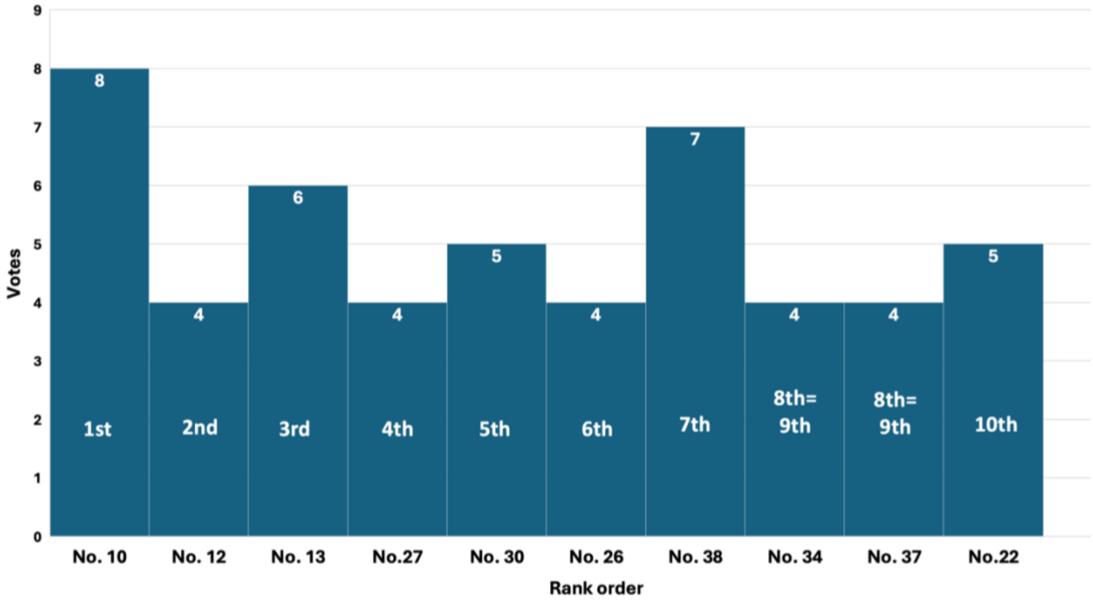

Figure 3: The alignment and divergence between voting and ranking results.

7.3 Findings of the nominal group study using framework analysis

In this section, the findings of the nominal group study derived from framework analysis (Parkinson et al., 2016; Ritchie & Spencer, 2002) are presented. Key themes on how to improve preparation for a relative's death are explored. Additionally, recommendations that were overlooked during the group meeting are addressed. Finally, a refined set of recommendations for healthcare professionals to better support families in this process is provided.

7.3.1 Themes on improving preparation for a relative's death

Following the framework analysis (Parkinson et al., 2016; Ritchie & Spencer, 2002), two main themes were developed that capture specialist palliative care professionals' perspectives on how families' preparation for a relative's death could be improved. These were: awareness of difficulties, and a multidimensional approach is necessary. Each theme included several subthemes, which are presented in **Table 9** and discussed in the subsequent sections.

Table 9: Themes on improving preparation for a relative's death.

Themes	Subthemes
1. Awareness of difficulties	*1.1 Insufficient competencies in end-of-life care among healthcare professionals* *1.2 Family involvement in end-of-life decision-making is essential but challenging* *1.3 Inadequate care in non-palliative care units* *1.4 Limitations in current legal provisions and healthcare policies*
2. A multidimensional approach is necessary	*2.1 Providing high-quality care for patients and families* *2.2 A continuous and comprehensive end-of-life care network is essential* *2.3 Improving death literacy among the public* *2.4 The need to engage the government and conduct further research*

Theme 1: Awareness of difficulties

This theme was developed to capture participants' reflections on the obstacles to family death preparation and highlights participants' recognition of these difficulties as the foundation for formulating tailored and appropriate support. Although the nominal group meeting was designed to generate recommendations for improving family death preparation, participants also reflected on the barriers that may hinder families from engaging in this process. They emphasised that acknowledging these challenges is a necessary first step toward developing effective, context-sensitive solutions. This recognition informed the rationale behind the recommendations generated during the group meeting. This main theme was further derived into several subthemes, as presented below.

Subtheme 1.1: Insufficient competencies in end-of-life care among healthcare professionals

Participants observed that some healthcare professionals continued to demonstrate limited competencies in end-of-life care, which hindered their ability to support families in preparing for a relative's death. A central concern was inadequate communication skills, particularly a reluctance to engage in conversations about death-related topics. As one participant noted, *"Many healthcare staff just avoid and refuse to talk about it (referring to death-related topics)" (Participant C)*. Effective communication was regarded as essential for shaping positive end-of-life experiences for both patients and families: "*I believe this aspect (end-of-life communication skills) is very important because it will directly affect the patient's and the families' end-of-life care experience*" *(Participant C)*. Despite this recognition, initiating open discussions remained difficult due to the emotional sensitivity of these topics and the involvement of multiple stakeholders, including patients, families, and other healthcare professionals.

Another prominent challenge involved communicating life expectancy. Families frequently asked how much time their relative had left, yet healthcare teams often struggled to provide answers. As one participant explained, *"We are most frequently asked by patients' families, how much time does my father…my mother have left? This is actually the question we get asked the most" (Participant D)*. Participants regarded this information as essential for enabling families to set realistic care goals, make informed medical decisions, and prepare for what was to come. Prognostic communication was therefore seen as central to the overall quality of end-of-life care, although conveying such information was described as inherently difficult due to uncertainty in survival predictions.

The unpredictable nature of illness trajectories, particularly among *"patients with non-cancer diagnoses" (Participant B)*, was identified as an additional barrier. Moreover, many healthcare professionals were unfamiliar with using prognostic survival estimation tools. As one participant stated: *"Healthcare professionals were not familiar with using prognostic survival estimation tools" (Participant D)*.

Discrepancies also emerged between the prognostic information provided by clinicians and the expectations of families. Clinicians often relied on statistical probabilities framed within time periods (for example, a 30-day survival probability of less than 30 per cent), whereas families typically preferred clearer estimates expressed in terms of duration (for example, "weeks" or a range such as 14-55 days). These differences complicated prognostic communication and contributed to misaligned expectations during the death preparation process.

Subtheme 1.2: Family involvement in end-of-life decision-making is essential but challenging

Family involvement in decision-making at the end of life was regarded as essential, yet participants noted that it was often difficult to achieve in clinical practice. They acknowledged that Taiwanese culture places strong value on family roles, particularly in healthcare decision-making. However, differing opinions among family members frequently led to disagreements, sometimes escalating into arguments and, ultimately, *"feelings of regret" (Participant B)*. Participants therefore emphasised the importance of assisting families in reaching consensus on end-of-life decisions wherever possible, especially when decisions were being made on behalf of a dying relative.

Despite this recognised importance, achieving family consensus in practice was described as challenging for several reasons. A key barrier was the limited time available to healthcare professionals. As one participant observed, *"I have noticed that medical staff seem to have limited time to engage in in-depth discussions with families (Participant A)*. In addition, ensuring that all key family members were present for these discussions was often difficult. Even when some were involved, they frequently struggled to understand the medical information provided or found it challenging to convey what they had learned to other relatives. As one participant reflected:

> *"Another issue is health literacy. Many families still have limited health literacy, which creates communication barriers. For example, a family member might understand what a physician is explaining, but when trying to convey this information to other relatives, they may struggle and feel uncertain." (Participant F)*

These challenges underscored the need for healthcare professionals to communicate medical information in a way that was accessible and understandable to families. This, in turn, shaped the overall end-of-life decision-making process. This issue was noted not only by participants with medical or nursing backgrounds but also by those from other professional disciplines. It also echoed earlier concerns discussed in Subtheme 1.1 regarding the communication skills of healthcare professionals, while highlighting the influence of family dynamics. The process of sharing medical information was shaped not only by individual family members' ability to comprehend and communicate, but also by the family's established patterns of interaction.

Subtheme 1.3: Inadequate care in non-palliative care units

From the participants' perspective, specialist palliative care played a vital role in helping families prepare for the death of a relative. However, late referrals often left families with limited time and few opportunities to engage in this process. Palliative care was typically introduced only when a patient's condition was considered terminal or when curative treatment was no longer an option. This delay was attributed to the underdevelopment of generalist palliative care services in non-specialist settings, where healthcare professionals lacked both specialist training and even a basic understanding of palliative care. As one participant explained:

> *"The involvement of early palliative care is vital because, at present, most cases transition directly from disease treatment to palliative care. However, the role of the generalist palliative care service in this process is still ignored." (Participant I)*

Concerns were also raised about inadequate end-of-life care in non-palliative care settings, particularly in intensive care units, primary care, and community environments. Despite the high number of deaths occurring in intensive care units, the quality of end-of-life care in these settings was described as insufficient. Similarly, the absence of comprehensive end-of-life care in primary care and community services often leaves patients and families with no alternative but to seek hospital-based support.

Subtheme 1.4: Limitations in current legal provisions and healthcare policies

A final challenge in preparing for a relative's death concerned the broader national framework in which families were situated. This framework encompassed existing legal structures and healthcare policies, particularly Taiwan's Patient Right to Autonomy Act and National Healthcare Insurance system, both of which were highlighted by participants. Limitations within these systems were seen as hindering families from adequately preparing for an impending death.

Advance care planning was generally viewed as beneficial for supporting family death preparation. However, the Patient Right to Autonomy Act sets out strict legal requirements, including the stipulation that such discussions must take place in designated qualifying hospitals. As a result, some healthcare professionals were perceived as approaching advance care planning primarily as a legal obligation rather than a holistic opportunity for reflection and communication. One participant explained:

> *"Such actions (referring to conducting advance care planning consultations in non-qualifying hospitals) are not permitted under current policies." (Participant H)*

Participants also pointed to limitations within the National Healthcare Insurance system, which was considered insufficient in meeting the needs of all dying patients. This was especially problematic for individuals living in rural areas with limited medical resources, or for those unable or unwilling to seek care in hospital settings. As one participant noted:

> *"Don't assume that the National Healthcare Insurance can cover all dying patients' needs in Taiwan." (Participant D)*

Although palliative care services, including hospice home care, are covered under the National Healthcare Insurance system, they are primarily delivered by hospital-based teams. This institutional concentration was perceived to restrict access to appropriate end-of-life care for people in less urbanised areas or those who preferred to receive care at home.

Taken together, the challenges identified in Theme 1 show that the obstacles to preparing for a relative’s death extend beyond individual and interpersonal dynamics to include systemic and policy-related barriers. Addressing these complex and interconnected issues requires a multidimensional approach, as explored in the following theme.

Theme 2: A multidimensional approach is necessary

This theme outlines the recommendations identified as necessary to improve families’ experiences of preparing for the death of a relative. Participants emphasised that a multidimensional approach was essential, recognising the complex and nuanced nature of this preparation process.

Subtheme 2.1: Providing high-quality care for patients and families

Participants emphasised the importance of ensuring high-quality care for both patients and families when considering how to improve preparation for a relative’s death. Meeting the needs of the dying person was seen as essential not only in its own right but also as a critical part of supporting families through this process. Appropriate end-of-life care was described as responsive to the patient’s evolving condition and extending beyond physical needs to include psychological, social, and spiritual dimensions. Particular attention was given to psychological and spiritual care, such as helping patients to “fulfil *unfinished business” (Participant G)* or engage in *“life review” (Participant H)*, both regarded as integral to achieving a good death. As one participant noted, *“Helping patients to have a good death is part of helping families prepare for the death” (Participant A)*.

Other aspects of family death preparation included resolving relational matters between the dying person and their relatives and making *“funeral arrangements in line with religious and cultural beliefs” (Participant J)*. Cultural appropriateness was therefore framed as a core component of high-quality care. Legacy creation was also emphasised as a way of supporting continuing bonds between the deceased relative and surviving family members. One participant explained:

> *“The first recommendation I wrote about is to help patients leave behind a presence. This means that the patient leaves behind objects that signify their existence, such as writing letters, voice or video recordings, or creating hand moulds. We implemented*

> *them in clinical practice to ensure that, even after the patient has died, their presence is still remembered and documented by their family." (Participant E)*

Equally important was the involvement of families in end-of-life care, which was seen to enhance their overall preparation experience. Guiding families to provide physical care for the dying relative was regarded as particularly meaningful:

> *"I believe it is important to encourage family members to do something for the patient, such as participating in the patient's care, rather than leaving them with a sense of passively waiting for death. By teaching them how to assist with personal care tasks, such as oral care, we can help them feel that they are still contributing meaningfully, even at this stage." (Participant G)*

Family involvement was also described in terms of *"being present during the final moments" (Participant J)* and *"taking part in end-of-life decision-making" (Participant B)*. Supporting these decisions required careful attention to factors such as *"the illness trajectory" (Participant B)* and *"life expectancy" (Participant D)*, alongside *"receiving informational support from healthcare professionals" (Participant A)*. Participants repeatedly stressed the importance of *"understanding and respecting the dying relative's preferences on end-of-life matters" (Participants B, D, H)* and *"achieving family consensus" (Participant J)*.

Overall, providing high-quality end-of-life care was seen as a way of improving families' experiences of death preparation. This required healthcare professionals to develop core competencies, including the ability to identify and address patient and family needs, estimate life expectancy, and communicate prognostic information in a sensitive manner. Skills in facilitating end-of-life decision-making, such as through *"family meetings" (Participant G)*, were also considered essential, reflecting the cultural significance of a family-centred approach in Taiwanese society. In addition, participants highlighted the importance of professional knowledge of end-of-life legislation and sensitivity to religious and cultural practices, including funeral arrangements and rituals. Strengthening these competencies required dedicated education for both healthcare professionals and students. As one participant stated:

> *"End-of-life care is a fundamental right for everyone, and there should be mandatory*

> *courses on this topic in all healthcare professional development curricula." (Participant B)*

This subtheme highlights the clinical care dimension of family death preparation, particularly at the level of individual healthcare professionals. Enhancing competencies in end-of-life care through appropriate training and education was considered essential for ensuring that both patients and families receive the support they need.

Subtheme 2.2: A continuous and comprehensive end-of-life care network is essential

As discussed in Subtheme 1.3, inadequate provision of palliative and end-of-life care posed a significant challenge to family death preparation, particularly in non-palliative care settings such as intensive care units, primary care, and community environments. To address this, participants stressed the need to establish a continuous and integrated end-of-life care network within the healthcare system. A central element of this approach was strengthening generalist palliative care services in non-specialist settings. Such a network would ensure that patients and families receive appropriate care across hospital, community, and primary care contexts. As one participant explained:

> *"So, can we have a continuous system that spans from within the hospital, across different departments or units, to the community, and even to primary care, such as local clinics, to provide patients and their families with good palliative and end-of-life care?... I believe that there needs to be a comprehensive plan to develop it." (Participant F)*

Participants also noted that support in preparing for an impending death should not be confined to traditional definitions of "family members", typically those related by blood or marriage. Instead, they recommended broadening the scope to include other significant individuals in the patient's life, such as *"those in relationships that are not openly acknowledged by the patient's family or society and individuals in cohabiting partnerships lacking legal recognition" (Participant F)*. They further drew attention to the needs of Taiwanese new immigrants, a term that broadly refers to individuals who have settled in Taiwan and acquired legal residence or citizenship through marriage, naturalisation, or other migration pathways, distinct from temporary labour migrants (Kasai, 2022). Participants observed that this group continues to receive limited attention in end-of-life care, which can affect their experiences when preparing for a relative's death. Collectively, participants emphasised the importance of adopting an inclusive approach to identifying those who play meaningful roles in a patient's life. Such an approach ensures that high-quality end-of-life care encompasses not only legally or biologically defined family members but also others who are closely connected to the patient, particularly individuals or groups whose relationships may not be socially accepted or formally recognised within Taiwan's culturally diverse society.

This subtheme places particular emphasis on the healthcare system, underscoring the need for systemic reform and structural integration to achieve comprehensive and inclusive palliative and end-of-life care, which in turn can better support families in preparing for a relative's death.

Subtheme 2.3: Improving death literacy among the public

Improving death literacy among the public was regarded as essential for helping families prepare for the death of a relative. Participants emphasised the need to encourage a shift in public attitudes towards death-related topics, enabling individuals to better understand what to expect and how to approach the process. They recommended that the public be educated on preparations related to death and dying, including *"advance care planning, discussions about the preferred place of death, decisions about post-death clothing, funeral arrangements, expressing gratitude to the dying relative, and financial planning" (Participant H)*. Importantly, such preparation was seen as something that should begin early, rather than being delayed until death was imminent.

To support this goal, participants proposed multiple methods of raising death literacy and awareness. Suggestions included *"engaging religious groups and organisations to provide the public with death education" (Participant F)*, *"organising events such as death festivals and Death Cafés" (Participant B)*, and *"producing and distributing relevant films" (Participant H)*. These initiatives reflected a belief that death preparation should be viewed as a societal responsibility rather than a matter left to individual families alone. As one participant explained:

> *"Death preparation should be framed as a societal issue so that the public can start paying attention to it in their everyday lives. It should be presented as a topic that can*

> *be discussed over the long term, allowing people to engage in ongoing conversations about it." (Participant B)*

Although this subtheme focuses on the societal dimension of family death preparation, participants stressed that enhancing public death literacy is closely connected to the experiences of individuals and families.

Subtheme 2.4: The need to engage the government and conduct further research

As previously discussed, improving family death preparation required a multidimensional approach. This included providing high-quality care for patients and families through well-trained healthcare professionals, strengthening end-of-life care services within the healthcare system, and increasing public death literacy through education. Participants emphasised that these initiatives should be further supported by active government involvement. The government was viewed as playing a vital role in overseeing, evaluating, and regulating palliative and end-of-life care across the country. In addition, participants highlighted the importance of high-quality research to guide policy development and inform clinical practice. As one participant suggested:

> *"The government needs to establish relevant policies (on delivering palliative and end-of-life care), such as monitoring or incentive systems. However, research support is essential when creating these policies. I believe these are areas where government involvement is necessary." (Participant F)*

This final subtheme highlights the central role of government and research in advancing family death preparation. More broadly, Theme 2 demonstrates that support must be addressed in a multidimensional way across four levels: individual, systemic, societal, and national.

Building on these thematic findings derived from the framework analysis (Parkinson et al., 2016; Ritchie & Spencer, 2002), the next section turns to the recommendations developed through the framework analysis, which translate these themes into practical and actionable guidance for healthcare professionals in supporting families as they prepare for a relative's death.

7.3.2 Recommendations following the framework analysis

Through the framework analysis, all 42 initial recommendations generated from the nominal group meeting were revised to enhance clarity and practical relevance, drawing on the discussions that took place during the session. These modified recommendations are provided in **Appendix 5**.

While the thematic findings in Section 7.3.1 highlight the challenges and underlying principles of improving family death preparation, the recommendations outlined here translate those insights into more concrete guidance. As reflected in Theme 2, supporting families requires a multidimensional approach spanning four levels: individual, systemic, societal, and national. At the individual level, recommendations focused on strengthening healthcare professionals' competencies in end-of-life care through targeted education and training to ensure high-quality care for patients and families. The systemic level addressed the organisation and delivery of palliative and end-of-life care services within the healthcare system. At the societal level, recommendations emphasised improving public death literacy to encourage more informed and open discussions about death and dying. At the national level, participants stressed the importance of government involvement in policy development and research to advance initiatives in family death preparation. Although this multidimensional perspective was seen as essential, it did not indicate which levels should be prioritised or the order in which they should be implemented. To address this, the top ten recommendations, selected and prioritised by participants through voting and ranking during the nominal group meeting, were used to establish an order for practical implementation.

Taken together, the multidimensional framework encompassing individual, systemic, societal, and national levels provided a comprehensive structure for analysing and integrating the 42 modified recommendations (see **Appendix 5**) and guided the synthesis into four finalised recommendations. As shown in **Table 10**, these finalised recommendations each comprise several related modified recommendations along with their implementation priorities. This overview clarifies how the modified recommendations informed the finalised recommendations, ensuring transparency in the framework analysis process. The following sections elaborate on these four finalised recommendations in detail.

Finalised recommendation 1: Providing appropriate end-of-life care to patients and their families necessitates that healthcare professionals possess competencies in this field, which should be cultivated through adequate professional education

This recommendation integrated three interdependent components: the delivery of appropriate end-of-life care, the development of professional competencies, and the provision of, and access to, relevant education and training. These elements were regarded as essential for improving family death preparation in Taiwan.

Delivering appropriate end-of-life care for patients and families was considered central. Such care should be responsive to the patient's changing condition and extend beyond physical needs to include psychological, social, and spiritual dimensions, with the overall aim of supporting a good death. Psychological and spiritual care should involve helping patients fulfil final wishes, resolve unfinished business, and engage in life review. Families also require emotional and informational support, including clear explanations of what to expect during the dying process. Practical actions such as helping to arrange funerals in accordance with cultural and religious beliefs, addressing unresolved relational matters, and facilitating legacy-building activities (for example, recordings or hand moulds) were seen as important for enabling closure and sustaining ongoing bonds.

Families should be actively involved in end-of-life care. This includes participating in the patient's physical and personal care, accompanying them throughout the dying process, especially during the final moments, and contributing to decision-making. Achieving family consensus, respecting patient preferences, and taking life expectancy into account were regarded as critical for appropriate decision-making.

Healthcare professionals require comprehensive training in end-of-life care to support these practices. Core competencies include recognising signs of dying, estimating life expectancy, and communicating effectively with patients, families, and colleagues. Skills in involving families in end-of-life discussions, for example, through shared decision-making and family meetings, are also essential. Professionals should be confident in initiating advance care planning discussions and knowledgeable about relevant legislation, religious practices, and cultural customs. End-of-life care should be integrated into professional curricula, with teaching methods such as case studies, bedside teaching, and hands-on practice.

Finally, as noted in Section 7.2, an error during the voting stage of the nominal group meeting resulted in eight initial recommendations receiving the same number of votes, with three (Recommendations 1, 3, and 4) mistakenly excluded from the final top ten. These were subsequently incorporated into this finalised recommendation during the framework analysis, given their strong relevance and consistency with the overall theme.

Finalised recommendation 2: The significance of active government involvement and research is needed to support the delivery of appropriate palliative and end-of-life care

This recommendation, developed from the framework analysis, was designated as the second-highest priority for implementation. Unlike the top priority, which focused on delivering high-quality end-of-life care, this recommendation adopted a national-level approach to strengthening family death preparation. A central aspect was the recognition that government leadership is needed to develop policies and allocate resources that ensure equitable access to high-quality palliative and end-of-life care services. Such services are essential for enabling families to prepare adequately for the death of a relative.

The government should take responsibility for developing, coordinating, auditing, and monitoring palliative and end-of-life care systems. Rather than concentrating only on passing new laws, attention should be directed towards ensuring the effective implementation of existing legislation, such as the Patient Right to Autonomy Act, and formulating supportive policies that make these frameworks workable in practice. This includes establishing clear guidelines, incentive structures, and monitoring mechanisms to ensure that patients and families can access consistent and equitable services. In addition, promoting death-related education for both healthcare professionals and the general public is essential. Sustained governmental investment in research is also required to support high-quality studies that evaluate existing systems, inform policy development, and guide educational initiatives. This emphasis on research highlights its vital role in improving family death preparation.

Several key research directions were identified. First, studies should explore patients’ experiences of dying and end-of-life care within community settings in Taiwan. Second, further research is required to examine the influence of governmental policies and legal frameworks on the delivery of palliative and end-of-life care, including whether national healthcare policies, such as Taiwan's National Healthcare Insurance, adequately meet the needs of dying patients. Third, investigations should assess the impact of legislation, such as Taiwan's Patient Right to Autonomy Act, on healthcare professionals' engagement in advance care planning. Finally, the development and refinement of prognostic tools for survival estimation were highlighted as priorities, as these would enable clinicians to predict life expectancy more accurately and better meet Taiwanese families' expectations.

Finalised recommendation 3: Strengthening palliative and end-of-life care services within the healthcare system is essential, with particular emphasis on further developing generalist palliative care and integrating these services into non-specialist care units

As outlined in the second priority recommendation, ensuring access to high-quality palliative and end-of-life care is fundamental to helping families prepare for the death of a relative. Building on this, the third priority recommendation emphasises how such care can be strengthened within the healthcare system.

At its core, this recommendation highlights the need for structure and systemic reforms, calling for a more coordinated and consistent approach to delivering palliative and end-of-life care as a strategy to enhance family death preparation. A central proposal was the development of a continuous and comprehensive palliative and end-of-life care network within the healthcare system. This would require expanding generalist palliative care services and reinforcing the capacity of primary care and community-based settings to provide such care across all levels of the system.

It was also recommended that palliative and end-of-life care services be integrated into non-specialist care units, particularly intensive care units, to better support families during the dying process. In addition, comprehensive provision should address the needs of all individuals with life-limiting conditions and those close to them, rather than focusing solely on immediate family members. This includes recognising and supporting patients' significant others who may not be legally or formally acknowledged, such as individuals in long-term relationships important to the patient but without legal recognition. Ensuring inclusivity for these often-overlooked groups was considered essential to delivering comprehensive palliative and end-of-life care.

Finalised recommendation 4: It is essential to increase the public's death literacy and awareness of issues surrounding death, alongside encouraging a shift in societal attitudes towards death-related topics through targeted and culturally sensitive public education initiatives

This recommendation, developed through the framework analysis, was designated as the final priority for implementation and emphasises the importance of adopting a societal-level approach to improve family death preparation. At its core is the recognition that preparing for a relative's death should be understood not only as a clinical responsibility or a private family matter but also as a broader social concern requiring collective awareness and engagement.

Efforts should therefore focus on enhancing the public's death literacy and raising awareness about death and dying through targeted education initiatives. A range of strategies was identified to achieve this goal, including partnering with advocacy groups and non-profit organisations, making effective use of social media platforms, hosting events such as death festivals and Death Cafés, and producing and distributing educational films. In addition, engaging religious groups and faith-based organisations was recommended to ensure that public education initiatives are culturally sensitive and responsive to diverse community needs.

Table 10: Finalised recommendations following the framework analysis. [a]

Finalised recommendations following the framework analysis	**Recommendations modified by framework analysis** [b]
Recommendation 1: Providing appropriate end-of-life care to patients and their families necessitates that healthcare professionals possess competencies in this field, which should be cultivated through adequate professional education	Nos. 1, 2, 3, 4, 5, 7, 8, 10, 11, 12, 13, 14, 15, 16, 26, 27, 35, 37, 39
Recommendation 2: The significance of active	Nos. 25, 30, 31, 32,

government involvement and research is needed to support the delivery of appropriate palliative and end-of-life care	33, 34, 42
Recommendation 3: Strengthening palliative and end-of-life care services within the healthcare system is essential, with particular emphasis on further developing generalist palliative care and integrating these services into non-specialist care units	Nos. 6, 9, 17, 18, 19, 20, 21, 28, 40
Recommendation 4: It is essential to increase the public's death literacy and awareness of issues surrounding death, alongside encouraging a shift in societal attitudes towards death-related topics through targeted and culturally sensitive public education initiatives	Nos. 22, 23, 24, 29, 36, 38, 41

[a] Each finalised recommendation encompasses several modified recommendations integrated through framework analysis, and the numbering reflects their implementation priorities.

[b] Details of the 42 modified recommendations corresponding to each finalised recommendation are provided in Appendix 5.

These four finalised recommendations and their implementation order, developed through the framework analysis, were discussed earlier. Although grounded in the original recommendations proposed by participants and informed by the discussions during the nominal group meeting, the wording of the final recommendations was refined and differed from the participants' original expressions. Additionally, the scope of prioritisation shifted from the top ten recommendations to a distilled set of four. The implementation order of these finalised recommendations was determined based on the priorities established during the nominal group meeting. Ideally, these refined recommendations and their order would have been presented to participants for review. However, this step was not undertaken due to the absence of prior consent. Further reflections on the framework analysis are presented below.

7.4 Reflections on framework analysis

The framework analysis led to the development of two main themes related to improving family death preparation. The first theme, awareness of difficulties, served as a foundational step in understanding why certain recommendations were proposed. The second theme, a multidimensional approach is necessary, provided a broader perspective by framing the recommendations across four interconnected levels:

individual, systemic, societal, and national. This thematic approach enabled a more holistic interpretation, allowing all proposed recommendations to be evaluated within a wider systematic context rather than viewed in isolation.

The framework analysis also created space to review and reflect on the nominal group meeting process itself, particularly the stages of listing, clarifying, voting on, and ranking the recommendations. This enabled me to move beyond simply refining participant-generated recommendations and instead examine the group meeting process and the discussions that informed them. This shift offered valuable insights into the context and rationale underpinning the recommendations, contributing to a more comprehensive understanding of their development.

Although the nominal group technique theoretically emphasises preserving participants' original wording, this approach can sometimes limit the clarity and practical applicability of recommendations, thereby hindering their dissemination and implementation. In this study, the framework analysis adopted an interpretative stance, refining the original recommendations to enhance their clarity, feasibility, and relevance rather than strictly maintaining the participants' original phrasing. Ideally, these refined recommendations should have been returned to participants for feedback and to determine whether the original consensus remained unchanged. However, as previously noted, this was not possible due to the lack of prior consent for follow-up engagement.

7.5 Chapter summary

The findings of the nominal group technique study on developing recommendations for improving family death preparation have been presented in this chapter. Combined with those reported in Chapters Four (Paper 1, systematic review), Five (Paper 2, qualitative interview study), and Six (Paper 3, qualitative interview study), all findings of this thesis are now presented in full. Before synthesising and discussing these findings to provide an overarching account of how families in Taiwan can better prepare for the death of a relative, the next chapter offers methodological reflections on using the nominal group technique in Palliative Care, drawing on the experience of conducting the study in Taiwan, a non-Western context.

CHAPTER 8: METHODOLOGICAL REFLECTIONS TO SUPPORT GOOD PRACTICE IN USING NOMINAL GROUP TECHNIQUES: INSIGHTS FROM APPLICATIONS IN PALLIATIVE CARE STUDIES (PAPER 4)

8.1 Overview

The fourth paper (Liang, Xiong, & Preston, 2025) presents methodological reflections on the application of the nominal group technique in palliative care. It draws on the experiences of conducting the third study of this thesis, which employed this method to address the final research objective of the thesis:

> *To develop and prioritise culturally sensitive recommendations for healthcare professionals to better support families in preparing for the death of a relative within the Taiwanese context.*

This paper provides a detailed account of how the nominal group technique was applied to generate recommendations for improving family death preparation in Taiwan. It also identifies methodological challenges encountered in using this technique in palliative research and offers practical recommendations to inform future applications of the method.

The published paper is reproduced in the following section.

Methods and Methodology

PALLIATIVE MEDICINE

Methodological reflections to support good practice in using nominal group techniques: Insights from applications in palliative care studies

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Abstract

Background: High-quality recommendations require rigorous methods based on strong evidence to improve clinical practice. In palliative and end-of-life care, expert consensus is sometimes achieved through nominal group techniques. However, its practical challenges are often underestimated, potentially compromising the rigour and the quality of the recommendations.

Methodological reflections: The methodological reflections on developing recommendations using the nominal group technique are discussed in this paper. These reflections are drawn from its theoretical foundations and applications in palliative care research, including a Taiwanese study on preparing families for a relative's death. We highlight key issues such as the omission of pilot meetings and the underestimation of practical challenges in conducting group meetings, including time constraints and real-world uncertainties, especially during the stages of listing, clarifying, voting and ranking recommendations. Cultural factors are often overlooked, as seen in the example study, where the moderator avoided interruptions to show respect and politeness during the meeting. Additionally, valuable data gathered during meetings is often underutilised. These factors collectively can undermine the quality of recommendations. Based on these insights, we offer suggestions for improvement.

Key suggestions: Pilot meetings should be conducted and reported to demonstrate how they inform the main meeting, ensuring research rigour and recommendation quality. Sufficient time should be allocated for listing and clarifying recommendations and in societies with specific etiquettes (e.g. minimising interruptions to show politeness). Further qualitative analysis of meeting transcripts is suggested to better understand the context and rationale behind the recommendations and enhance their applicability and clarity.

Keywords

Nominal group technique, consensus methods, recommendation development, interpretive qualitative analysis, framework analysis

What is already known about the topic?

- Developing practice recommendations based on evidence using rigorous and transparent methods is essential for enhancing healthcare quality through formal consensus methods such as the nominal group technique.
- The nominal group technique is a structured method for identifying priorities, reaching consensus and developing recommendations, but despite its wide use in healthcare research, it remains underutilised in palliative care.

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What this paper adds?

- We reinforce the value of conducting pilot meetings and highlight the practical challenges of conducting nominal group technique meetings, as difficulties arise from multiple tasks, time constraints, practical complexities and real-world uncertainties, particularly during the recommendation listing, clarification, voting and ranking phases.
- Cultural factors in applying the nominal group technique are overlooked, as shown in the example study, including the need for more time to summarise and record participants' verbal recommendations in written Traditional Chinese (which uses complex characters with many strokes) and the necessity of adhering to etiquette by minimising interruptions to demonstrate politeness.
- Existing palliative care research using nominal group techniques often underutilises valuable qualitative data from group meetings, overlooking opportunities to reflect on their conduct or address practical challenges that have been encountered during the process through post-meeting qualitative analysis.

Implications for practice, theory or policy

- Pilot meetings should be conducted and reported to show how they inform the main meeting, ensuring research rigour to improve recommendation quality.
- Sufficient time should be allocated for conducting nominal group technique meetings, particularly for listing and clarifying recommendations, with culturally appropriate consideration given to societies where interruptions are avoided to show politeness, necessitating prior arrangements made with participants.
- Further qualitative analysis of group meeting transcripts through a more interpretive qualitative approach (e.g. framework analysis), particularly of discussion during recommendation listing and clarification, is recommended to reflect on meeting conduct, gain deeper insights into the context and rationale behind participant-generated recommendations, and enhance their applicability and practicability.

Background

Implementing research findings into clinical practice is essential for enhancing patient care and maintaining healthcare quality.[1–3] The quality of recommendations depends on the strength of the underlying evidence.[1] In palliative and end-of-life care research, expert consensus together with engaging practitioners in the stage of developing evidence-based recommendations is vital.[2–4] Formal consensus methods, such as the Delphi method and nominal group technique, are commonly used to establish consensus and involve practitioners in the process.[5–9]

The nominal group technique, developed in the 1970s, is a structured method for generating recommendations that prioritise group consensus over diverse perspectives.[8,10–12] Unlike the multi-round Delphi method, it is more time-efficient and less demanding for participants, requiring only a single session.[5] This method ensures equal participation opportunities to contribute,[5,11] preventing domination by certain individuals, a common issue in focus groups.[13,14] The technique comprises four stages: preparation, sampling, group meeting and data analysis[5,11,12,15] (Table 1). The preparation stage involves practical tasks such as planning the meeting, setting its duration, and arranging space and equipment, alongside research-related tasks like gathering relevant evidence[5,7,9] and conducting pilot meetings.[5] In the sampling stage, participants with diverse expertise are selected, usually through purposive sampling,[5,9,12] to enhance data quality and minimise social hierarchy effects.[5] Nominal group meetings typically involve five to ten participants, depending on the research scope and participants' availability, ensuring adequate data collection while providing equal opportunities for all participants to contribute.[5,9,15]

Group meetings are the core of the nominal group technique, following a structured process of introduction, recommendation generation, listing, voting and ranking.[5,11] The moderator begins by outlining objectives and expected outcomes, followed by brief participant introductions.[11,15] Relevant research evidence is presented before introducing the meeting's research questions.[5,16,17] Participants then generate recommendations individually and silently, without discussion.[5,11,12] Next, they take turns sharing one recommendation at a time, trying to avoid repetition while promoting equal participation and diverse input.[12,15,18] A discussion phase follows for clarification before voting and ranking to reach consensus.[11,15] The meeting concludes with a summary of key outcomes, expressions of gratitude and final questions.[5] Meetings typically last 90–120 min,[5,15] depending on group size, the number of research questions and available time.[18] Two moderators usually lead the session, with one facilitating and the other observing and taking notes. Collected data, including recommendation lists, counts and voting results, are analysed using quantitative and qualitative methods.[5,15]

The nominal group technique serves multiple research purposes, including developing recommendations, solving problems, establishing priorities and building consensus.[5,8,19] It is suited to explore sensitive or under-researched topics,[5] which are common in palliative care. Although widely applied in healthcare and nursing,[6] its application in palliative care research remains limited.[20] This paper aims

Table 1. Process of the nominal group technique.[5,6,11]

Stages	Main tasks
Preparation	Organising the meeting procedures, such as scheduling and securing meeting space and equipment. Preparing a synthesis of evidence on research topics to be presented to participants. Conducting a pilot meeting to test the meeting procedures and research questions to be presented during the meeting.
Sampling	Recruiting participants based on the study's inclusion and exclusion criteria.
Running group meeting	The meeting procedure involves an introduction, presentation of relevant research evidence, silent recommendation generation, recommendation listing and clarification, voting and ranking, and conclusion.
Data analysis	Data from nominal group technique meetings, including recommendation counts, recommendation lists, and voting and ranking results, is typically analysed using quantitative and qualitative methods.

to provide methodological reflections on the technique, drawing from its theoretical foundations and applications in selected exemplar palliative care studies. While focused on this field, the insights may be relevant more broadly.

Relevant literature was identified through Scopus and Google Scholar using the keywords 'nominal group technique' and 'palliative care'. Sixteen papers published between 2006 and 2024 were selected based on relevance to palliative care.[16,21–35] A summary of how the method has been used is available in the supplementary file (S1). Collectively, these studies demonstrate the technique's adaptability. It has been used to explore research conduct.[24,26] research priorities,[16] clinical practice,[28,31,32] outcome measurement[29,33,35] and professional education.[23] Many studies included participants in varied roles,[16,21,24–33,35] such as patients, family members and healthcare professionals,[24,35] demonstrating the technique's capacity to capture diverse perspectives. Some studies combined the technique with other research methods.[21,24,28] Seven studies presented relevant evidence during meetings,[16,24–29] which can enhance recommendation quality, participant engagement and group cohesion.[5,7] However, nine studies omitted this step,[21–23,30–35] possibly to emphasise participants' lived experiences, underscoring the method's flexibility.

Challenges in applying the nominal group technique were reported in 11 studies (see Table 2 for details), including participant recruitment,[21,22,24,26–29,35] the conduct of the meeting,[24,34,35] reaching consensus,[33] data analysis,[24,34,35] and verification of recommendations with participants after the meeting.[23,26] In contrast, five studies did not state any challenges.[16,25,30–32] Overlooking these issues can compromise methodological rigour and the quality of recommendations produced. These challenges are further reflected upon in relation to our study, as discussed below.

A practical example of the nominal group technique

The example study is part of a larger project aimed at improving the preparation for a relative's death in Taiwan[36–38] underpinned by critical realism, acknowledging that truth is contextualised [39] This study aimed at developing recommendations for healthcare professionals on preparing families for a relative's death using the nominal group technique. On 8th July 2023, a nominal group meeting was held in Taiwan with ten specialist palliative care professionals, including two physicians, six nurses, one psychologist, and one chaplain. The participants generated and voted upon 42 recommendations, resulting in a prioritised list.

Methodological reflections on the nominal group technique

The real-world challenges of applying the nominal group technique are explored, addressing both its theoretical foundations and practical applications in palliative care research.

The absence of pilot meetings or poor reporting

Pilot meetings are recommended to refine meeting procedures, improve the clarity of research questions to be presented and enhance moderator confidence.[5,12,15,40] By addressing potential challenges in advance, they help ensure smoother main sessions and improve recommendation quality.[5,9,40] For methodological rigour and transparency, changes made following pilot findings and their impact on the formal session should be reported. However, pilot meetings were often omitted or poorly documented in the exemplar palliative care studies.[16,21,24–35] Only two studies reported conducting pilot meetings.[22,23] One found no relevant outcomes,[23] while the other extended discussion time but made no protocol changes.[22] However, the pilot involved research team members rather than intended participants (family caregivers) and lacked details on the original or revised discussion duration, limiting transparency.

In contrast, our study reinforced the value of pilot meetings by providing feedback that refined the main session. The pilot, held on 8 June 2023 with 10 specialist palliative care nurses who did not participate in the main meeting, tested all procedures and led to key modifications. While recommendations are usually grouped into

Table 2. Challenges reported in exemplar palliative and end-of-life studies using the nominal group technique[a].

Authors, year, country	Challenges encountered in practice					Key
	Participant-related	Conduct of meeting	Establish consensus	Data analysis	Participant rechecking	
Aspinal et al.[35], UK		1		2		1 = Research question potentially interpreted differently across groups
Tuffrey-Wijne et al.[34], UK	3			2		2 = Analysing data across groups
Pastrana et al.[33], Germany			4			3 = Challenges in grouping and ranking for participants with limited literacy
Higginson et al., 2013, UK [24]	5	6,7		8		4 = Diverse recommendations made consensus difficult.
Rice et al.[22], USA, Canada	5					5 = Limited participant diversity – hard to get non-health care professionals
de Wolf-Linder et al.[29], Ireland	5					6 = Limited time to conduct meeting to reach consensus
Walshe et al.[28], UK	5					7 = Limited time to create clear recommendations
Dhingra et al.[27], 2022, USA	5					8 = Difficulty analysing recommendations that had multiple parts
Hussain et al.[26], 2022, UK	5				9	9 = Findings not presented to participants for feedback
Hökkä et al.[23], Europe					9	
Walshe et al.[21], UK	5					

[a]Five of 16 studies did not report any challenges.[16,25,30–32] UK: United Kingdom, USA: United States.

themes during the clarification stage[18] or in post-meeting analysis,[15,35] pilot feedback suggested introducing predefined themes, such as clinical care and education, during the listing stage. This helped identify recurring recommendations and streamline voting and ranking. Other refinements included sharing meeting objectives, procedures and research questions with participants in advance to allow for preparation and questions beforehand. Typing recommendations into a laptop and using voting software to improve efficiency and reduce manual errors was also suggested. Recognising the need for sufficient time, the meeting duration was extended from 140–150 min to allow more time for presenting evidence and listing and clarifying recommendations while slightly reducing the time for voting and ranking.

Lack of clarity in defining group consensus

Establishing group consensus is a central goal of the nominal group technique. For methodological rigour, researchers should clearly define what constitutes consensus, including how it will be identified and measured.[5] Theoretically, consensus refers to the degree of individual or overall group agreement and whether the collective views demonstrate sufficient alignment.[5] In practice, consensus is typically reached through independent voting and ranking, followed by aggregation of results without further participant comments.[11] Additional voting rounds may be conducted if needed.[5] Importantly, verifying that participants accept the final outcomes confirms whether consensus has been achieved. This poses a methodological challenge in studies involving multiple groups, where researchers must decide whether to assess consensus within each group or across all groups collectively.

In the exemplar palliative care studies, definitions and processes for reaching consensus varied in rigour and transparency. Some followed clear procedures,[24,25] while others lacked sufficient detail.[16,22,23,27,29–32,34,35] Most commonly, consensus was achieved by selecting the top five[27,29–32,34,35] or top ten[16,21,23] recommendations after a single one voting round. However, few studies reported whether participant feedback was sought or whether additional rounds were conducted to confirm agreement. Only one study explicitly stated that consensus was reached when participants had no further comments and results were finalised [25] while another defined consensus as full participant agreement during the clarification phase rather than the ranking process.[22] Moreover, multigroup studies rarely described how consensus was established across groups.[22,23,27,31,34,35] A few used follow-up online surveys to assess cross-group consensus.[17,24,32,41,42] Some used statistical measures such as median score and interquartile ranges,[17,24,41,42] while another asked participants from multiple groups to prioritise the top five recommendations based on perceived importance.[32]

However, these approaches seldom addressed whether any disagreement remained, raising concerns about the robustness of consensus verification. Follow-up surveys may offer a practical solution for assessing consensus across groups.

In our example study, 42 recommendations were voted upon, and the 10 receiving the highest number of votes were prioritised. As the results were accepted by all participants, no additional voting rounds were required.

Overall, the lack of consistent definition and transparent reporting criteria for establishing consensus can compromise the reliability of nominal group technique studies. Clear operationalised definitions and explicit procedures for establishing consensus are essential for ensuring methodological rigour.

Underestimate the practical challenges of conducting group meetings

Practical challenges in conducting nominal group meetings are often underestimated, yet they can undermine the rigour of the method and the quality of recommendations developed.[9] One possible reason for this may be the technique's inherent flexibility. Although theoretically structured, the nominal group technique varies in formats, research objectives and participant needs.[6,18,35,43] Meetings may be conducted in person or online[6] and may involve a single session or multiple sessions with different groups,[8,12,17,31,35] held either simultaneously[12,17] or asynchronously.[8,31,35] Standard procedures involve listing recommendations without discussion, grouping similar ones and prioritising them through ranking and votes.[5] However, the procedure of generating recommendations can be different. While recommendations are often written during meetings,[35] some studies asked participants to prepare them in advance.[8,19] Some adaptations allow discussion during the listing phase or grouping recommendations into broader themes during meetings.[18,40,43] This adaptability is evident in the exemplar palliative care studies. Some conducted one in-person meeting[25,30,33]; others organised multiple in-person sessions for different groups, either simultaneously[16,24,26,29] or asynchronously.[22,27,28,31,32,34,35] Some opted for multiple online sessions for separate groups at different times.[21,23] These format and timing choices reflect efforts to accommodate participants while maintaining the integrity of the consensus process. However, most studies did not report challenges encountered during meetings.[16,21–23,25–33] Only a few noted specific difficulties,[24,35] such as applying the same research question to different types of participants.[35]

The structured design and practical flexibility of the nominal group technique are strengths, but they do not eliminate implementation challenges.[18,43] In our example study, despite a pilot meeting conducted, several issues arose during recommendation listing, clarification, voting and ranking. These challenges stemmed from managing multiple tasks under time pressure, linguistic complexity and real-world uncertainties. While recommendations should be recorded as accurately as possible to preserve participants' original wording,[12,15] it was difficult in practice. None of the exemplar palliative care studies reported challenges with capturing participants' voices,[16,21–35] but in our case, recording participants' verbal recommendations in written Traditional Chinese, a language with complex characters and many strokes, within time constraints was challenging. This increased time pressure also raised the risk of human errors in subsequent voting and ranking stages. In our study, eight recommendations tied in voting, but three of the tied ones were missed in the final listing of the top ten recommendations.

Technologies, such as laptops, projectors and voting software, can streamline the meeting process and reduce manual errors.[21–23,31] However, technical difficulties may still arise. In our case, typing handwritten recommendations in Traditional Chinese for voting software was more time-consuming than in English, increasing the likelihood of errors. Additionally, Mentimeter was planned to be used for ranking, but it failed during the meeting despite prior testing, so we had to switch to paper-based ranking.

Our study illustrates that practical challenges of conducting nominal group meetings can occur even after pilot meetings. Greater attention to these real-world barriers is essential to ensure robust application of the nominal group technique.

Insufficient attention to cultural contexts

Cultural context is often overlooked in applying the nominal group technique.[43] This limitation is apparent in the exemplar palliative care studies, likely due to studies predominately being conducted in Western societies, including the United Kingdom,[16,17,21,24–26,28,32,34,35,41,42] Europe,[23,29–31,33] the United States[27] and Canada.[22] Our study underscores the importance of considering cultural factors when applying the nominal group technique,[43] particularly in non-Western contexts, to ensure both methodological rigour and cultural sensitivity.

In our example study conducted in Taiwan, cultural and linguistic factors affected the recommendation listing stage and prolonged the session. Summarising participants' verbal recommendations during the listing stage was challenging. Participants struggled to make succinct suggestions, often presenting multiple recommendations at once, and had difficulty articulating their thoughts on death preparation. These patterns may reflect communication styles within Taiwanese culture.[44] Consequently, the moderator needed to interpret participants' statements, identify key points being made and confirm these with them. Despite awareness of time constraints, the moderator did not necessarily interrupt participants to manage the session, as avoiding interruptions to show respect and politeness is a cultural norm in Taiwan.[44] Additionally, writing recommendations in Traditional Chinese slowed down the real-time documentation process. Therefore, much more time was spent on listing, clarifying and discussing recommendations than expected; our entire session still exceeded the adjusted duration (150 min) based on a pilot by approximately 80 min.

Underutilisation of the rich qualitative data from group meetings

A reductionist approach, consolidating similar recommendations during meetings to minimise post-meeting analysis, is often used in the data analysis of the nominal group technique,[10] leading to methodological challenges.[12] Consequently, greater emphasis is placed on quantitative data for voting and ranking outcomes and cross-group comparisons.[43] In contrast, qualitative analysis tends to be inconsistently applied and usually limited to the synthesis of participant-generated recommendations.[17] In-depth analysis of meeting transcripts is rare and often poorly reported,[45] leading to underutilisation of rich qualitative data from group meetings and loss of contextual insights into how recommendations are developed.[15,43]

This pattern is reflected in the exemplar palliative care studies. Voting and ranking results were typically analysed using descriptive statistics and compared across groups when needed.[22,27,31,34,35] Qualitative data, including participant-generated recommendations,[17,22,23,28,31,35] scribe notes[26,29] and meeting transcripts,[25,27,32,33] were analysed less consistently. Most studies focused on synthesising recommendations or scribe notes, often neglecting deeper insights available in transcripts.[22,23,26,28,29,31,35] Thematic analysis was commonly used[23,25–29,33,35], while some studies applied content analysis,[22,32] or did not specify the method.[17,24,31]. A few studies omitted post-meeting qualitative analysis,[16,30,34] possibly due to using reductionist approaches during meetings, which reduced the need for further analysis.[10]

While some exemplar palliative care studies analysed transcripts,[25,27,32,33] few reflected on how meetings were conducted or practical challenges encountered. In our example study, challenges arose despite prior piloting. Although the moderator aimed to remain neutral,[40,45] interactions during the recommendation listing and clarification stages proved complex. Time constraints and data complexity contributed to errors in voting and ranking, with recommendations made on the day missing important information from deeper discussions. This highlighted the need to critically examine the conduct of group meetings and the researcher's role. An interpretive qualitative approach can offer greater insight into the context and reasoning behind participants' recommendations and enhance the relevance and applicability of findings.

In our study, framework analysis was chosen to allow structured interpretation within a predefined theme framework.[46,47] The process followed five stages: familiarisation, framework development, indexing, charting, and mapping and interpretation.[47] The meeting recording was transcribed and reviewed to familiarise the researcher with the data. A framework was developed that included the recommendations listed and agreed upon by participants, along with the top 10 ranked recommendations. It also incorporated summaries of discussions about each recommendation (e.g. how they were developed through group interactions), reflections on the meeting process (e.g. missed or misunderstood recommendations), challenges faced by staff in death preparation, and refined recommendations for preparing patients and families for an expected death. This framework guided the annotation, categorisation and synthesis of data under relevant headings, enabling refinement, elimination of duplicates and consolidation of related recommendations. During this process, the three tied recommendations missed in the final ranking were reintroduced and incorporated into the refined top-ranked recommendations, which included predicting life expectancy, delivering appropriate end-of-life care and supporting families' psychological needs. Table 3 illustrates how this recommendation evolved into a more comprehensive form through analysis.

The final recommendations were developed from participants' input and discussions, but their wording was modified for clarity and practical relevance. The final recommendations were not returned to participants for review or re-ranking due to no consent obtained for a follow-up.

Our study demonstrates the value of in-depth transcript analysis using an interpretive approach. Although the nominal group technique emphasises preserving participants' original wording, this may limit the practical utility of recommendations. A more interpretive lens enhances clarity, feasibility and contextual relevance, while also providing deeper insights into the reasoning behind recommendations. It allows researchers to evaluate all recommendations within a broader context rather than focusing solely on the top ten generated during the meeting.

Suggestions for supporting good practice in using the nominal group technique

The nominal group technique aims to build consensus by engaging practitioners in generating and prioritising recommendations.[5,9] Based on our methodological reflections, we suggest several strategies for future research to strengthen its application and enhance recommendation quality (Table 4). These insights developed in palliative care research are relevant to other fields.

Pilot meetings should be conducted to test research questions to be presented, refine meeting procedures, and report their impact on the main meeting. If no

Table 3. Refining the top one recommendation from the nominal group meeting through framework analysis in the example study.

Charting stage of framework analysis							Refined recommendations after framework analysis
Recommendation generated from the meeting	Suggester	Ranking top 10	Discussion during the meeting	Reflections on the process of the meeting	Challenges previously experienced by staff	Refined recommendation after the charting stage	
Clinical care-related dimension **Healthcare staff can recognise dying signs and deliver care.**	Participant J	1st	Healthcare staff could recognise dying signs and alert family members that death was near, as family members aimed to accompany the patient during this critical period.	The listed strategy did not mention that it was crucial to alert family members to accompany the patient when death was near.	Missing the rationale	*Competencies* Healthcare staff should demonstrate competence in recognising dying signs, communicating effectively and timely with families about impending death, and delivering appropriate end-of-life care.	*Supplying tailored palliative and end-of-life care for patients, families, and significant others* • Healthcare staff should aim to predict life expectancy as accurately as possible, recognise dying signs, and deliver appropriate end-of-life care to patients and families. This includes: - Assist families in fulfilling the patient's last wishes and unfinished business (*patients)* - Assist the patient in creating a legacy that can serve as a means of connecting with their families after death (*patients)* - Assist the patient in reviewing his/her life (*patients)* - Communicate effectively and timely with families about the impending death *(families)* - Guiding families to participate in the physical care of the patient *(families)* Recognising and addressing families' psychological and emotional needs *(families)*

Table 4. Key suggestions for conducting nominal group techniques research.

Recommendations for researchers
Conduct a pilot nominal group meeting
• Pilot meetings should be conducted to pre-test research questions to be presented and meeting procedures.
• Adjustments based on pilot findings should align with specific research needs and be clearly justified.
• Pilot findings and their impact on the main meeting should be documented and reported.
• Pilot meetings can serve as main meetings if no significant changes to the meeting procedures are required, and this should be planned (e.g. obtaining informed consent from participants).
Define group consensus
• Definition of group consensus should be clearly stated, including when predetermined agreement threshold met, such as through majority votes, ranking priorities or statistical measures, and when no significant objections remain.
Present relevant evidence if necessary
• Whether to provide participants with relevant evidence on research topics during group meetings should be clearly justified to ensure transparency in the research process. If included, the evidence should be synthesised and presented to participants in a clear and succinct manner.
Plan for practical challenges
• Allocate appropriately sufficient time and have help from experienced researchers/moderators to overcome the practical challenges of conducting nominal group meetings posed by multiple tasks, time pressure, practical complexities and real-world uncertainties.
Follow social norms in cultural contexts
• Consider social norms, communication styles, and behaviours deemed appropriate in cultural contexts.
• Allocate sufficient time, especially for conducting nominal group meetings in hierarchical societies emphasising politeness and respect for senior people.
Analyse the rich qualitative data from the group meeting process
• Review the conduct of nominal group meetings and reflect on the researcher's role in these processes through additional in-depth qualitative data analysis, such as framework analysis.
• Analyse the discussion during recommendation listing and clarification to gain deeper insights into the context and rationale behind participant-generated recommendations.
• The final list of refined recommendations should be presented to participants for review.

significant changes to the procedures are required, these pilot meetings can serve as main meetings, and data can be analysed to generate findings. This should be planned so that informed consent can be obtained. We also recommend that researchers clearly justify whether relevant evidence will be presented to participants during meetings to enhance transparency.

It is important to anticipate and address practical challenges when conducting group meetings, as strictly following the original plans is often unrealistic and may compromise the quality of recommendations. These challenges, often underreported in the literature, can persist even after pilot meetings due to multiple tasks, time constraints, practical complexities and real-world uncertainties. Such issues are particularly evident during the recommendation listing, clarification, voting and ranking stages. Cultural considerations are also essential when applying the nominal group technique. In societies where interruptions are avoided as a sign of respect and politeness, allocating sufficient time for group meetings, particularly during the recommendation listing and clarification stages, and using it efficiently is vital. Prior arrangements to accommodate participants' communication styles can help ensure they fully express their recommendations.

Although time-consuming, in-depth analysis of meeting transcripts, particularly discussions during recommendation listing and clarification, using an interpretive qualitative approach is highly recommended for future studies. This approach allows for reflection on the group meeting process and the researcher's role and can address practical challenges encountered during the process. It provides deeper insights into the context and rationale behind participant-generated recommendations, refining them for better applicability. To assess if the original consensus has changed, the final list of refined recommendations should be presented to participants for review, with the possibility of re-ranking the recommendations.

Conclusion

The nominal group technique serves various research purposes and has significant potential to advance palliative care research and other fields. While methodologically structured, it remains flexible and can be adapted to specific research objectives or participant needs. Drawing from its theoretical foundations and practical applications in palliative care, we provide methodological reflections and identify key challenges: the absence of pilot meetings, neglecting practical challenges in conducting group meetings, insufficient attention to cultural factors and underutilisation of valuable data generated during meetings. These issues can undermine research rigour and the quality of recommendations. We also offer suggestions to address these methodological challenges to strengthen the application of the nominal group technique, including culturally appropriate approaches. This paper will support the development of more contextually relevant and implementable recommendations.

Author contributions

H-JL, NP and QX contributed to the conceptualisation of the paper. H-JL drafted and revised the manuscript. All authors reviewed and approved the final version for submission.

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Ethics approval

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Data management and sharing

There is no data.

Supplemental material

Supplemental material for this article is available online.

References

1. Platz T. Methods for the development of Healthcare practice recommendations using systematic reviews and meta-analyses. *Front Neurol* 2021; 12: 699968.
2. Haines A and Donald A. Making better use of research findings. *BMJ* 1998; 317: 72–75.
3. Curtis K, Fry M, Shaban RZ, et al. Translating research findings to clinical nursing practice. *J Clin Nurs* 2017; 26: 862–872.
4. Voznyuk S, Carter RZ and Ridley J. A pragmatic approach to selecting a grading system for clinical practice recommendations in palliative care. *Palliat Med* 2025; 39: 176–185.
5. Jünger S and Payne S. The crossover artist: consensus methods in health research. In: Walshe C and Brearley S (eds) *Handbook of theory and methods in applied health research: questions, methods and choices*. UK: Edward Elgar, 2020, pp.199–213.
6. Foth T, Efstathiou N, Vanderspank-Wright B, et al. The use of Delphi and Nominal Group Technique in nursing education: a review. *Int J Nurs Stud* 2016; 60: 112–120.
7. Black N, Murphy M, Lamping D, et al. Consensus development methods: a review of best practice in creating clinical guidelines. *J Health Serv Res Policy* 1999; 4: 236–248.
8. Redman S, Carrick S, Cockburn J, et al. Consulting about priorities for the NHMRC National Breast Cancer Centre: how good is the nominal group technique. *Aust N Z J Public Health* 1997; 21: 250–256.
9. Fink A, Kosecoff J, Chassin M, et al. Consensus methods: characteristics and guidelines for use. *Am J Public Health* 1984; 74: 979–983.
10. Delbecq AL and Van de Ven AH. A group process model for problem identification and program planning. *J Appl Behav Sci* 1971; 7: 466–492.
11. Harvey N and Holmes CA. Nominal group technique: an effective method for obtaining group consensus. *Int J Nurs Pract* 2012; 18: 188–194.
12. Van de Ven AH and Delbecq AL. The nominal group as a research instrument for exploratory health studies. *Am J Public Health* 1972; 62: 337–342.
13. O. Nyumba T, Wilson K, Derrick CJ, et al. The use of focus group discussion methodology: insights from two decades of application in conservation. *Methods Ecol Evolut* 2018; 9: 20–32.
14. Wong LP. Focus group discussion: a tool for health and medical research. *Singapore Med J* 2008; 49: 256–260.
15. Gallagher M, Hares T, Spencer J, et al. The nominal group technique: a research tool for general practice? *Fam Pract* 1993; 10: 76–81.
16. Stevinson C, Preston N, Todd C, et al. Defining priorities in prognostication research: results of a consensus workshop. *Palliat Med* 2010; 24: 462–468.
17. Preston NJ, Fayers P, Walters SJ, et al. Recommendations for managing missing data, attrition and response shift in palliative and end-of-life care research: part of the MORECare research method guidance on statistical issues. *Palliat Med* 2013; 27: 899–907.
18. McMillan SS, King M and Tully MP. How to use the nominal group and Delphi techniques. *Int J Clin Pharm* 2016; 38: 655–662.
19. Fox WM. The improved nominal group technique (INGT). *J Manage Dev* 1989; 8: 20–27.
20. Coombes L, Harðardóttir D, Braybrook D, et al. Achieving consensus on priority items for paediatric palliative care outcome measurement: results from a modified Delphi survey, engagement with a children's research involvement group and expert item generation. *Palliat Med* 2023; 37: 1509–1519.
21. Walshe C, Dunleavy L, Preston N, et al. Understanding barriers and facilitators to palliative and end-of-life care research: a mixed method study of generalist and specialist health, social care, and research professionals. *BMC Palliat Care* 2024; 23: 159.
22. Rice DB, Cañedo-Ayala M, Turner KA, et al. Use of the nominal group technique to identify stakeholder priorities and inform survey development: an example with informal caregivers of people with scleroderma. *BMJ Open* 2018; 8: e019726.

23. Hökkä M, Ravelin T, Coupez V, et al. Core palliative care competencies for undergraduate nursing education: international multisite research using online nominal group technique. *J Palliat Care* 2024; 39: 217–226.
24. Higginson IJ, Evans CJ, Grande G, et al. Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC Med* 2013; 11: 1–11.
25. Harrop E, Liossi C, Jamieson L, et al. Oral morphine versus transmucosal diamorphine for breakthrough pain in children: methods and outcomes: UK (DIPPER study) consensus. *BMJ Support Palliat Care* 2023; 13: e1019–e1028.
26. Hussain JA, White IR, Johnson MJ, et al. Development of guidelines to reduce, handle and report missing data in palliative care trials: a multi-stakeholder modified nominal group technique. *Palliat Med* 2022; 36: 59–70.
27. Dhingra L, Braveman C, Roberts K, et al. Low hospice utilization in New York State: framework for compiling and ranking barriers. *J Palliat Med* 2022; 25: 1524–1532.
28. Walshe C, Kinley J, Patel S, et al. A four-stage process for intervention description and guide development of a practice-based intervention: refining the Namaste Care intervention implementation specification for people with advanced dementia prior to a feasibility cluster randomised trial. *BMC Geriatr* 2019; 19: 1–11.
29. de Wolf-Linder S, Dawkins M, Wicks F, et al. Which outcome domains are important in palliative care and when? An international expert consensus workshop, using the nominal group technique. *Palliat Med* 2019; 33: 1058–1068.
30. Tuffrey-Wijne I, Wicki M, Heslop P, et al. Developing research priorities for palliative care of people with intellectual disabilities in Europe: a consultation process using nominal group technique. *BMC palliative care* 2016; 15: 1-11.
31. van Riet Paap J, Vissers K, Iliffe S, et al. Strategies to implement evidence into practice to improve palliative care: recommendations of a nominal group approach with expert opinion leaders. *BMC Palliat Care* 2015; 14: 1–6.
32. Dening KH, Jones L and Sampson EL. Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. *Palliat Med* 2013; 27: 409–417.
33. Pastrana T, Radbruch L, Nauck F, et al. Outcome indicators in palliative care—how to assess quality and success. Focus group and nominal group technique in Germany. *Support Care Cancer* 2010; 18: 859–868.
34. Tuffrey-Wijne I, Bernal J, Butler G, et al. Using Nominal Group Technique to investigate the views of people with intellectual disabilities on end-of-life care provision. *J Adv Nurs* 2007; 58: 80–89.
35. Aspinal F, Hughes R, Dunckley M, et al. What is important to measure in the last months and weeks of life?: A modified nominal group study. *Int J Nurs Stud* 2006; 43: 393–403.
36. Liang H-J, Xiong Q, Lin P-C, et al. 'A good ending but not the end': exploring family preparations surrounding a relative's death and the Afterlife–a qualitative study. *Palliat Med* 2024; 38(10): 1184–1193.
37. Liang H-J, Xiong Q, Lin P-C, et al. 'Regrets become a lasting source of pain': a qualitative study on family caregivers' experiences leading up to a relative's death. *Palliat Med* 2025; 39(3): 401–412.
38. Liang H-J, Xiong Q, Remawi BN, et al. Taiwanese family members' bereavement experience following an expected death: a systematic review and narrative synthesis. *BMC Palliat Care* 2024; 23: 14.
39. McEvoy P and Richards D. A critical realist rationale for using a combination of quantitative and qualitative methods. *J Res Nurs* 2016; 11: 66–78.
40. Carney O, McIntosh J and Worth A. The use of the nominal group technique in research with community nurses. *J Adv Nurs* 1996; 23: 1024–1029.
41. Evans CJ, Benalia H, Preston NJ, et al. The selection and use of outcome measures in palliative and end-of-life care research: the MORECare international consensus workshop. *J Pain Symptom Manage* 2013; 46: 925–937.
42. Gysels M, Evans CJ, Lewis P, et al. MORECare research methods guidance development: recommendations for ethical issues in palliative and end-of-life care research. *Palliat Med* 2013; 27: 908–917.
43. McMillan SS, Kelly F, Sav A, et al. Using the nominal group technique: how to analyse across multiple groups. *Health Serv Outcomes Res Methodol* 2014; 14: 92–108.
44. Yum JO. The impact of Confucianism on interpersonal relationships and communication patterns in East Asia. *Commun Monogr* 1988; 55: 374–388.
45. Mullen R, Kydd A, Fleming A, et al. A practical guide to the systematic application of nominal group technique. *Nurse Res* 2021; 29: 14–20.
46. Parkinson S, Eatough V, Holmes J, et al. Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qual Res Psychol* 2016; 13: 109–129.
47. Ritchie J and Spencer L. Qualitative data analysis for applied policy research. In: Bryman A and Burgess RG (eds) *Analyzing qualitative data*. UK: Routledge, 2002, pp.173–194.

8.2 Chapter summary

Paper 4, a reflective methodological paper on applying the nominal group technique in palliative care, has been presented in this chapter. Several limitations were identified, including insufficient attention to practical challenges, limited consideration of cultural influences, and underuse of qualitative data from meetings. In response, recommendations are provided to support future nominal group technique research, including adopting a more interpretative approach to analysing meeting transcripts. In the following discussion chapter, the thesis findings will be synthesised to provide a comprehensive overview of how families in Taiwan can better prepare for a relative’s death. This synthesis will address the overarching research question and situate the findings within a broader context.

CHAPTER 9: DISCUSSION

This thesis included three studies exploring family death preparation in Taiwan from different perspectives. The first was a systematic review (Paper 1, i.e., Chapter Four) that synthesised evidence on Taiwanese families' bereavement experiences following an expected death, highlighting that family death preparation can shape the bereavement adjustment. The second was a qualitative interview study (Papers 2 and 3, i.e., Chapters Five and Six) that examined how family caregivers prepared for a relative's death, showing how cultural values, religious beliefs, and familial responsibilities influenced decision-making, caregiving, and emotional expression. Building on these insights, a third study used the nominal group technique (Chapter Seven) to develop recommendations with healthcare professionals on supporting families in preparing for a relative's death. Methodological reflections on the use of this technique in the palliative care context were also presented (Paper 4, i.e., Chapter Eight), offering suggestions for enhancing its use in future research.

In this discussion chapter, findings from the three studies are brought together to address the overarching research question. A Taiwan-specific conceptual model of family death preparation is introduced and situated in relation to existing Western frameworks. The findings are then interpreted through relevant theoretical perspectives. Finally, the chapter outlines my original contributions to knowledge, clinical practice, and methodology, and concludes with a reflection on its strengths, limitations, and my reflexivity.

9.1 A summary of the key findings and specific research objectives

The overarching research question was: “How can families in Taiwan better prepare for the death of a relative?” In this section, a summary of the key findings is presented, outlining how the overarching question was addressed and how each specific research objective was achieved.

9.1.1 Summary of findings from Paper 1

> *Objective 1: To systematically analyse published literature on the bereavement experiences of Taiwanese family members following an expected death and to identify culturally appropriate bereavement theories relevant to the Taiwanese context.*

The systematic review examined Taiwanese families' bereavement experiences following an expected death. A comprehensive search of five electronic databases was conducted without date restrictions up to 20 October 2022, and a narrative synthesis approach (Popay et al., 2006) was applied to analyse and integrate findings from 17 studies.

Four main themes were generated and are illustrated in Figure 2 of Paper 1: (1) multiple impacts of the death, (2) problem-based coping strategies, (3) the importance of maintaining connections, and (4) influential religious beliefs and rituals. A key finding was that family members' experiences during the end-of-life period, particularly caregiving responsibilities, perceptions of care quality, and preparation for death, shaped the subsequent bereavement. Bereavement was therefore understood to be continuous with family death preparation rather than a separate phase. Maintaining continuing relationships with the deceased person was central to bereavement, often sustained through religious rituals intended to support the deceased person's afterlife. This suggests that the continuing bonds theory (Klass & Silverman, 1996; Steffen & Klass, 2018) provides a culturally appropriate framework in the Taiwanese context. Additionally, the suppression or concealment of strong emotions was identified as a normative practice influenced by cultural values and religious beliefs.

9.1.2 Summary of findings from Papers 2 and 3

> *Objective 2: To explore Taiwanese family caregivers' experiences of preparing for a relative's death within specialist palliative care settings.*
>
> *Objective 3: To examine how Taiwanese families' approaches to death preparation are influenced by cultural context and how such preparations shape their subsequent bereavement experiences.*

A qualitative interview study with 22 primary family caregivers was conducted following the death of a relative who had received specialist palliative care. Data were collected through semi-structured interviews and analysed using reflexive thematic analysis (Braun & Clarke, 2024).

Paper 2 focused on family caregivers' preparations before the death of a relative and how these efforts shaped bereavement. The actions and considerations undertaken by families during this period are illustrated in Figure 1 of Paper 2 (Liang, Xiong, Lin, et al., 2025). Central to these preparations were making the best possible end-of-life decisions and providing competent caregiving, both viewed as essential for reducing regrets. Preparations for decision-making included protecting the dying relative from emotional distress, deciding whether and how to involve them in discussions, respecting their preferences, maintaining family harmony through consensus-building, and drawing on professional support. Caregiving preparations involved fulfilling responsibilities, developing care competence, making personal sacrifices, and meeting the dying relative's last wishes. These actions were understood as ways of ensuring comfort for the dying relative and easing bereavement for the family.

Paper 3 explored preparations for the time of death and the post-death period, as illustrated in Figure 1 of Paper 3 (Liang, Xiong, Lin, et al., 2024). Families emphasised achieving a culturally appropriate death through dignified handling of the body (kept clean, well-dressed, eyes and mouth closed), meaningful funerals, and rituals to support the deceased relative's afterlife and continuing bonds. Emotional restraint was also considered necessary, with families suppressing strong emotions during dying and bereavement as a way of protecting the deceased relative's peace. These findings are consistent with those from the systematic review (Paper 1) but deepen understanding of how cultural and religious practices shape Taiwanese families' approach to death preparation.

9.1.3 Summary of findings from the nominal group technique study (Chapter Seven) and Paper 4

Objective 4: To develop and prioritise culturally sensitive recommendations for healthcare professionals to better support families in preparing for the death of a relative within the Taiwanese context.

A nominal group technique study was conducted with ten specialist palliative care professionals to generate recommendations for improving family death preparation. As detailed in Chapter Seven, participants initially identified 42 recommendations during the group meeting. Through framework analysis (Parkinson et al., 2016; Ritchie & Spencer, 2002), two main themes were developed. The first emphasised the importance of recognising challenges that hinder families from engaging in death preparation, viewing this as a necessary starting point for formulating effective recommendations. The second highlighted the need for a comprehensive and multidimensional approach, addressing individual, systemic, societal, and national levels. Based on these themes, four finalised recommendations were produced to guide culturally appropriate support in Taiwan.

Paper 4 provided methodological reflections on applying the nominal group technique in palliative care, drawing on the Taiwanese study and a review of exemplar research (Liang, Xiong, & Preston, 2025). Several limitations were identified, including limited use and poor reporting of pilot meetings, unclear definitions of group consensus, insufficient attention to practical challenges, and limited consideration of cultural influences such as hierarchy and conversational politeness. In addition, qualitative data from meetings were often underutilised. To strengthen future application of the technique, recommendations included conducting and reporting pilot meetings, addressing social and cultural factors, and paying greater attention to qualitative analysis of meeting transcripts, with particular focus on the listing and clarification phases. A more interpretative approach could deepen understanding of the reasoning behind participant-generated recommendations, support critical reflection on group processes, and improve the contextual relevance and feasibility of recommendations.

9.2 A culturally grounded conceptual model of family death preparation in Taiwan

A conceptual model is presented in **Figure 4** to illustrate how family death preparation is understood and enacted in Taiwan. The model was developed from the findings of the three studies and informed by earlier conceptualisations introduced in the background chapter. Previous research has described family death preparation as a multidimensional process involving cognitive, emotional, and behavioural readiness, alongside the completion of medical, psychosocial, spiritual, and practical tasks (Durepos et al., 2019; Hebert et al., 2009; Nielsen et al., 2016). Such work highlights the complexity of the process and the importance of healthcare professionals in supporting families (Hebert et al., 2006; Hebert et al., 2009).

The Taiwanese model builds on these understandings but extends them by embedding family death preparation within East Asian cultural, religious, and social contexts. While drawing on dimensions identified in Western literature, it expands them by reflecting the lived experiences of Taiwanese families. The model identifies four interrelated domains, including clinical, relational, cultural-religious, and socio-structural, that together illuminate how families in Taiwan prepare for a relative's death. These domains demonstrate that preparation is not limited to medical tasks or individual readiness, but is deeply rooted in cultural and religious traditions, collective responsibilities, and broader structural influences.

Each domain is described below, illustrating how the Taiwanese model both shares features with wider East Asian approaches and introduces elements that are distinct to Taiwan's cultural and healthcare context.

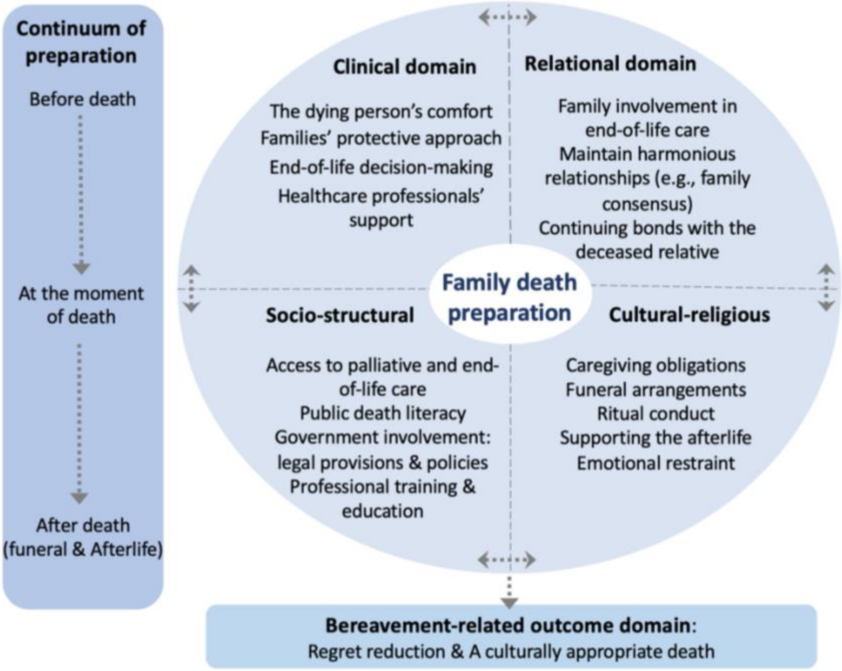


Figure 4: A conceptual model of family death preparation in Taiwan.

Clinical domain

The clinical domain highlights how the well-being of the dying person in the period leading up to death was supported through collaboration between families and healthcare professionals. Families took responsibility for providing care to ensure the dying relative's physical, psychosocial, and spiritual comfort, while professionals contributed expertise and resources to support this care. This collaborative dynamic was also evident in end-of-life decision-making, where the way decisions were made also influenced the well-being of the dying person. A distinctive feature of Taiwanese practice was the family-centred and protective approach to end-of-life decision-making. As shown in both the interview (Papers 2 and 3) and nominal group studies (Chapter Seven), decision-making was rarely viewed as the patient's responsibility alone but as a process shared with, and often led by, the family. During this process, healthcare professionals needed to balance respect for patient autonomy with recognition of the importance of family involvement and family wishes.

The dying person's role in decision-making was carefully negotiated. Both families and healthcare professionals sought to respect the patient's wishes; however, families placed greater emphasis on shielding the patient from emotional distress. This was evident in the practice of selective involvement, in which families decided whether, when, and how to include the dying person in decisions, guided by their understanding of the dying person's values and the sensitivity of the issues under discussion. For families, selective involvement was not regarded as paternalism but as an act of care, limiting exposure to potentially distressing conversations while still honouring known or inferred preferences. This protective logic also extended to information-sharing practice. Families in this research often asked clinicians to disclose prognostic details, including life expectancy, to family members first, allowing them to determine how much information to share with the dying relative. Sensitive non-medical information, such as another relative's illness, was likewise withheld by family members to preserve the dying person's peace of mind.

These practices have also been observed in Taiwan (Hu et al., 2002; Lin et al., 2017) and across other East Asian contexts (Cheng et al., 2025; Martina et al., 2021). They align with broader East Asian approaches to clinical care, where collective and protective decision-making and family-mediated disclosure are common. In Japan, families frequently play a central role in medical decision-making (Ito et al., 2010). They are often consulted before patients are informed of a serious diagnosis (Matsumura et al., 2002), and in some cases, decisions are made solely by the family without involving the patient (Tanaka et al., 2021). Similarly, in South Korea, non-disclosure remains common when families perceive the information as harmful (Mo et al., 2012), and decisions regarding life-sustaining treatments are often made on family members' input, reflecting the enduring influence of the family in end-of-life decision-making (Park et al., 2021). In China, decisions are likewise frequently made collectively with the family rather than individually by the patient (Cheng et al., 2025). Taiwanese practice, therefore, reflects this regional ethos of collective responsibility, where protecting the patient is regarded as integral to good care, an ethos grounded in Confucian values of filial piety, familial duty, and relational harmony (Chen & Fan, 2010; Inglehart & Baker, 2000; Yum, 1988). These themes are examined further in Section 9.4.

In this clinical domain, how Taiwanese families balance two interrelated goals is illustrated: ensuring the dying relative's comfort and enacting their perceived protective role in medical decision-making and information disclosure. End-of-life care is delivered through collaboration between families and professionals, but with strong expectations that families remain central to this process. This positions the Taiwanese model within a distinctively East Asian paradigm of relational and family-centred care, providing a foundation for understanding the relational domain discussed below.

Relational domain

The relational domain highlights the central role of the family in end-of-life care, where responsibilities for decision-making, caregiving, and accompanying the dying relative were shared among family members. Findings from the qualitative interview (Papers 2 and 3) and nominal group technique studies (Chapter Seven) show that these responsibilities were understood as collective duties. Preserving harmony within the family was a recurring concern, with participants emphasising consensus-building as a way of avoiding conflicts in end-of-life matters. This emphasis on shared responsibility and harmony reflects a family ethic of obligation, a feature also noted in other East Asian contexts (Chen & Fan, 2010). For example, a study in China found that family harmony was often prioritised over the patient's own wishes, and preserving harmony was considered essential for achieving what family members perceived as a good death (Cheng et al., 2025).

The relational orientation was also evident in professional practice. In the nominal group study (Chapter Seven), healthcare professionals described family meetings as a valuable means of facilitating shared decision-making and achieving consensus, echoing findings from earlier Taiwanese research (Yu et al., 2024). Such practices reflect a model of care in which agreement among relatives is viewed as essential for maintaining family cohesion and ensuring effective care delivery. Evidence from Japan shows that family meetings can improve families' psychological well-being (Fukui et al., 2013), while in Taiwan, they have been associated with greater engagement in palliative care and a reduced likelihood of cardiopulmonary resuscitation (Yu et al., 2024). By creating opportunities for open discussions about treatment options, care goals, and personal concerns, this approach may help alleviate families' emotional distress at the end of life and reduce unnecessary medical interventions. Consensus-building through family meetings is therefore not only a cultural preference but also a practice with potentially measurable clinical and emotional benefits.

Another feature of the relational domain identified in this research was preparation for continuing relationships with the deceased relative. Across all three studies, cultivating bonds before death and sustaining them afterwards was regarded as an essential aspect of both family death preparation and the bereavement process. Preparations included religious practices, such as anticipating reunion in the afterlife, and non-religious acts, such as legacy creation or memory making. Relational continuity was therefore viewed as an integral part of family death preparation, linking the final phase of life with the continuing presence of the deceased person in family life. Comparable traditions have been observed in Hong Kong (Chan et al., 2005) and across East Asia (Le et al., 2025), where ancestor worship and enduring familial ties reflect obligations that extend beyond death to include ritual care for ancestors (Hsu et al., 2009; Lee, 2010).

The relational domain demonstrates how collective responsibilities, consensus-building to preserve family harmony, and preparation for continuing bonds shape family relationships and interactions when preparing for a relative's death in Taiwan. These practices demonstrate that family death preparation is not limited to the dying phase but spans the boundary between life and death, maintained through cultural and religious frameworks that are examined further in the next section on the cultural-religious domain.

Cultural-religious domain

The cultural-religious domain captures the influence of cultural values and religious beliefs on how Taiwanese families prepare for a relative's death. These influences were evident across all three phases of preparation: before death, at the moment of death, and after death. Central to this domain was the emphasis on ensuring the deceased relative's well-being in the afterlife, which shaped families' rituals, behaviours, and understandings of what constitutes a good death. Findings from all three studies in the thesis consistently show that these values guided families' priorities as death approached.

Findings from this research also reveal that ritual practices surrounding dying and death, from the deathbed to the funeral, were seen as essential to supporting the dying person's transition to a better afterlife. Conducting these rituals in accordance with cultural and religious expectations was viewed as a moral obligation. As shown in both the qualitative interview (Papers 2 and 3) and nominal group technique studies (Chapter Seven), funerals were described not only as marking the end of life but also as vital for the deceased relative's continuing well-being after death, a finding consistent with earlier Taiwanese research (Shih et al., 2009) and also reported across East Asia. For example, in China (Cheng et al., 2025) and Hong Kong (Chan et al., 2005), parents' funerals are central expressions of filial duty and family continuity, allowing children to repay their parents through respectful posthumous treatment and to maintain the ancestral line (Yick & Gupta, 2002). These findings underscore that in Taiwan, rituals surrounding dying and death are not merely cultural customs but moral obligations grounded in Confucian values, especially filial piety, which remains influential across the region (Hsiung et al., 2025; Wu, 2006; Yeh et al., 2013).

Another defining feature of this domain is emotional restraint, identified in both the systematic review (Paper 1) and the interview study (Papers 2 and 3). Suppressing overt expressions of grief at the deathbed or funeral was understood as protecting the dying relative's peace and facilitating a smoother transition to the afterlife. At the same time, emotional restraint preserved social harmony, reflecting Confucian and collectivist values that emphasise relational interdependence and the avoidance of conflict (Brewer & Chen, 2007). This dual function, ensuring the deceased person's spiritual well-being while maintaining harmony among the living, positions emotional restraint as a cultural and religious norm, also observed in Chinese societies (Li et al., 2024), such as Hong Kong (Bond, 1993; Chow et al., 2006). Emotional restraint should therefore be understood as a culturally and religiously appropriate practice, rather than merely the suppression of emotion.

Cultural and religious values also shaped how families defined a good death. In Taiwan, this is commonly expressed as Hǎo zǒu (好走, "to depart well"), a concept that extends beyond symptom control to include family presence at the deathbed, respectful handling of the body (kept clean, well-dressed, eyes closed, mouth shut), and the assurance that the deceased relative would not suffer in the afterlife. Religious rituals and emotional restraint were regarded as central means of achieving this goal. Regional comparisons reveal both shared influences and distinctive emphases in defining a good death. In China, funerals continue to play a central role in achieving a good death, although concerns about the afterlife are less pronounced than in Taiwan, possibly reflecting lower levels of religiosity (Cheng et al., 2025). In Japan, a good death is more often associated with the quality of the dying process itself, particularly symptom control and relational closeness, rather than with funeral rites or afterlife preparation (Hirai et al., 2006; Ikari et al., 2022; Miyashita et al., 2007). These comparisons highlight Taiwan's distinctive religious orientation, which sustains a particularly strong focus on the afterlife.

The cultural-religious domain illustrates how Taiwanese families embed death preparation within moral, cultural, and religious frameworks that link dying with post-death continuity. Through ritual practices, emotional restraint, and afterlife considerations, family death preparation is understood not only as caring for the dying relative but also as fulfilling familial obligations that extend beyond death. These obligations intersect with broader societal and institutional factors, which are addressed in the socio-structural domain.

Socio-structural domain

The socio-structural domain captures the systemic and policy-level factors that shape families' ability to prepare for a relative's death. It highlights how the healthcare system, public awareness of dying and death, and government policy influence the extent to which families can engage in death preparation. These issues were particularly emphasised in the nominal group technique study (Chapter Seven), where specialist palliative care professionals identified the need for structural and policy reforms to better support families.

Within the healthcare system, participants underscored the importance of coordinated and consistent palliative and end-of-life care services. Expanding access to generalist palliative care alongside specialist provision was regarded as essential for ensuring that families across different geographical and institutional settings could obtain timely support, a concern echoed in European evidence (Gómez-Batiste et al., 2017). These findings align with international calls for integrated models to meet population needs and reduce inequities (Stjernswärd et al., 2007b). Strengthening healthcare professionals' competencies through training and continuing education was also highlighted, reflecting global evidence of persistent skills gaps and the need for stronger professional preparation in end-of-life care (Centeno et al., 2017).

At the societal level, participants emphasised adopting a public health and community-based approach to dying and death to improve death literacy and normalise conversations about the end of life. Death literacy refers to the knowledge and skills that enable people to access, understand, and act upon end-of-life care options (Noonan et al., 2016). Increasing public awareness of death-related issues through community engagement initiatives was viewed as a way to empower families to speak more openly and prepare more effectively for a relative's death. Evidence from the United Kingdom illustrates this potential: the Good Grief Festival, designed to engage the public in open discussions about death, dying, grief, and bereavement, was found to increase attendees' confidence in talking about grief and supporting someone who is bereaved

(Selman et al., 2023). These findings align with international movements such as compassionate communities (Kellehear, 2013), which reframe dying and death as shared social responsibilities rather than solely medical concerns (Breen et al., 2022; Kellehear, 2013; Sallnow et al., 2022; Selman, 2024).

Government and policy were recognised as pivotal in creating the structural conditions that enable family death preparation. Participants highlighted the importance of clear legal provisions, sustained investment in palliative care infrastructure, and continued research to strengthen evidence-based practice. These perspectives echo global debates that identify the integration of palliative care into national health strategies as essential for equitable access to care and sustainable quality (Callaway et al., 2018; Stjernswärd et al., 2007a). In Taiwan, legislation such as the Natural Death Act (2000) (Laws & Regulations Database of The Republic of China/Taiwan, 2000) and the Patient Right to Autonomy Act (2019) (Laws & Regulations Database of The Republic of China/Taiwan, 2019) represents progress, but the continued dominance of hospital-based palliative care and the uneven reach of community-based services, especially to rural areas, reveal persistent gaps.

The socio-structural domain demonstrates that families' ability to prepare for a relative's death is shaped not only by personal, cultural, or relational resources but also by the availability of supportive structures embedded with healthcare systems and wider society.

Interconnections between domains

The four domains of family death preparation do not operate in isolation but are closely interrelated. For example, decisions about the place of death may simultaneously reflect clinical considerations, cultural and religious beliefs about what constitutes a good death, family dynamics in reaching consensus, and the availability of end-of-life care services. Similarly, the practice of emotional restraint illustrates the overlap between cultural-religious values, social expectations of relational harmony, and clinical approaches to communication and information disclosure. These interconnections show that family death preparation is not merely a medical or individual responsibility, but a collective, relational, and socially embedded process. Effective support for this preparation, therefore, requires coordination across clinical, policy, and community stakeholders and should remain consistent with prevailing cultural values and social expectations.

Bereavement-related outcome domain

In addition to the four core domains, the Taiwanese model includes a further dimension related to bereavement outcomes. Families' ability to minimise regrets and achieve a culturally appropriate death strongly influenced their subsequent bereavement experiences. As shown in the systematic review (Paper 1) and the qualitative interviews (Papers 2 and 3), bereavement was particularly challenging when families perceived poor-quality care or felt that they had not fulfilled their responsibilities, such as decision-making, caregiving, or ensuring the dying relative’s comfort. These perceptions often generated feelings of regret, guilt and self-blame, which in turn complicated the bereavement process (Stroebe et al., 2007).

The bereavement-related outcome domain illustrates that adequate family death preparation can function as proactive bereavement support. By reducing regret and enabling a culturally appropriate death, preparatory actions taken before the death directly shaped families’ post-death bereavement experiences. Preparation included fulfilling caregiving responsibilities, making good end-of-life decisions, and conducting ritual practices. Conversely, inadequate preparation in these areas left families vulnerable to more difficult bereavement trajectories, underscoring the importance of providing sufficient guidance and resources before the death occurs. In this way, bereavement cannot be understood in isolation from what happens before death but must be viewed as continuous with the process of family death preparation (Lichtenthal et al., 2024). The Taiwanese model demonstrates that the foundations of bereavement adjustment lie in how families prepare, care, and fulfil obligations prior to the death.

Having outlined the culturally grounded conceptual model of family death preparation in Taiwan, the next step is to situate it in relation to established Western frameworks. This comparison highlights both shared concerns and distinctive cultural emphases, clarifying the model’s contribution to international understandings of family death preparation.

9.3 Comparing the Taiwanese and Western models of family death preparation

To explore similarities and differences in family death preparation between Taiwan and Western contexts, two established Western frameworks are compared with the Taiwanese model developed in this thesis: Hebert's Theoretical Framework of Preparedness for End-of-Life (Hebert et al., 2006; Hebert et al., 2009) and Durepos's Caregiver Preparedness for End-of-Life in Dementia model (Durepos, Ploeg, Sussman, et al., 2020; Durepos et al., 2019). Hebert's framework, developed in the United States, was grounded in a literature review and empirical refinements, while Durepos's model, from Canada, extended this work through concept analysis and further testing.

All three models recognise family death preparation as complex and multidimensional, but they diverge in emphasis. Hebert's (2006; 2009) and Durepos's frameworks (2020; 2019) prioritise the family caregiver's individual readiness, framing preparation largely as an individualised and pre-death activity. Durepos's model extends this focus by highlighting coping with anticipated loss. By contrast, the Taiwanese model advances a more relational and continuous perspective. Rather than centring solely on family caregivers' psychological adjustment, it emphasises the dying person's needs, the achievement of a good death, and the performance of cultural and religious rituals that extend into the post-death period. Preparation is thus reframed not as ending with death but as a sequence of practices and responsibilities continuing into bereavement.

The models also differ in their approach to relational influences. In Hebert's framework (2006; 2009), communication with healthcare professionals is central, reflecting the medicalised orientation of end-of-life care in the United States. Durepos's model (2020; 2019), while less focused on professional involvement, highlights reconciliation and closure between family caregivers and the dying relative. The Taiwanese model instead prioritises consensus-building, family harmony, and continuing bonds with the deceased relative. This reflects a collectivist orientation in which the family is the unit of care and moral responsibility. While Western models tend to emphasise relational resolution before death, aiming for emotional closure and a sense of completion, the Taiwanese model highlights the continuation of relationships beyond death as both expected and desirable.

Cultural and structural dimensions mark another divergence. The Taiwanese model situates preparation within religious beliefs, social expectations, and policy conditions, including professional training, public death literacy initiatives, and legislation. These elements are largely absent in Western frameworks (Durepos, Ploeg, Sussman, et al., 2020; Durepos et al., 2019; Hebert et al., 2006; Hebert et al., 2009), which tend to place greater emphasis on advance care planning. In Hebert's model (2006; 2009), advance care planning is described as a facilitator of preparation, while in Durepos's model (2020; 2019), it acts as a trigger for the process. Yet neither framework elaborates on how advance care planning shapes families' engagement in death preparation. In contrast, the Taiwanese model assigns advance care planning a relatively minor role, as families place greater focus on relational and ritual obligations that define adequate death preparation within their cultural context. This reflects both cultural priorities and that advance care planning has only recently entered public discourse in Taiwan, within the past decade (Wang, 2023).

A final point of contrast concerns bereavement. Both Western models acknowledge links between family death preparation and bereavement outcomes but treat bereavement primarily as a post-death phenomenon related to adjustment and mental health (Durepos, Ploeg, Sussman, et al., 2020; Durepos et al., 2019; Hebert et al., 2006; Hebert et al., 2009). The Taiwanese model instead integrates bereavement into the preparation process itself, identifying pre-death practices, such as caregiving, decision-making, and ensuring a culturally appropriate death, as pivotal in shaping bereavement outcomes. This reflects a cultural view that bereavement adjustment depends on whether families have fulfilled obligations and enabled a meaningful transition for the dying relative.

Overall, these comparisons show that while all three models recognise family death preparation as multidimensional, the Taiwanese model differs in at least three ways: (1) its temporal scope (continuous versus pre-death), (2) its orientation of responsibility (collective versus individual), and (3) its integration of cultural and structural influences (see **Table 11**). By embedding preparation within moral and cultural contexts, the

Taiwanese model extends Western conceptualisations and reframes family death preparation as a socially situated process that links dying, death, and bereavement into a continuous trajectory.

Table 11: Comparison of Taiwanese and Western models of family death preparation.

Dimension	**Hebert's framework (2006; 2009) (United States)**	**Durepos's model (2020; 2019) (Canada)**	**Taiwanese model (this study)**
Development & context	Literature review; later refined with empirical studies of family caregivers of terminally ill patients	Built on Hebert's framework; integrated concept analysis; applied to family caregivers of persons with dementia	Empirical development through qualitative interviews, systematic review, and nominal group technique with family caregivers and professionals in palliative care
Primary aim	Address caregiver preparedness across cognitive, emotional, and behavioural domains	Achieve caregiver preparedness (medical, psychosocial, practical, spiritual, cognitive, affective, behavioural)	Minimise regret; Achieve a culturally appropriate death
Temporal scope	Preparation during the pre-death period	Preparation during the pre-death period	Preparation as continuum, spanning before and after death
Core focus	Caregiver readiness and communication with healthcare professionals	Caregiver coping and adaptation to anticipated loss	Dying relative's well-being, fulfilment of familial obligations, and performance of cultural and religious rituals
Relational orientation	Emphasis on caregiver-professional relationships	Emphasis on closure in caregiver-dying relative relationship	Emphasis on family harmony and continuing bonds with the deceased relative
Role of cultural and religious beliefs	Minimal emphasis	Minimal emphasis	Central: religious rituals and cultural practices shape preparation
Role of socio-structural factors	Limited attention	Limited attention	Explicitly considered (e.g., professional training, public death literacy, and government involvement)
Role of advance care planning	Highlighted as a facilitator of preparation	Viewed as an antecedent/trigger for preparation	Not central
Bereavement orientation	Viewed as a post-death outcome; link acknowledged but mechanisms unspecified	Viewed as a post-death outcome; link acknowledged but mechanisms unspecified	Seen as an integrated outcome; pre-death actions (e.g., caregiving, decision-making, rituals) shape post-death adjustment

9.4 Exploring research findings through theoretical perspectives

In this section, the research findings are examined through theoretical perspectives to show how family death preparation in Taiwan is shaped both by cultural values and by the influence of Western palliative care models. Confucian familism (Badanta et al., 2022; Hwang, 1999) is used to explain why families assume collective responsibility for preparing for a relative's death, while Hofstede's cultural dimensions theory (Hofstede, 1984, 2001) situates these practices within a broader collectivist orientation. Modernisation theory (Ntini, 2016; Tipps, 1973) highlights how family death preparation has been reshaped by globalisation, professionalisation, and the diffusion of Western palliative care models, exposing tensions created by transferring Western-oriented approaches into Taiwanese settings. Postmodern perspectives (Jeong-ho & Naehui, 2022) are then used to question Western universalism and to support calls for decolonising palliative care, a theme developed further in Section 9.5.

Although findings from the systematic review (Paper 1) and the qualitative interview study (Papers 2 and 3) have been discussed in published papers, this section extends those accounts by synthesising and interpreting them through these theoretical lenses. In doing so, it demonstrates how Taiwanese family death preparation is grounded in cultural traditions yet continually reshaped by structural and global influences, particularly the introduction of Western palliative care. This analysis offers a critical perspective that reveals both commonalities and divergences from Western contexts.

9.4.1 End-of-life decision-making and caregiving

Family-centred decision-making and autonomy in tension

A family-centred, consensus-oriented, and protective approach to decision-making was identified in this research. End-of-life choices were understood not as the sole responsibility of the patient but as collective family duties (Mo et al., 2012). Discussions aimed to reach consensus to preserve family harmony, with potentially distressing information often filtered through family members before reaching the patient (Chen & Fan, 2010). This approach reflects Confucian familism (Hwang, 1999) and collectivism (Hofstede, 1984, 2001). Familism emphasises role-based obligations, expressed through protecting dying relatives from distress during end-of-life decision-making (Badanta et al., 2022). When the dying relative is a parent, adult children's involvement in decision-making and their effort to ensure that choices convey respect and gratitude are viewed as expressions of filial piety. Collectivism, meanwhile, underscores interdependence and relational cohesion (Hsu et al., 2009; Yum, 1988). From this perspective, limiting a patient's direct involvement in certain decisions can be understood not as paternalism but as an act of care, intended to reduce emotional burden while still aligning with the patient's known or inferred preferences (Bowman & Singer, 2001).

In many Western contexts, palliative care models prioritise individual autonomy as the foundation of bioethics (Inglehart, 2008). Autonomy safeguards patient choice and independence, reflecting the assumption that the individual is the primary moral unit (Gómez-Vírseda et al., 2019; Tan Kiak Min, 2017). Taiwan has incorporated these ideas into legal and clinical practices through mechanisms such as informed consent and surrogate decision-making (Gómez-Vírseda et al., 2019). In practice, however, autonomy is often negotiated alongside family involvement and consensus, as shown in this research and supported by other studies in other East Asian contexts (Matsumura et al., 2002; Mo et al., 2012). From the perspective of modernisation theory (Ntini, 2016; Tipps, 1973), this reflects how global discourses of autonomy have entered Taiwanese palliative care but have been adapted rather than replacing existing cultural values (Inglehart & Baker, 2000). Autonomy is thus reframed relationally, integrating both patient wishes and family consensus within shared decision-making processes (Lee et al., 2024). This highlights the challenges of applying Western concepts of autonomy across cultural settings, particularly where emotional protection and collective harmony are prioritised.

Relational autonomy and whole-family care

Findings from this research suggest that relational autonomy offers a culturally appropriate framework for understanding end-of-life decision-making in Taiwan. The concept has been proposed as a more suitable approach to end-of-life care across cultures (Donchin, 2001; Gómez-Vírseda et al., 2019), including in collectivist societies such as Taiwan (Tan Kiak Min, 2017). It recognises individuals as socially embedded, highlighting the need to consider relational and structural factors in decision-making (Gómez-Vírseda et al., 2020; Mackenzie & Stoljar, 2000). At the practical level, relational autonomy is enacted through shared decision-making processes such as family meetings (Grignoli et al., 2018; Yu et al., 2024). This approach was identified in both the interview (Papers 2 and 3) and nominal group studies (Chapter Seven) and is also supported by Western palliative care evidence (Hudson et al., 2021; Hudson et al., 2008).

In Taiwan, relational autonomy is reflected not only in family decision-making but also in the palliative care philosophy of “whole-family care” (全家照護, quán jiā zhào hù) (Chao, 2015). The relational features observed in my research align with this philosophy, which regards the family as the unit of care and emphasises the assessment of family dynamics, genograms, and significant family events as part of clinical practice. This highlights that decisions and care responsibilities are embedded in wider relational networks rather than resting solely with the patient. While this differs from many Western systems, where the patient is usually prioritised as the primary unit of care, family-inclusive practices are also gaining recognition in some Western contexts (Broom & Kirby, 2013). These comparisons show that models of care and decision-making are diverse and shaped by context, and no single framework is universally applicable.

The interview study (Papers 2 and 3) also revealed that patients’ voices were sometimes partial or absent, with family consensus outweighing their stated preferences. This pattern has been observed in Taiwan (Lee et al., 2024) and other East Asian contexts (Cheng et al., 2025). Participants in this research described family consensus as a key component of the best possible decision, intended to reduce conflict and maintain harmony within the family. Within Taiwanese cultural values, this was perceived as culturally appropriate rather than a denial of autonomy. From the perspective of relational autonomy, contextual factors such as family dynamics are recognised as important influences on decision-making (Gómez-Vírseda et al., 2019). However, the framework also maintains that the patient’s wishes should remain central and take precedence when they conflict with family preferences. In this light, prioritising family consensus over the patient’s voice may risk silencing patient agency. These findings suggest that even relational autonomy requires cultural adaptation and cannot be assumed to resolve all challenges in end-of-life decision-making (Asagumo, 2022; Krishna et al., 2015).

Caregiving as a moral duty and relational obligation

Findings from this research revealed that end-of-life caregiving carried multiple meanings for Taiwanese families, encompassing both the fulfilment of familial responsibilities and the provision of comfort to the dying relative. Sacrifices in caregiving, such as adjusting work schedules, enduring physical strain, or setting aside personal needs, were often described as integral to doing one's utmost, as shown in the interview study (Papers 2 and 3). These practices reflect Confucian familism (Hwang, 1999), which frames caregiving as a moral expectation, and collectivist values that locate care responsibility within the family rather than the individual (Hofstede, 1984, 2001).

Most participants in this research were adult children caring for their parents. Within this relational context, providing direct care for dying parents was understood as an expression of loyalty, gratitude, and filial responsibility, regardless of the quality of past interactions (Hsiung et al., 2025; Wu, 2006; Yeh et al., 2013). Evidence from Chinese communities in the United Kingdom shows similar expectations, with direct involvement in caring for dying parents regarded as essential, reflecting the persistence of filial caregiving norms even within a professionalised care system (Fang et al., 2015). These examples illustrate that filial caregiving expectations persist across cultural settings. In Taiwan, caregiving is therefore framed less as a technical task and more as a relational obligation and a symbol of moral virtue (Hwang, 1999).

In many Western contexts, caregiving is often discussed in terms of burden, burnout, and the need for self-care (Angelo et al., 2013). Although intensive caregiving has sometimes been linked to poor bereavement outcomes (Lai et al., 2014), both the systematic review (Paper 1) and the interview study (Papers 2 and 3) found a different pattern. Families who provided longer or more demanding caregiving often described reduced regret and more positive bereavement experiences, as they felt they had fulfilled their responsibilities and done their best. This finding aligns with some Western evidence (Lowers et al., 2020) and suggests that the relationship between caregiving intensity and bereavement outcomes can vary across cultural contexts. Caregiving can be both demanding and meaningful, highlighting the need for caution when applying concepts such as caregiver burden universally without regard for cultural meaning and context.

Modernisation, professionalisation, and evolving filial piety

Modernisation theory (Ntini, 2016; Tipps, 1973) helps explain how developments in modern palliative care have reshaped, but not displaced, Taiwanese end-of-life practices. My findings show that the expansion of institutional infrastructures and professional roles has provided new resources and guidance (Howarth, 2007; Zaman et al., 2017), yet families remain central to both decision-making and caregiving. The interview (Papers 2 and 3) and nominal group studies (Chapter Seven) highlight the growing role of healthcare professionals in supporting families to make confident decisions and provide care. Rather than diminishing family responsibility for end-of-life care, professionalisation has complemented and adapted family involvement within these practices (Krishna et al., 2015).

Filial piety further illustrates this adaptation under modernisation. Traditionally associated with respecting, obeying, and repaying parents (Yum, 1988), filial piety has evolved in contemporary Taiwan (Wu, 2006). While unquestioning deference is now less common, the obligation to care for ageing or ill parents remains influential (Hsiung et al., 2025; Wu, 2006; Yeh et al., 2013). In the interview study (Papers 2 and 3), most participants, who were adult children, described caregiving as a way of repaying their parents for their upbringing, even when past relationships were strained (Fang et al., 2015; Yum, 1988). In this way, filial piety continues to motivate caregiving, but in forms that have adapted to modern social and medical contexts.

Summary

End-of-life decision-making and caregiving in Taiwan are interwoven practices shaped by Confucian familism, collectivism, and evolving filial piety, while also influenced by the professionalisation of palliative care and global discourses of autonomy. Families remain central, with autonomy understood relationally and caregiving framed as a moral duty that is both demanding and meaningful. These findings demonstrate that autonomy and caregiving acquire culturally specific meanings through the interaction between enduring traditions and modern healthcare systems. While particularly visible in Taiwan, similar family-centred approaches are also evident in other settings, including minority communities in Western countries (Bennett et al., 2018; Fang et al., 2015). This underscores the need to interpret end-of-life practices within their social and cultural frameworks, recognising diversity rather than assuming uniformity.

9.4.2 Religion, spirituality, and cultural definitions of a good death

Religious beliefs, spirituality, cultural continuity

Religious beliefs remained central to Taiwanese families' experiences of death, dying, and bereavement, as shown across all three studies in this thesis. Despite modernisation, religiosity in Taiwan remains pluralistic and overlapping, with families often drawing simultaneously on Buddhism, Taoism, and folk traditions (a blend of Buddhism, Taoism, and Confucianism) (Weller, 2020). Some practices, such as support-chanting (助念, Zhùniàn) at the deathbed, have become cultural norms extending beyond explicitly religious settings (Shih, 1982). From the perspective of modernisation theory (Ntini, 2016; Tipps, 1973), this persistence challenges the assumptions that modernisation inevitably leads to secularisation. In many Western societies, secularisation has reduced the social significance of religion, and palliative care often operates within secular frameworks, where spiritual care focuses on existential rather than ritual meanings (Howarth, 2007; McNamara, 2001; Zaman et al., 2017). Nevertheless, religious traditions continue to influence end-of-life care in some Western communities, suggesting that secular and religious approaches can coexist within the same cultural landscape.

In Taiwan, religious and cultural frameworks remain integral to end-of-life care and bereavement, coexisting with medical systems and professionalised palliative care (Bennett et al., 2018; Fang et al., 2015). This helps explain why Clinical Buddhist Chaplains are included in palliative care teams and why rituals from the deathbed to the funeral remain essential, as reflected in the interview study (Papers 2 and 3) and in other Taiwanese literature (Cheng et al., 2016; Shih et al., 2009). Professionals routinely assess patients' religious identities and ritual needs, and palliative care inpatient units must provide designated spaces such as viewing rooms for post-death rituals. These rooms are often furnished with Buddhist statues, Christian symbols, or other religious artefacts. When a deceased patient is taken from the ward, staff accompany the body and the family to the lift, bowing in a farewell ritual (diàn tī sòng bié, 電梯送別, “lift send-off”).

Such practices illustrate how spiritual care in Taiwan integrates ritual expression and afterlife preparation as essential components of care (Shih et al., 2009).

Cultural and religious framings of a good death

Findings from this research suggest that a culturally appropriate death (好死, hǎo sǐ, meaning "a good death") in Taiwan is relational, ritualised, and collectively experienced, echoing earlier findings from Hong Kong (Chan et al., 2005). It extends beyond the moment of dying to include bodily dignity, funeral rites, and the deceased relative's well-being in the afterlife. Families in the interview study (Papers 2 and 3) emphasised the importance of maintaining a dignified appearance at death and holding meaningful funerals, reflecting the Confucian principle of shèn zhōng (慎終, "carefully handling the end of life"). Funerals provided both social recognition and emotional closure, while a peaceful appearance, such as a clean and well-dressed body with eyes closed, embodied the saying 'sǐ yě míng mù' (死也瞑目, "death with closed eyes"), symbolising a smooth transition free from worries.

Beliefs about the afterlife also shaped Taiwanese families' understandings of a good death (Chan et al., 2005). Ancestor traditions, Buddhist teachings on rebirth (往生, wǎng sheng), and the widespread use of the term "rebirth" instead of "death" reflect families' continuing concern for the deceased relative's well-being (Hsu et al., 2009; Weller, 2020). At the same time, freedom from pain (Meier et al., 2016; Miyashita et al., 2008b; Miyashita et al., 2007; Steinhauser, Clipp, et al., 2000; Wilson & Hewitt, 2018) and a natural death (Miyashita et al., 2008a) were also central values in defining a good death, identified both in previous studies and in this research. Families consistently emphasised comfort and symptom management, aligning with Confucian ideals such as 'kǎo zhōng mìng' (考終命), one of the Five Blessings (wǔfú, 五福), which aspires to a peaceful death free from suffering. Expressions used by participants in the interview study (Papers 2 and 3), such as "allowing nature to take its course" (shùn qí zì rán, 順其自然) and "accepting destiny" (tìng tiān mìng, 聽天命), further illustrate this worldview (Bennett et al., 2018).

Negotiating a good death under modernisation

Findings from this research show that the negotiation of a good death in Taiwan reflects the coexistence of legal, moral, and cultural frameworks. The introduction of Western palliative care has influenced Taiwanese understandings of a good death but has not displaced existing cultural frameworks. The Natural Death Act (2000) (Laws & Regulations Database of The Republic of China/Taiwan, 2000) institutionalised do-not-resuscitate orders, resonating with the ideal of a natural death while creating tension in end-of-life decision-making. This tension is particularly evident in relation to filial piety, which remains a deeply held value in Taiwan (Hsiung et al., 2025; Wu, 2006; Yeh et al., 2013) . Adult children may feel pressure to “do everything possible” (救到底, jiù dào dǐ) to save a parent’s life, both as an expression of filial devotion and to avoid social criticism if life-sustaining treatment is withdrawn (Bowman & Singer, 2001), as also supported by recent evidence from China (Jeon & Jing, 2023). Such dilemmas illustrate how legal provisions and cultural obligations intersect, requiring families to navigate between medical principles and filial as well as social expectations. These dilemmas were not explicitly observed in the qualitative interview study (Papers 2 and 3), possibly because participants’ relatives were already receiving specialist palliative care, where do-not-resuscitate decisions were accepted as part of clinical practice. However, participants described these decisions as emotionally challenging for families, reflecting the moral tensions between clinical guidelines and filial responsibility.

Western notions of a good death often emphasise autonomy and control, sometimes extending to the hastening of death in debates on assisted dying (Howarth, 2007; Kehl, 2006; Meier et al., 2016). Taiwanese families, by contrast, more commonly described death as predestined by higher powers or natural law, as supported by this research and others (Bennett et al., 2018). Yet professional frameworks in Taiwan increasingly incorporate autonomy as a quality indicator in palliative and end-of-life care (Cheng et al., 2016). For example, the Good Death scale developed in Taiwan includes autonomy but omits religion and afterlife (Cheng et al., 2008). This selective adoption illustrates how professional practice draws on Western frameworks without fully aligning with family perspectives, revealing the coexistence of secular and religious understandings of a good death.

The interview study (Papers 2 and 3) also revealed that dying at home is not universally viewed as a good death; its meaning depends on patients' needs, family beliefs, and practical circumstances. Modernisation has reshaped the place of death in Taiwan, reflecting trends observed in Western societies (Jiang & May, 2021; Lewis, 2007). A Taiwanese study found that institutionalisation has shifted most deaths into hospitals: between 2007 and 2018, hospital deaths rose from 40.2% to 53.9%, while home deaths declined from 55.7% to 35.1% (Chiang & Kao, 2021). Traditionally, dying at home embodies the belief of luò yè guī gēn (落葉歸根, "fallen leaves return to the roots"), long regarded as a marker of a good death in Taiwan and other Chinese communities (Cheng et al., 2025). However, findings from this research indicate that what constitutes an appropriate place of death has become more flexible and situational, shaped by the patient's health conditions, family values, and the care options available. This variability has also been noted in previous studies (Miyashita et al., 2008b; Miyashita et al., 2007; Steinhauser, Christakis, et al., 2000). Families in my research who chose hospital care for its medical expertise and resources but still wished the patient could die at home often arranged symbolic compromises, such as enabling the patient to take their final breath at home, a practice that continues to be observed in Taiwan (Lin & Chou, 2024). These practices demonstrate how medicalisation and cultural values are continually negotiated as families seek to reconcile institutional realities with deeply rooted cultural expectations of a good death.

Summary

Religious and cultural beliefs continue to underpin Taiwanese understandings of a good death, shaping spiritual care, ritual obligations, and preparation for the afterlife. At the same time, legal and professional frameworks have introduced new emphases, such as autonomy, which coexist with and are reinterpreted through local values. These orientations are not simply oppositional but demonstrate how ritual, relational, and professional practices are woven together in end-of-life care. Although these dynamics are particularly visible in Taiwan, similar patterns can be observed elsewhere, such as in religious communities within Western societies that continue to value ritualised and relational forms of end-of-life care. Taken together, these findings highlight the importance of situation notions of a good death within their social and cultural contexts

(Zaman, 2025). Building on this, how emotional expression and continuing bonds are negotiated within these cultural and professional frameworks is explored in the next section.

9.4.3 Emotional restraint, continuing bonds, and bereavement continuity

Emotional restraint as a cultural practice

My findings show that the emotional restraint demonstrated by Taiwanese families during death preparation and bereavement should be understood as a culturally and religiously appropriate practice with multiple layers of meaning. Both the systematic review (Paper 1) and the qualitative interview study (Papers 2 and 3) found that families often suppressed overt expressions of grief during the dying process and funeral (Li et al., 2024). Drawing on Buddhism and Taiwanese folk religion, emotional restraint was interpreted as facilitating a smoother transition to the afterlife, consistent with earlier evidence from Hong Kong (Chow et al., 2006). Confucian familism (Badanta et al., 2022; Hwang, 1999) and collectivist values (Hofstede, 1984, 2001) further reinforced this norm. Emotional control was understood as a means of protecting the dying relative's peace, avoiding burdening others, and preventing loss of face (丟臉, diu lian, meaning "loss of dignity") in public, as also reported in other studies (Koo et al., 2006; Penson, 2004; Yick & Gupta, 2002). The appropriateness of emotional expression was context-dependent, negotiated relationally and situationally, and, as shown in other research, shaped more by cultural and religious expectations than by individual preferences (Bonanno et al., 2004; Westphal et al., 2010).

Taiwan's emphasis on emotional restraint contrasts with dominant Western bereavement models, which often assume that emotional release is inherently beneficial for adjustment (Lindemann, 1963; Parkes, 1985; Worden, 2018). These assumptions have also influenced Taiwanese professional practice. In the nominal group study (Chapter Seven), healthcare staff encouraged families to express their emotions openly but struggled to reconcile this approach with the families' cultural preferences for restraint. This reflects a professional dilemma in which clinicians recognise the importance of emotional support but find it challenging to offer in a way that aligns with cultural expectations of emotional restraint.

The practice of emotional restraint is not unique to Taiwanese families. A study in France, for instance, found that healthcare professionals caring for dying patients in nursing homes also regulated or suppressed their emotions, not because of cultural or religious norms, but as a strategy of self-protection to sustain their capacity to provide effective care (Umubyeyi et al., 2024). This comparison illustrates that while the meanings and functions of emotional restraint vary across contexts and groups, the practice itself is widespread, underscoring the need to move beyond simple cultural binaries.

Continuing bonds as a relational framework

Maintaining continuing bonds with the deceased relative was central to Taiwanese family death preparation and bereavement, as evidenced in both the systematic review (Paper 1) and the interview study (Papers 2 and 3). These findings suggest that the continuing bonds theory (Klass & Silverman, 1996; Steffen & Klass, 2018) resonates more strongly with Taiwanese practices than earlier detachment-based models (Bowlby, 1961, 1977). Developed in the United States and influenced partly by Japanese ancestor rituals (Klass, 1996), the theory highlighted the prevalence of ongoing connections with the deceased person. While Western evidence acknowledges that such bonds can be initiated before death (Hedtke & Winslade, 2004), they are typically framed as post-death and non-religious practices, such as remembering the deceased person (Supiano et al., 2020), engaging in inner dialogue, or keeping memory objects (Riegel et al., 2023). These interpretations reflect assumptions grounded in individualism and secularisation, which differ from Taiwanese understandings.

Findings from this research show that continuing bonds in Taiwan are broader and more encompassing, integrating pre-death, religious, and collective dimensions (Root & Exline, 2014). Families often initiate bonds before death (Hedtke & Winslade, 2004), treating them as part of preparing for a relative's death and extending them into the post-death period. While Western applications frequently highlight psychological or emotional connections through non-religious acts such as memory-making or legacy creation (Riegel et al., 2023), my research found that Taiwanese practices gave equal or greater weight to ritual and religious acts intended to enhance the deceased relative's afterlife. As shown in both the systematic review (Paper 1) and the interview study

(Papers 2 and 3), religious traditions strongly shaped these bonds. Families spoke with the dying relative about reunion in the afterlife based on their shared religious beliefs, such as the concept of yuán (緣), a key notion in Buddhism and a widely held belief in Chinese society that frames relationships as predestined and continuous (Chan et al., 2005; Lee et al., 2017). Ancestor worship, rooted in the Confucian principle of zhuīyuǎn (追遠, honouring one's ancestors), illustrates that bonds are not only emotional but also moral and relational obligations that extend filial duty beyond death (Hsu et al., 2009; Shih, 2010; Weller, 2020; Yao, 2000). Thus, in the Taiwanese context, continuing bonds are simultaneously emotional ties and expressions of religious beliefs, Confucian familism, and filial continuity (Badanta et al., 2022; Hwang, 1999).

Evidence on the role of continuing bonds in bereavement adjustment remains mixed (Benore & Park, 2004; Boelen et al., 2006; Field & Friedrichs, 2004; Stroebe et al., 2010; Worden, 2018). Some studies suggest that maintaining such bonds can be beneficial. For example, individuals may find comfort in believing that the deceased relative is free from suffering in the afterlife (Hung, 2013; Jung & Hung, 2017). Other research highlights potential risks, including difficulties in adapting to the loss (Carr & Sharp, 2014; Clarke et al., 2003) or greater emotional distress (Boelen et al., 2006; Field & Friedrichs, 2004). However, in my research, continuing bonds in Taiwan were generally associated with positive bereavement outcomes. This suggests that the meaning and function of continuing bonds are not universal but are shaped by cultural, religious, and social frameworks (Root & Exline, 2014).

Building on these findings, Taiwanese practices extend the continuing bonds theory (Klass & Silverman, 1996; Steffen & Klass, 2018) in two ways (**Table 12**): temporally, by establishing bonds before death as an integral part of family death preparation; and structurally, by embedding them in collective, moral, and religious obligations. These insights demonstrate that while the continuing bonds theory remains valuable for understanding Taiwanese bereavement, it requires adaptation to account for non-Western contexts where relational, cultural, and religious dimensions play a central role (Root & Exline, 2014).

Table 12: Extensions of the continuing bonds theory.

Dimension	**Original version**	**Taiwanese extensions**
Timing	Recognised mainly after death, framed as part of bereavement	Begin before death, integrated into family death preparation
Focus	Primarily psychological, emotional & individual	Collective, relational & religious
Form	Mainly non-religious (e.g., taking photos)	Combination of non-religious and religious (e.g., reunion conversations, offerings, rituals for the afterlife, ancestor worship)
Underlying assumptions	Individual autonomy, secular orientation, psychological internalisation	Interdependence, filial duty, and religious continuity (e.g., death as a transition rather than an endpoint)
Function	Bonds serve primarily as post-death adjustment processes	Bonds serve also as preventive strategies, and as moral/religious obligations

Bereavement as continuity of preparation and preventive care

Findings across all three studies in this thesis confirm that bereavement in Taiwan is not understood as a discrete stage beginning after death, but as the continuation of family death preparation. While similar perspectives have been discussed by some Western scholars (Lichtenthal et al., 2024), they remain underrepresented in mainstream bereavement theories. Most existing models conceptualise bereavement primarily as a post-death process of adaptation (Stroebe & Schut, 2010; Worden, 2018). As noted in the background chapter, these theories emerged largely from Western contexts and often emphasise psychological or social factors rather than collective and ritual obligations. Stage- and phase-based models, such as attachment and loss theory (Bowlby, 1961, 1977), stress emotional release and the resolution of grief through detachment from the deceased person. The dual process model (Stroebe & Schut, 1999, 2010) allows oscillation between loss- and restoration-oriented activities but still situates bereavement as beginning after death. Although the concept of anticipatory grief recognises pre-death responses (Nielsen et al., 2016), it focuses mainly on individual emotional adjustment to an expected loss and does not encompass the broader scope of family death preparation, including fulfilling obligations and preventing regrets, as found in my research.

Findings from my research further show that culturally appropriate family death preparation can function as a form of preventive bereavement care, shaping bereavement before death occurs. Western evidence seldom specifies which components of such preparation shape bereavement outcomes (Kim et al., 2017; Schulz et al., 2015), but these were identified in this research. As shown in the interview study (Papers 2 and 3), whether families fulfilled their responsibilities to the dying relative, minimised regret, and achieved a culturally appropriate good death influenced their bereavement experiences. Both the systematic review (Paper 1) and the interview study (Papers 2 and 3) showed that inadequate preparation, such as poor symptom control, limited participation in caregiving, or failure to make good end-of-life decisions and organise meaningful funerals, often led to feelings of regret, guilt, and self-blame, thereby complicating bereavement adjustment. By contrast, fulfilling familial obligations through decision-making, caregiving, dignified body handling, and ritual and funeral preparation enabled families to feel they had done their utmost, which in turn supported smoother bereavement.

These practices, including fulfilling familial obligations, minimising regret, and achieving culturally appropriate good death, can therefore function as preventive strategies that shape bereavement before death. Bereavement in Taiwan was thus evaluated through a moral lens, where adjustment depended on whether duties were fulfilled and regrets minimised. This moral framing reflects Confucian relational ethics (Badanta et al., 2022; Hwang, 1999), in which bereavement experiences are shaped by the fulfilment of obligations, offering an alternative moral and cultural perspective for understanding bereavement in palliative care.

Summary

The need to support families in bereavement is recognised in both Taiwanese and Western palliative care models (Chao, 2015; Ferrell et al., 2018; Radbruch et al., 2020).

Both approaches emphasise that poor bereavement outcomes can potentially be prevented through preparatory support before death (Lichtenthal et al., 2024). However, despite these similarities, their orientations also differ. In Taiwan, emotional restraint and continuing bonds are integral to this process, functioning as cultural and religious practices that connect family death preparation with bereavement. While Western bereavement models focus mainly on post-death adaptation, the Taiwanese case illustrates an alternative trajectory in which preparing for a relative's death, including caring for the dying relative and fulfilling familial obligations, is central. These findings underscore the importance of understanding bereavement within its social and cultural context and of developing bereavement care that aligns with local values and practices.

9.4.4 Structural and systemic influence on family death preparation

Legal frameworks and advance care planning

Taiwan's adoption of autonomy-centred models is most evident in its legal frameworks (Cheng et al., 2016). The Natural Death Act (2000) (Laws & Regulations Database of The Republic of China/Taiwan, 2000) and the Patient Right to Autonomy Act (enacted in 2016 and implemented in 2019) (Laws & Regulations Database of The Republic of China/Taiwan, 2019) enshrine the principle of patient choice at the end of life or when mental capacity is lost. However, these laws have been adapted through family involvement, reflecting Taiwanese culture, which values collective decision-making (Badanta et al., 2022). This pattern was also evident in my research. Unlike most Western contexts (Rietjens et al., 2017), the Patient Right to Autonomy Act requires at least one family member to participate in advance care planning consultations, consistent with Confucian expectations that decisions are shared with family members (Badanta et al., 2022; Hwang, 1999). Yet findings from the interview study (Papers 2 and 3) suggest that this design still underestimates the importance of maintaining harmony among relatives through consensus-building, which often takes precedence over individual preferences (Lee et al., 2024).

The Patient Right to Autonomy Act also stipulates that advance care planning consultations must take place in designated hospitals with specified professionals (a physician, nurse, social worker or psychologist). Participants in the nominal group study (Chapter Seven) expressed concern that these requirements risk reducing advance care planning to a procedural task rather than an ongoing dialogue. From the perspective of modernisation theory (Ntini, 2016; Tipps, 1973), these developments illustrate rationalisation and professionalisation, but also show how globalised norms are reinterpreted through cultural negotiation.

While advance care planning is designed to clarify individual preferences in case of lost mental capacity (Rietjens et al., 2017), Western scholars have critiqued it as overly future-oriented, noting that preferences can change over time and that not all patients lose decision-making capacity at the end of life (Malhotra et al., 2022; Morrison et al., 2021). Consistent with these critiques, findings from this research suggest that what patients and families need is better described as advance care preparation: an evolving process that supports ongoing conversations about future care, shared decision-making, and broader aspects of death preparation (Malhotra et al., 2022). This approach reframes advance care planning from static documentation of future preferences to a dynamic process of preparation.

Service design: Specialist-focused and hospital-centred palliative care

As shown in the nominal group study (Chapter Seven), the development of palliative care in Taiwan has been characterised by a strong emphasis on specialist and hospital-based services, with limited expansion of generalist and community-based care (Cheng et al., 2016). Generalist palliative care refers to care provided in non-specialist settings, where all clinicians are expected to possess basic palliative care competencies (Quill & Abernethy, 2013). Specialist palliative care, by contrast, focuses on complex cases and provides education and support for generalist providers (Gómez-Batiste et al., 2017; Quill & Abernethy, 2013). This pattern reflects the rationalisation of palliative care under modernisation, privileging institutional expertise and professional authority (Tipps, 1973), while narrowing the space for family- and community-based approaches that remain central to cultural understandings of end-of-life care in Taiwan.

This Taiwanese trajectory contrasts with international recommendations advocating integrated palliative care models that link hospitals, community, and primary care, balancing generalist and specialist roles according to the complexity of patients' and families' needs. The World Health Organisation (2014) and national strategies in countries such as the United Kingdom emphasise community-based and primary care-led palliative care as essential for equitable access and sustainability (Gómez-Batiste et al., 2017; Murray et al., 2015). Concentration of resources in hospitals and specialist services has consequently limited investment in primary and community-based palliative care capacity, a pattern also observed internationally (Murray et al., 2015; Quill & Abernethy, 2013).

Taiwan's Hospital at Home initiative, launched in 2024 (National Health Insurance Administration, 2024), aims to extend hospital-level services into patients' homes and residential institutions. However, by replicating hospital procedures within community settings, it risks reinforcing professional dominance rather than promoting meaningful community-embedded forms of care. These dynamics correspond closely to the relational and socio-structural domains of the Taiwanese model of family death preparation, as outlined in Section 9.2. While families view caring for a dying relative as a collective duty grounded in cultural and familial obligations, the healthcare system continues to privilege institutional and professional authority. This misalignment highlights the need for palliative and end-of-life care services that more effectively integrate the contributions of families, communities, and professionals.

Professional education and its limitations

Professional education and training in Taiwan reflect Western orientations toward scientific rationality and standardisation. One example is the Checklist of Good Death Preparation, developed more than two decades ago and still used in education and clinical practice. (Chao, 2000a, 2000b). The checklist includes items on body handling, religious rituals, and funeral arrangements, aligning with some cultural elements identified in the interview study (Papers 2 and 3). However, it omits aspects central to families, such as continuing bonds and afterlife preparation (Shih et al., 2009). Similarly, professionals in the nominal group study (Chapter Seven) acknowledged the importance of religion but rarely addressed it explicitly, often treating it as beyond their professional scope. This reflects a deeper tension: the dominance of scientific rationality in professional training tends to marginalise cultural, religious and afterlife concerns, even though families consistently view them as essential. At the same time, the checklist merges patient and family tasks, implicitly reflecting a collectivist orientation consistent with Confucian familism (Inglehart & Baker, 2000). This supports the empirical findings of this thesis, which emphasise that supporting the dying patient cannot be separated from supporting families in preparing for death.

Summary

Structural and systemic factors, including legal frameworks, institutional design, and professional training, have embedded autonomy, rationalisation, and professionalisation into Taiwanese palliative care. At the same time, these frameworks coexist with local cultural and religious traditions that emphasise family consensus, filial duty, and afterlife preparation. This coexistence generates tensions: autonomy-centred laws do not fully capture consensus-seeking practices; hospital policies marginalise family and community roles; and professional education often sidelines religion and the afterlife as beyond the scientific domain. These observations highlight the need to understand palliative and end-of-life care in Taiwan as shaped by the interaction between global frameworks and local cultural values, rather than as a straightforward adoption of Western models.

The findings in this section show that Taiwanese family death preparation is shaped by cultural, religious, relational, and systemic factors, while also incorporating elements of global palliative care. These dynamics highlight the importance of interpreting practices within their social and cultural contexts, demonstrating that similarities and differences with Western models emerge through ongoing processes of adaptation and negotiation. Building on these insights, the culturally situated findings are discussed in the next section to explore how they contribute to the global knowledge base of palliative care and bereavement.

9.5 Rethinking and decolonising palliative care and bereavement: Insights from Taiwanese practices

9.5.1 Rethinking palliative care and bereavement

Postmodern perspectives challenge modernist assumptions of a single trajectory of progress, typically characterised by secularisation, rationalisation, and individualisation (Jeong-ho & Naehui, 2022). Instead, they emphasise plurality and contextuality. Taiwanese practices exemplify alternative pathways that broaden the understandings of what palliative care and bereavement can mean in diverse settings. Rather than following a linear path toward secular modernity, Taiwanese approaches demonstrate how global models are integrated with local cultural traditions. The differences between Taiwanese and Western approaches to palliative care and bereavement can be synthesised across several key dimensions, as summarised in **Table 13**. This table draws together insights from Section 9.4 and my reflections on palliative care in both Taiwan and the United Kingdom, first introduced in the background chapter.

Table 13: Varied emphases in Taiwanese and Western approaches to palliative care and bereavement.

Dimension	Taiwanese context	Western contexts
Definition of a good death	Often relational, ritualised, afterlife-oriented (e.g., funeral rites)	Often individual-centred, with more emphasis on autonomy and control
Unit of care & Autonomy	Family frequently treated as the primary unit; decisions emphasise consensus	Patient usually treated as the primary unit; family supported but secondary to patient autonomy
Spirituality & Religion	Strongly embedded in religious beliefs and rituals; includes afterlife preparation; inpatient unit spaces adapted for post-death rituals	Spiritual care often secularised; more focus on existential meaning
Bereavement care	Preventive: family death preparation (e.g., minimising regret, fulfilling familial responsibilities, achieving a good death) shapes bereavement; emotional restraint viewed as protective and relational	More reactive: bereavement support often framed as post-death interventions (e.g., grief counselling); emotional release often assumed to be beneficial

Both Taiwanese and Western approaches to palliative care emphasise holistic care, recognising the need to address the physical, psychological, social, and spiritual dimensions (Radbruch et al., 2020; World Health Organisation, 2002). Yet the weight assigned to these dimensions differs. In much Western literature, autonomy and individual control are treated as central indicators of care quality (Meier et al., 2016). In Taiwan, greater priority is often placed on family consensus, cultural rituals, and religious frameworks (Badanta et al., 2022; Hwang, 1999). These patterns suggest that holistic care is not a universal checklist but must be interpreted through local priorities. From a postmodern perspective (Jeong-ho & Naehui, 2022), these distinct emphases represent equally valid expressions of holistic care.

Similar diversity appears in definitions of a good death, a central concern of palliative care worldwide (Radbruch et al., 2020; World Health Organisation, 2002). Taiwanese families emphasise family presence, bodily dignity, meaningful funerals, and the deceased person’s well-being in the afterlife, treating death as a transition rather than an end (Chan et al., 2005; Shih et al., 2009). In much Western literature, a good death is more often associated with autonomy and individual control, sometimes extending to debates on assisted dying (Howarth, 2007; Kehl, 2006; Meier et al., 2016). These are tendencies rather than absolutes: religious communities in Western societies also value ritual and spiritual continuity, while some Taiwanese families give greater weight to autonomy. From a postmodern standpoint (Jeong-ho & Naehui, 2022), these variations demonstrate that there is no single, universal definition of a good death but multiple culturally situated understandings (Zaman, 2025).

The family as a unit of care provides another illustration of diversity. In Taiwan, families are explicitly recognised as the primary unit of care (Chao, 2015), whereas in many Western systems the patient is treated as the main unit, with families supported in a secondary role (Rietjens et al., 2017). Both perspectives value family involvement but balance patient and family priorities differently. From a postmodern perspective (Jeong-ho & Naehui, 2022), whether care is family-centred or patient-centred should be viewed as reflecting culturally specific assumptions about personhood rather than as fixed opposites.

Spiritual care also highlights divergent emphases. In Taiwan, it is expressed through religious practices: Buddhist chaplains, ritual acts, and afterlife preparation are embedded in palliative care (Shih et al., 2009). Rituals such as support-chanting at the deathbed and the "lift send-off" are not peripheral but integral to how families and professionals approach death. In many Western contexts, spirituality is more often framed in existential or secular terms, with less focus on ritualised religious practices, particularly in clinical environments (Howarth, 2007; McNamara, 2001; Zaman et al., 2017). These contrasts demonstrate that spiritual care should reflect its cultural contexts, integrating ritual and religious elements where central and existential dimensions where more relevant.

As discussed in Section 9.4.3, bereavement in Taiwan is understood as preventive. Poor bereavement outcomes can be avoided through how families prepare, care, and fulfil familial obligations before death. Emotional restraint and continuing bonds are integral to family death preparation rather than confined to post-death adjustment. These orientations, though not repeated here in detail, exemplify how culturally grounded values produce alternative pathways that challenge assumptions embedded in mainstream Western bereavement theories.

In sum, Taiwanese practices highlight that autonomy, holistic care, definitions of a good death, family involvement, spirituality, and bereavement care are not universal categories but culturally negotiated. Postmodern perspectives (Jeong-ho & Naehui, 2022) encourage recognition of these variations not as deviations from a norm but as plural expressions of what palliative care and bereavement can mean. This provides a foundation for questioning the universal authority of Western frameworks and rethinking them as culturally specific approaches situated alongside others.

9.5.2 Decolonising palliative care and bereavement

Palliative care and bereavement cannot be grounded in a single universal framework (McNamara, 2001; Zaman et al., 2017). Instead, they are culturally situated practices, and Taiwanese experiences provide a critical lens through which to challenge and enrich global models. Findings from my research suggest that culturally appropriate palliative care in Taiwan is characterised not only by the relief of suffering through holistic care, but also by family-centred decision-making, fulfilment of caregiving obligations, and the integration of religious and ritual practices that address both bereavement and the afterlife. In this sense, Taiwanese practice represents a rebalancing of shared elements shaped by local cultural and religious values. While the core elements of palliative care and bereavement, such as holistic approaches, the pursuit of a good death, family support, spiritual care, and bereavement care, are widely shared, their relative emphasis differs across contexts. From a postmodern perspective (Jeong-ho & Naehui, 2022), this underscores the need to question the universal claims of Western frameworks and to understand them instead as culturally specific.

Decolonising palliative care and bereavement does not mean rejecting Western models but decentring them by repositioning them as one set of culturally grounded approaches among many and treating them as equally valid contributions (Hamilton et al., 2022). This shift requires moving from exporting Western norms to fostering dialogue across cultural contexts. Rather than focusing solely on adapting Western frameworks, decolonising approaches recognise local traditions, values, and beliefs as integral to the global knowledge base of palliative care and bereavement (Rosa et al., 2022; Sallnow et al., 2022). In this regard, cultural humility offers a more appropriate orientation (Foronda et al., 2016). Unlike the notion of cultural competence, which assumes cultural knowledge can be mastered and risks reducing culture to a checklist of practices (Schuster-Wallace et al., 2022), cultural humility emphasises continuous self-reflection, recognition of power imbalances, and openness to learning from families as co-experts in shaping care (Foronda et al., 2016). Applied to the Taiwanese context, this means acknowledging that practices such as consensus-based decision-making, ritual engagement, emotional restraint, and continuing bonds are not peripheral but central to how families define appropriate preparation for death and bereavement.

At the same time, decolonising approaches to palliative care and bereavement must avoid oversimplification. Cultural sensitivity should not collapse into a binary of individualism versus collectivism, as this risks reinforcing stereotyping (Schuster-Wallace et al., 2022). Individualist societies include people who value family-based decision-making, just as collectivist societies include those who prioritise personal choice (Hofstede, 2001). Recognising this fluidity prevents cultural values from being essentialised and highlights the diversity that exists both across and within societies. Framing Taiwanese practices in this way reinforces that they do not stand in opposition to Western models but illustrate how different cultural contexts generate distinctive emphases, all of which hold value for global understandings of care.

Nevertheless, the model proposed in this thesis is not without limitations. With ongoing globalisation and increasing Western influence, questions remain as to whether it can retain cultural sensitivity and adapt to future shifts in social structures and values. From a postmodern perspective (Jeong-ho & Naehui, 2022), such diversity and fluidity should be viewed as normative rather than exceptional. Taiwanese practices, therefore, not only critique Western universalism but also exemplify how plural and context-specific approaches can enrich global understandings of palliative care and bereavement. This analysis underscores the need for decolonising approaches that recognise local values and practices as central in shaping care. In doing so, it repositions Taiwanese experiences as valid forms of knowledge and provides a foundation for the next section, which outlines the thesis's original contributions to knowledge, clinical practice, and methodology.

9.6 Original contributions to knowledge, clinical practice, and methodology

The original contributions of this thesis to knowledge, clinical practice, and research methodology in palliative and end-of-life care are outlined in this section (**Table 14**). A key contribution is the development of a culturally grounded conceptual model of family death preparation in Taiwan, which integrates clinical, relational, cultural-religious, and socio-structural dimensions. This model provides a reference point for future comparative research and offers new insights into Western frameworks by presenting a culturally nuanced account of how preparation is enacted in Taiwan. In particular, it demonstrates a continuum of preparation extending from the pre-death phase through the dying process, the funeral, and the afterlife. This trajectory, shaped by Confucian values, religious beliefs, and collectivist social structures, is absent from existing Western models (Durepos, Ploeg, Sussman, et al., 2020; Durepos et al., 2019; Hebert et al., 2006; Hebert et al., 2009), which focus primarily on the pre-death stage.

The Taiwanese model also shows that family death preparation is influenced not only by cultural traditions but also by broader socio-structural factors, including government policy, legislation, and the education and training of healthcare professionals. This perspective extends beyond Western approaches, which tend to focus either on the healthcare system (Hebert et al., 2006; Hebert et al., 2009) or on families' coping strategies (Durepos, Ploeg, Sussman, et al., 2020; Durepos et al., 2019). These findings highlight dimensions often overlooked in Western frameworks and provide a culturally grounded understanding of how families prepare for a relative's death. They contribute to global knowledge and inform clinical practice, particularly in non-Western contexts.

Another important contribution is the reframing of palliative care practices by emphasising the centrality of family involvement, the enduring role of religion, and culturally specific interpretations of a good death (Schuster-Wallace et al., 2022). In Taiwan, end-of-life decision-making is family-centred, consensus-oriented, and protective of the dying relative, offering a culturally specific interpretation of relational autonomy. The concept of a good death is expanded to include not only the dying process but also funeral rituals and the afterlife, underscoring the significance of religious belief (Chan et al., 2005; Shih et al., 2009). These findings challenge the assumed universality of dominant Western palliative care paradigms and contribute to global debates on how palliative care systems can be made more culturally responsive and inclusive.

Findings from this thesis also contribute new perspectives on bereavement support and theory. They show that bereavement in Taiwan is understood as a continuation of family death preparation, where pre-death practices, such as ensuring the dying relative's comfort, fulfilling obligations, avoiding regret, and achieving a good death, shape post-death bereavement outcomes. These findings indicate that culturally embedded family death preparation can function as a proactive and preventive form of bereavement care before death occurs (Lichtenthal et al., 2024). Furthermore, emotional restraint, often viewed negatively in Western contexts (Lindemann, 1963; Parkes, 1985; Worden, 2018), is shown in Taiwan as a culturally and religiously appropriate practice that supports both relational harmony and the dying person's peace before and after death. Together, these insights extend Western bereavement theories, which have focused primarily on post-death interventions (Stroebe & Schut, 2010; Worden, 2018), by highlighting the importance of culturally embedded practices and the need for frameworks that recognise variation in how grief is expressed.

The findings further extend the continuing bonds theory (Klass & Silverman, 1996; Steffen & Klass, 2018) by showing that connections with the deceased relative are not only maintained after death but also actively cultivated before death as part of family death preparation. In Taiwan, such bonds are embedded in cultural and religious values and practices, broadening the continuing bonds theory beyond its individual and psychological focus. This provides a more culturally responsive understanding of bereavement and underscores the importance of recognising these practices in clinical care.

On a methodological level, my research demonstrates the value of the nominal group technique (Jünger & Payne, 2020) for developing practice-oriented recommendations in collectivist societies. Based on methodological reflections on its application in palliative care research, several challenges were identified. These included the limited use of pilot meetings, insufficient analysis of qualitative data, and the underestimation of cultural influences. The research offers practical guidance for future research, emphasising the need to conduct pilot meetings, account for cultural factors, and adopt a more interpretative qualitative approach to analysing group meeting discussions.

In sum, this culturally contextualised research provides a comprehensive understanding of how families in Taiwan prepare for a relative's death, moving beyond Western-oriented evidence. It contributes to knowledge by developing a new conceptual model, to practice by reframing family involvement, religion, and bereavement support, to theory by extending the continuing bonds framework (Klass & Silverman, 1996; Steffen & Klass, 2018), and to methodology by critically reflecting on the use of the nominal group technique (Jünger & Payne, 2020). These contributions offer new conceptual, practical, and methodological insights that enrich global understandings of palliative and end-of-life care. In the following section, the strengths and limitations of this thesis are discussed.

Table 14: Summary of original contributions of this thesis to knowledge, clinical practice, and research methodology.

Domain	Key contributions	Reference
Knowledge	• Developed a Taiwan-specific conceptual model of family death preparation (clinical, relational, cultural-religious, socio-structural, bereavement domains) • Identified a continuum of preparation from pre-death to afterlife • Demonstrated specific components of family death preparation shape bereavement: reducing regret & achieving a good death	Papers 1, 2, 3 & Chapter Seven
Clinical practice	• Reframed palliative care practice by emphasising family centrality and religious beliefs • Broadened the concept of a good death to include funeral rituals and afterlife considerations • Provided culturally specific interpretations of relational autonomy (family-centred, consensus-oriented, protective end-of-life decision-making) • Contributed to global debates on making palliative care models more culturally responsive and adaptable	Papers 2, 3
Bereavement care	• Extended bereavement care by framing pre-death preparation as preventive support (e.g., fulfilling obligations, making good end-of-life decisions) • Highlighted emotional restraint as culturally and religiously appropriate	Papers 1, 2
Theory	• Extended the continuing bonds theory by showing bonds cultivated during dying, embedded in religious beliefs and rituals	Papers 1, 3
Methodology	• Demonstrated the use of the nominal group technique in collectivist societies • Provided critical reflections and practical guidance on the culturally sensitive application of the nominal group technique	Paper 4

9.7 Strengths and limitations of the thesis

The strengths and limitations of the systematic review and the qualitative interview studies have been discussed in Papers 1 (Chapter Four), 2 (Chapter Five), and 3 (Chapter Six). This section focuses on the strengths and limitations of the nominal group technique study (Chapter Seven), while also considering the overarching strengths and limitations of the thesis as a whole.

9.7.1 Strengths of the thesis

A key strength of this thesis is the use of a sequential, multi-method design to explore the complexity of family death preparation. Three studies, using different methods and perspectives, were conducted to address the overarching research question: "How can families in Taiwan better prepare for the death of a relative?" This design enabled a multidimensional understanding of the topic from diverse stakeholder perspectives and allowed findings from each study to inform the next.

The systematic review (Paper 1), conducted using a narrative synthesis approach (Popay et al., 2006), examined family death preparation from retrospective perspectives, focusing on families' bereavement experiences following a relative's death. By including qualitative, quantitative, and mixed-methods studies published in both English and Traditional Chinese, the review broadened the evidence base and provided a culturally inclusive synthesis. The findings identified family death preparation as a vital factor influencing bereavement outcomes in Taiwan, but also revealed limited clarity regarding which specific components of preparation shape post-death adjustment. This gap underscored the need for further empirical research and informed the design of the qualitative interview study.

The qualitative interview study (Papers 2 and 3), analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2022b), explored how families prepared for a relative's death. Recruiting participants from multiple regions of Taiwan enhanced the diversity of the dataset and strengthened the transferability of the findings to other family-centred cultural contexts. The study also identified the pivotal role of healthcare professionals in supporting families during death preparation, highlighting the need to include professional perspectives. This insight informed the design of the subsequent nominal group technique study.

The nominal group technique study (Chapter Seven) engaged specialist palliative care professionals from multiple disciplines, including medicine, nursing, psychology, and chaplaincy, across hospitals in different regions of Taiwan. The disciplinary and geographic diversity of participants provided valuable insights into the personal, structural, societal, and institutional factors shaping professional roles in supporting families. This study broadened the understanding of family death preparation by incorporating socio-structural dimensions and generated practice-oriented recommendations to strengthen support for families in the Taiwanese context.

A dedicated methodological paper (Paper 4) provided a critical reflection on the use of the nominal group technique (Jünger & Payne, 2020) in palliative care research. It identified both the value and challenges of applying this method in collectivist settings and underscored the need for culturally sensitive adaptations. This reflection adds a distinctive methodological contribution to the thesis, highlighting not only significant findings but also innovations in research design and practice.

Another major strength is the sustained commitment to cultural and linguistic sensitivity throughout the research process. The researcher’s clinical, cultural, and academic background facilitated rapport-building and enabled meaningful data collection (Krys et al., 2025). All interviews and nominal group discussions were conducted in participants’ native languages (Traditional Chinese and Taiwanese), allowing the expression of culturally embedded concepts. Several strategies were employed to preserve linguistic nuance, including delaying translation into English until the later stages of analysis and retaining selected Traditional Chinese terms in the presentation of findings. A bilingual supervisor supported the interpretation of language-specific meanings, enhancing both the rigour and cultural sensitivity of the analysis.

Overall, the sequential multi-method design, combined with methodological innovation and cultural-linguistic sensitivity, represents a rigorous and original approach in palliative and end-of-life care research. These features enhance the originality, rigour, and transferability of the findings. In addition to these strengths, several limitations of the thesis are discussed below.

9.7.2 Limitations of the thesis

Several limitations should be acknowledged to contextualise the findings. While the Taiwanese setting enabled a rich, in-depth exploration of family death preparation in a non-Western context, this cultural specificity may limit the transferability of findings to societies where the role of the family and collectivist values are less pronounced. In addition, all three studies focused on expected deaths, which may also limit their relevance to unexpected deaths, such as suicide.

From a methodological perspective, the systematic review (Paper 1) focused on Taiwanese families living in Taiwan and did not include those residing overseas, whose bereavement experiences may differ due to the influence of other social and cultural environments (Bennett et al., 2018; Fang et al., 2015). Although this focus enhanced the review's relevance to the Taiwanese context, it excluded the voices of Taiwanese families abroad. While a second reviewer participated in article screening, data extraction, analysis, and synthesis were conducted solely by the researcher. This single-researcher approach may have influenced the rigour of the review, although this was mitigated through ongoing discussion and critical feedback from supervisors. The review was underpinned by a critical realist position (Bhaskar, 2008), which assumes that reality exists but is context-dependent. Therefore, the findings should be interpreted as shaped by both available evidence and the Taiwanese cultural setting.

The qualitative interview study (Papers 2 and 3) also has several limitations. It included only bereaved family caregivers whose relatives had received specialist palliative care, thereby excluding those in non-specialist settings, which may limit understanding of experiences in contexts with fewer palliative care resources or support. The retrospective design also limits the transferability of findings to families currently undergoing death preparation. Participants' memories may have been influenced by their later perceptions of the patient's dying process and death, feelings of regret, or retrospective justification of past decisions. Nevertheless, bereaved family caregivers were uniquely positioned to reflect on the full trajectory of preparation, and reflexive thematic analysis (Braun & Clarke, 2006, 2022b) enabled an in-depth exploration of their experiences. Variation in participants' relationships with the deceased relative (e.g., adult child, spouse, sibling) and in diagnoses (cancer and non-cancer) may limit the applicability of findings to particular groups, as the study did not focus on any specific relationship or diagnostic category. Recruitment through specialist palliative care teams may also have resulted in participants who were more likely to report positive experiences, potentially underrepresenting more distressed or marginalised voices. In addition, the study did not include participants from ethnic minority groups in Taiwan, such as Indigenous peoples and new immigrants who have settled and obtained legal residence or citizenship through marriage, naturalisation, or other migration pathways (Kasai, 2022). Immigrants' beliefs and practices around death and dying are often shaped by both their culture of origin and that of their new country, which can make their experiences particularly complex (Bennett et al., 2018; Bowman & Singer, 2001; Fang et al., 2015).

The nominal group technique study (Chapter Seven) was limited to healthcare professionals working in specialist palliative care. The absence of participants from non-specialist palliative care settings, such as primary care, intensive care units, or long-term care, restricted the diversity of perspectives and may have oriented recommendations more strongly toward specialist service models. Moreover, as the study involved only Taiwanese professionals, the recommendations generated reflect the norms, policies, and legal frameworks of Taiwan's healthcare system, which may limit their applicability to other national or cultural contexts. While framework analysis (Parkinson et al., 2016; Ritchie & Spencer, 2002) strengthened the practical orientation of the findings, they remain contextually specific.

Finally, despite efforts to preserve cultural and linguistic meanings, the potential for subtle meaning loss during translation should be acknowledged. The systematic review (Paper 1) included articles written in Traditional Chinese, and all qualitative data were collected in either Traditional Chinese or Taiwanese. Translation into English was intentionally delayed until the later stages of analysis, and key Chinese terms were retained to preserve cultural nuance. Nevertheless, some meanings may not have been fully conveyed in the English presentation of findings. At the same time, retaining

Traditional Chinese terms strengthened the thesis's cultural integrity by reflecting concepts deeply embedded in the Taiwanese language and practices.

Taken together, these limitations reflect the inherent challenges of conducting culturally grounded, multilingual qualitative research on end-of-life issues. They highlight the difficulties of conveying culturally embedded meanings across languages and academic traditions. Recognising these limitations helps situate my contribution within their appropriate context and underscores the importance of interpreting the findings with cultural sensitivity. These reflections also point to directions for future research, which will be discussed in the concluding chapter.

9.8 Reflexivity in interpreting the findings

As discussed in the methodology and methods chapter, my subjectivity, shaped by my multiple positionings, including being Taiwanese, a family member who has experienced the death of close relatives, a specialist palliative care nurse trained primarily through Western evidence, and a PhD student trained in the United Kingdom, influenced the research design, data collection, and analysis. It also shaped how I interpreted the findings and engaged with culturally situated meanings of family death preparation.

Drawing on both my cultural background and clinical lens, I was able to recognise and interpret deeper meanings in data from the systematic review, the qualitative interview study, and the nominal group technique study (Krys et al., 2025). These perspectives informed my understanding of families' experiences and professionals' recommendations. At the same time, my clinical experience could have narrowed my focus, leading me to rely too heavily on practice-based knowledge rather than critically engaging with theoretical perspectives. Interpreting the findings as an insider, therefore, required continuous reflexive effort. I frequently reflected on whether my cultural and clinical viewpoints were taking precedence over theoretical analysis or introducing assumptions that were culturally incongruent. Ongoing engagement with relevant literature and regular supervisory discussions supported this reflexive process and strengthened the cultural sensitivity and trustworthiness of the analysis.

Although I share cultural values such as filial piety, family harmony, and belief in the afterlife with many participants, I was initially unaware of how deeply these values shaped their approaches to preparing for a relative's death. Conducting the research helped me recognise important differences between Taiwanese practices and dominant Western palliative care models, particularly regarding the role of the family, religion, and interpretations of a good death. For example, I had not anticipated that a culturally appropriate death in Taiwan extends beyond the dying process to include funeral rituals and efforts to ensure the deceased relative's afterlife. Similarly, the systematic review and interview study deepened my understanding that emotional restraint, such as avoiding loud crying or overt displays of grief, should be interpreted as a culturally and religiously appropriate practice rather than a lack of emotional engagement. My experiences visiting and volunteering in hospices in the United Kingdom also highlighted cultural contrasts in practice. For instance, in Taiwan, ensuring that the eyes of the deceased person are closed holds profound cultural significance, whereas in the United Kingdom, this detail carries little meaning.

This reflexive process became more personal when I experienced the unexpected loss of my mother while completing the thesis. This bereavement made the research both more emotionally challenging and more meaningful. I remained attentive to my emotional responses during writing and sought support from my supervisors and through short-term bereavement counselling. Having engaged in advance care planning with my mother and discussed her end-of-life and funeral preferences, my family and I were able to make decisions aligned with her wishes, including the decision to withhold dialysis. This experience deepened my appreciation of the significance of family death preparation and the role of minimising regret in bereavement. Families in the interview study often described how regret, if not addressed before death, can intensify grief afterwards. My own bereavement experience reinforced this insight and strengthened my empathy for the families who shared their stories. In addition, my involvement in my mother's care in the intensive care unit resonated with the findings of the nominal group technique study, particularly the concern that end-of-life care in non-palliative care settings, especially intensive care units, may be insufficient. This personal experience helped me understand more deeply the implications of my research findings for clinical practices.

Overall, this reflexive process enabled me to balance academic rigour with cultural sensitivity and to navigate the complexities of my subjectivity, shaped by my multiple positionings. It also enhanced the trustworthiness of the research by ensuring that interpretations were critically examined rather than taken for granted. Ultimately, reflexivity contributed to a richer, more contextually grounded account of family death preparation in Taiwan.

Building on the discussion in this chapter, the implications for future research, clinical practice, and policy are presented in the next chapter.

CHAPTER 10: CONCLUSION

The key findings, theoretical interpretation, and original contribution of this thesis have been presented in the discussion chapter. Based on these, a discussion of its implications for future research, clinical practice, education, and policy is outlined in this concluding chapter.

10.1 Areas for future research

Building on the findings and limitations of this thesis, several areas require further investigation within Taiwan and internationally. Although the research was conducted in Taiwan, its insights resonate across diverse cultural contexts, highlighting the need to expand understanding beyond Confucian societies and Western frameworks (Krys et al., 2025). A first priority is to examine family death preparation in other non-Western contexts to develop a more inclusive evidence base. Comparative studies involving East Asian populations, as well as Taiwanese and Chinese communities living in Western societies, could show how cultural values and healthcare systems shape preparation practices in different settings. Such work would generate culturally sensitive evidence and help to decolonise and decentre Western palliative care models (Rosa et al., 2022; Sallnow et al., 2022).

To deepen understanding of family death preparation in Taiwan, research should extend beyond the current focus on bereaved caregivers. It should include specific relational groups such as spouses and adult children, caregivers of individuals with conditions like dementia, families without access to specialist palliative care, and those in resource-limited settings (Durepos, Ploeg, Sussman, et al., 2020). Prospective longitudinal studies that follow families through the end-of-life trajectory are also needed to complement retrospective accounts and reveal how decision-making, caregiving roles, and emotional support develop over time (Nielsen et al., 2016). It is also important to include the perspectives of Indigenous peoples and new immigrants, whose beliefs and practices around end-of-life care may differ significantly (Bennett et al., 2018; Fang et al., 2015).

The tension between culturally embedded family practices and professional practices shaped by Western-oriented training also requires deeper exploration. Closely related is the issue of autonomy. The findings underscore that family involvement and consensus-building are central to end-of-life decision-making in Taiwan, reflecting a relational interpretation of autonomy that differs from individualistic Western models. Future studies engaging patients, families, and professionals could clarify how autonomy is enacted in collectivist contexts, contributing to global debates on relational autonomy (Gómez-Vírseda et al., 2019; Tan Kiak Min, 2017). In addition, further attention is needed to develop culturally appropriate emotional support strategies in Buddhist or collectivist settings, where emotional restraint may be regarded as appropriate (Lai et al., 2021). The perspectives of children and adolescents also remain underexplored in this topic, yet their roles in family-centred preparation in collectivist societies deserve closer study (Shih, 2010).

Future inquiry should also move beyond description to develop culturally grounded indicators and measurement tools for the evaluation of palliative and end-of-life care. Key elements of effective family death preparation were identified. These included achieving a culturally appropriate death, minimising bereavement-related regrets, and addressing broader structural influences such as professional education, continuity of end-of-life care, government policy, research investment, and public awareness. Evaluating these elements as quality indicators could strengthen palliative and end-of-life care in Taiwan and contribute to international debates on care quality standards (De Roo et al., 2013; Finkelstein et al., 2022).

Several emerging areas also deserve further exploration. Continuing relationships with the deceased relative were found to be central to family death preparation and bereavement in Taiwan, highlighting the relevance of the continuing bonds theory (Klass & Silverman, 1996; Steffen & Klass, 2018). Future work could explore how such relationships can be supported prior to death to promote positive bereavement outcomes. Emerging technologies such as artificial intelligence are beginning to shape new forms of remembrance and communication with the deceased person (Kawashima et al., 2023; Manevich & Aluma, 2025). Although this topic has not yet received sufficient attention, understanding how families interpret and use these technologies within their cultural and religious frameworks will be important for future palliative care and bereavement research. Research should also explore the potential benefits and ethical implications of these developments.

10.2 Implications for clinical practice

The findings have several implications for clinical practice. First, they highlight the importance of cultural humility and sensitivity in end-of-life care (Foronda et al., 2016). Recognising diversity among patients and families, maintaining openness, and showing respect are essential to ensure that high-quality palliative care reflects local values and beliefs. Evidence from Taiwan provides a valuable foundation for decolonising palliative care and prompting culturally responsive practice (Rosa et al., 2022; Sallnow et al., 2022). The study offers culturally grounded guidance for healthcare professionals in Taiwan and can also inform practice in other East Asian contexts, among Asian populations living in the West, and in any care settings where family-centred and collectivist values are important.

A key implication of this research is that family death preparation extends beyond the dying process into the funeral and even the afterlife. The findings reveal that, in Taiwan, rituals such as preparing the body, arranging meaningful funerals, and ensuring the deceased person’s well-being in the afterlife were integral to families’ understandings of a good death. These insights underscore the need for clinicians in any context to explore and respect culturally specific beliefs about death, including afterlife expectations and ancestor honouring. Such beliefs shape how families define a good death and approach dying. Healthcare professionals should actively understand and incorporate these perspectives into care, recognising that definitions of a good death vary widely across cultures (Zaman, 2025). Such cultural values also influence how families engage in decision-making and communication at the end of life.

End-of-life decision-making likewise requires cultural sensitivity. The findings indicate that, in Taiwan, family-centred, consensus-oriented, and protective approaches were often prioritised, with shielding the dying person from emotionally distressing conversations viewed as an act of care. Similar collective or protective decision-making patterns are reported in other collectivist societies, such as East Asia (Matsumura et al., 2002; Mo et al., 2012). For clinicians working in multicultural Western contexts, these examples highlight that respect for patient autonomy should be applied flexibly. When direct communication with the patient is not possible or when excluding the patient is culturally appropriate, healthcare professionals should support families in making decisions aligned with the patient’s known or inferred preferences, while navigating family dynamics and seeking consensus. Facilitating family meetings is a useful strategy for culturally sensitive decision-making and should be supported through multidisciplinary collaboration (Hudson et al., 2008). Multidisciplinary teamwork is also vital in helping families prepare for a relative’s death, as such preparation spans clinical, relational, cultural, and spiritual dimensions that require coordination across medicine, nursing, psychology, social work, and chaplaincy (Fernando & Hughes, 2019).

Another important implication is that family death preparation can function as a form of pre-death bereavement support. The findings suggest that minimising regret, fulfilling familial obligations, ensuring the dying person’s comfort, and achieving a good death were viewed as ways to prevent poor bereavement outcomes. Continuing bonds with the deceased relative were often cultivated before death through both religious and non-religious practices. These insights suggest that bereavement support need not be confined to the post-death period. Integrating culturally appropriate forms of family death preparation into anticipatory grief support could strengthen end-of-life and bereavement care globally (Lichtenthal et al., 2024).

Emotional expression also requires careful interpretation. The findings highlight that, in Taiwan, emotional restraint, such as avoiding overt display of grief, was often understood as protecting the dying person and ensuring their peace both before and after death. Clinicians should recognise that such restraint may be culturally appropriate in certain contexts and avoid pathologising it. Instead, they can create supportive environments that respect these expressions, whether through ritual facilitation or quiet presence. Recognising these culturally grounded forms of emotional expression is also vital for providing sensitive bereavement support.

Overall, while grounded in the Taiwanese context, the findings of this study illustrate broader principles for clinical practice in multicultural settings. Clinicians should explore culturally specific definitions of a good death, adapt medical decision-making approaches to local contexts, and recognise diverse emotional expressions, including restraint, as culturally meaningful. Such principles are fundamental to providing culturally responsive palliative and end-of-life care, not only in East Asian societies but also in increasingly multicultural healthcare systems worldwide.

10.3 Implications for professional education

Professional education and training in palliative and end-of-life care should prioritise cultivating cultural humility and sensitivity (Foronda et al., 2016). Rather than assuming the universality of Western models, training programmes need to help healthcare professionals recognise that high-quality care must reflect patients' and families' social and cultural values. In Taiwan, for example, a culturally appropriate good death is defined not only by comfort during the dying process but also by the performance of funeral rituals and beliefs about the afterlife. Integrating these culturally specific understandings of a good death into curricula reminds trainees that diverse values should be elicited and respected in all care settings.

To cultivate cultural humility effectively, training should encourage healthcare professionals to engage in reflexivity and self-awareness, both central elements of practising cultural humility (Foronda et al., 2016). Trainees should be guided to reflect on their own cultural assumptions, values, and emotional responses when working with death and bereavement, particularly when caring for patients, families, and colleagues from diverse backgrounds. Embedding reflective practice into education can strengthen self-awareness and enhance professionals' ability to deliver culturally sensitive care. Such approaches are equally relevant in multicultural Western contexts, where clinicians encounter patients and families with diverse cultural and religious expectations. The findings from this thesis provide a foundation for developing culturally tailored education that incorporates these principles into palliative and end-of-life care training, both in Taiwan and in multicultural Western settings.

Education should further prepare healthcare professionals to work with patients and families from backgrounds that value family-centred and consensus-based decision-making. The findings indicate that, in Taiwan, achieving family consensus to maintain harmony and protecting the dying relative from emotional distress were often prioritised over individual autonomy. Rather than viewing this as a departure from good practice, educators can use such examples to teach the concept of relational autonomy, where individual choices are understood within family relationships and cultural contexts (Donchin, 2001; Gómez-Vírseda et al., 2019). The findings can also inform training that equips professionals with the skills to navigate complex end-of-life decision-making in Taiwan, across East Asia, and in multicultural Western settings. When direct communication with the patient is not possible or when excluding the patient is culturally appropriate, education should focus on equipping professionals' ability to engage families effectively, understand and respect patients' preferences through family input, and facilitate consensus-building in a culturally sensitive manner.

Another area for professional education concerns emotional expression and bereavement. The findings highlight that emotional restraint was often viewed as an appropriate cultural and religious response in Taiwan. Training should therefore emphasise the importance of recognising diverse emotional expressions and challenge the assumption that open expression is the only beneficial form of adjustment (Bonanno et al., 2004; Westphal et al., 2010). Educational approaches should instead focus on understanding how emotional expression is shaped by cultural contexts, an insight that is particularly relevant in today's diverse healthcare environments.

In summary, education and training in palliative and end-of-life care should enable healthcare professionals to cultivate cultural humility, recognise cultural diversity in definitions of a good death, navigate family-centred decision-making where appropriate, and respect varied forms of emotional expression. Developing these competences is vital for delivering culturally responsive palliative and end-of-life care, not only in East Asian contexts but also in multicultural healthcare systems worldwide.

10.4 Implications for policy

The four finalised recommendations developed from the nominal group technique study (Chapter Seven) have important implications for policy. They indicate that supporting families in preparing for a relative's death requires a multidimensional approach across four interrelated levels: individual, systemic, societal, and national, as presented below.

At the individual level, policy should focus on strengthening healthcare professionals' competencies in palliative and end-of-life care. This includes ensuring the provision and access to targeted education and training that develop clinical skills, cultural sensitivity, and communication competence for engaging patients and families in end-of-life discussions. The findings suggest that such training could be incorporated into national education standards and supported through continuing professional development policies to enhance professionals' competence and ensure consistent care quality.

At the systemic level, policies must address the organisation and accessibility of palliative and end-of-life care services within healthcare systems by embedding inclusive service design, evaluation, and funding criteria (Gómez-Batiste et al., 2017). Equitable access to services across all care settings, including non-specialist palliative care units, primary care, community facilities, and rural or underserved areas, is essential to ensure that families can participate meaningfully in this process, regardless of their location or care context. Policies should also ensure inclusivity and equitable provision of services for diverse social groups, including ethnic minorities and marginalised communities, whose needs and experiences of death and bereavement may differ from majority cultural norms (Bennett et al., 2018; Fang et al., 2015). System-level policies should further promote interdisciplinary collaboration to ensure continuity of care across settings and among professional groups.

At the societal level, the recommendations highlight the importance of improving public death literacy to encourage more open and informed conversations about death and dying. Public education campaigns, community-based programmes, and media engagement can help normalise discussions about dying, reduce stigma, and enhance families' readiness for the emotional, relational, and cultural-religious dimensions of death preparation. These initiatives require sustained policy support and collaboration among government, healthcare providers, and community or religious organisations to ensure continuity and long-term engagement in prompting public awareness of death, dying, and bereavement.

At the national level, strong government leadership is critical to embed family death preparation within broader health and social policy agendas. National strategies should prioritise equitable access to professional training and continuing education on palliative and end-of-life care, expansion of services across care settings, and investment in culturally relevant research. National quality assurance frameworks should also include measurable indicators of family death preparation and bereavement-related outcomes. The findings of this study demonstrate that culturally appropriate family death preparation, such as ensuring the dying person’s comfort, fulfilling caregiving responsibilities, and minimising regret, can serve as family-centred outcomes for evaluating the quality of palliative and end-of-life care. These culturally grounded indicators are often overlooked in existing literature (Pasman et al., 2009). For instance, a recent cross-national study assessing the quality of death and dying, which included Taiwan, did not incorporate bereavement-related indicators such as regret, duty fulfilment, or cultural appropriateness (Finkelstein et al., 2022). Integrating bereavement-related measures into national quality assessment frameworks would broaden evaluation beyond patient-focused and process-based outcomes to include family-centred and culturally responsive indicators. Such an approach would acknowledge families as central participants in end-of-life care and ensure that their experiences are reflected in system-level assessments of care quality.

These policy recommendations provide a foundation for policymakers to strengthen professional training, clinical practice, policy development, and public awareness surrounding death and dying in Taiwan, thereby strengthening families' capacity to prepare for a relative’s death. Although developed within the Taiwanese context, these policy directions may also inform approaches in other Asian and collectivist societies. Implementing these multilevel strategies could help establish family death preparation as a core component of high-quality, culturally responsive palliative and end-of-life care.

10.5 Concluding remark

I set out to explore how families in Taiwan can better prepare for the death of a relative. The overarching research question of this thesis was addressed through three sequential studies using different methods: a systematic review that examined family death preparation from a post-bereavement perspective, a qualitative interview study involving bereaved family caregivers, and a nominal group technique study with specialist palliative care professionals. These multiple methods enabled a complementary and in-depth examination of family death preparation beyond Western contexts.

By centring the perspectives of Taiwanese families and healthcare professionals, a culturally grounded conceptual model of family death preparation was developed. This model integrates clinical, relational, cultural-religious, and socio-structural domains, and highlights family death preparation as a continuum that extends from the dying process into the funeral and the afterlife. It demonstrates that family death preparation is a complex, multidimensional process with direct implications for bereavement, and not solely a personal or clinical task. Rather, it is a relational and collective practice shaped by cultural and religious values, healthcare systems, and wider structural conditions.

Theoretical perspectives were employed to interpret these findings, revealing the limitations of Western-centric frameworks when applied in contexts where cultural and familial norms play a defining role in shaping end-of-life practices. Through Confucian familism (Badanta et al., 2022; Hwang, 1999) and Hofstede's collectivism (Hofstede, 1984, 2001), the central role of family in end-of-life care was better understood. Modernisation theory (Ntini, 2016; Tipps, 1973) illustrates how Western palliative care models, particularly patient autonomy and advance care planning, have been introduced into Taiwan, while postmodernism (Jeong-ho & Naehui, 2022) challenges their universal applicability.

Building on these theoretical insights, the findings support the development of culturally appropriate models of end-of-life care that honour diverse conceptions of a good death, acknowledge the significance of continuing relationships before death, and recognise the family as a central actor in caregiving and decision-making. They also expose a persistent tension between culturally embedded family practices and Western-oriented evidence and norms. Addressing this tension requires culturally sensitive approaches across clinical practice, professional education, and healthcare policy. Importantly, the findings highlight the role of family death preparation in minimising regret, underscoring the need for proactive and preventive bereavement support before death. Methodologically, the value of adapting the nominal group technique in collectivist settings was demonstrated, along with the importance of reflexivity and bilingual strategies for capturing culturally embedded meanings.

While the findings are grounded in Taiwan, they are transferable to other East Asian and collectivist societies and hold relevance for increasingly multicultural healthcare systems in the West. They remind us that preparing for a relative’s death is not only a medical or clinical matter, but also a profoundly cultural, relational, and structural process. As palliative and end-of-life care continues to evolve under the strong influence of Western models, the findings of this thesis emphasise the importance of developing and applying culturally grounded evidence. Doing so is essential to ensure that palliative and end-of-life care is not only clinically effective but also culturally appropriate, reflecting local values and beliefs while demonstrating cultural humility in practice. Ultimately, recognising the cultural and relational dimensions of preparing for a relative’s death is vital if palliative and end-of-life care is to meet the needs of families in Taiwan, across East Asia, and in multicultural contexts worldwide.

Appendices

Appendix 1: Reflexive thematic analysis for the qualitative interview study

Appendix 2: The nominal group technique guide

Appendix 3: Participant characteristics form for specialist palliative care professionals

Appendix 4: Ethical approval documents

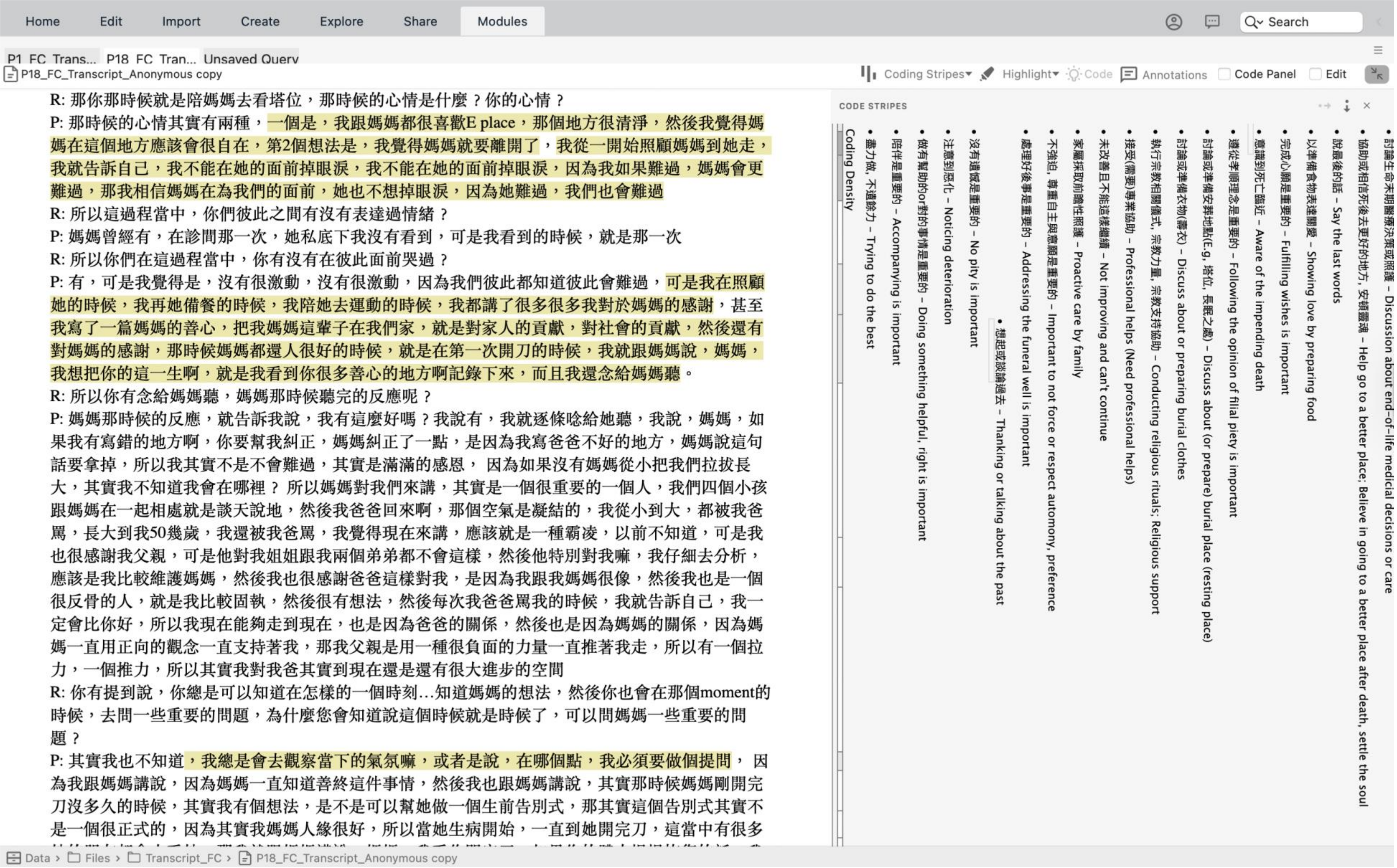
Appendix 5: The 42 modified recommendations corresponding to the four finalised recommendations

Appendix 6: Statement of authorship

Appendix 1: Reflexive thematic analysis for the qualitative interview study

Phase	What I did in the study
Dataset familiarisation	• All the interview audio recordings in Mandarin or Taiwanese were transcribed into Traditional Chinese. Anonymous transcripts were then produced for further analysis. • I highlighted interesting content regarding the research questions and took notes while reading the anonymous transcripts. • Wrote familiarisation notes for the whole dataset.
Coding the data	• Imported the anonymous transcripts in Traditional Chinese to NVivo software. • Coding each data item in Traditional Chinese with an inductive orientation, including semantic or latent codes. Certain example transcripts and codes were translated into English for discussions with supervisors while analysing data. • Went through the whole dataset to refine the coding in two rounds in a different order. • A list of final code labels with all the data relevant to each code in Traditional Chinese, and then translated into English.
Generating initial themes	• Put all the codes with relevant coded data together. • Clustered together the potentially connected codes to develop potential themes in relation to the research questions. • Used thematic maps to think about the relationship between initial themes and thought about the whole story of the analysis that addresses the research questions. • Gathered all the coded data extracts relevant to each initial theme.
Developing and reviewing themes	• Asked questions to guide the process of developing and reviewing themes; for example, “Does each theme have a central organising concept?”, “Is there a clear boundary for each theme?”, and “Are there enough rich data to support each theme?”. • Checked if the theme works in relation to the coded extracts and the entire dataset. • Refined and finalised the thematic map.
Refining, defining, and naming themes	• Write of a definition for each theme to illustrate the central organising concept, scope, and boundaries of the theme. • Naming themes. • No more than three theme levels.
Writing up	• Provide an overview of the analysis. • Consider the theme order to tell the whole story about the analysis in relation to the research questions. • Select a number of data extracts to support each theme. • Draw out analytic conclusions across themes. • Relate the analysis to the research questions and the wider context, such as the literature and theories.

Example of coding in reflexive thematic analysis for the qualitative interview study



R: 那你那時候就是陪媽媽去看塔位，那時候的心情是什麼？你的心情？

P: 那時候的心情其實有兩種，一個是，我跟媽媽都很喜歡E place，那個地方很清淨，然後我覺得媽媽在這個地方應該會很自在，第2個想法是，我覺得媽媽就要離開了，我從一開始照顧媽媽到她走，我就告訴自己，我不能在她的面前掉眼淚，我不能在她的面前掉眼淚，因為我如果難過，媽媽會更難過，那我相信媽媽在為我們的面前，她也不想掉眼淚，因為她難過，我們也會難過

R: 所以這過程當中，你們彼此之間有沒有表達過情緒？

P: 媽媽曾經有，在診間那一次，她私底下我沒有看到，可是我看到的時候，就是那一次

R: 所以你們在這過程當中，你有沒有在彼此面前哭過？

P: 有，可是我覺得是，沒有很激動，沒有很激動，因為我們彼此都知道彼此會難過，可是我在照顧她的時候，我再她備餐的時候，我陪她去運動的時候，我都講了很多很多我對於媽媽的感謝，甚至我寫了一篇媽媽的善心，把我媽媽這輩子在我們家，就是對家人的貢獻，對社會的貢獻，然後還有對媽媽的感謝，那時候媽媽都還人很好的時候，就是在第一次開刀的時候，我就跟媽媽說，媽媽，我想把你的這一生啊，就是我看到你很多善心的地方啊記錄下來，而且我還念給媽媽聽。

R: 所以你有念給媽媽聽，媽媽那時候聽完的反應呢？

P: 媽媽那時候的反應，就告訴我說，我有這麼好嗎？我說有，我就逐條唸給她聽，我說，媽媽，如果我有寫錯的地方啊，你要幫我糾正，媽媽糾正了一點，是因為我寫爸爸不好的地方，媽媽說這句話要拿掉，所以我其實不是不會難過，其實是滿滿的感恩， 因為如果沒有媽媽從小把我們拉拔長大，其實我不知道我會在哪裡？ 所以媽媽對我們來講，其實是一個很重要的一個人，我們四個小孩跟媽媽在一起相處就是談天說地，然後我爸爸回來啊，那個空氣是凝結的，我從小到大，都被我爸罵，長大到我50幾歲，我還被我爸罵，我覺得現在來講，應該就是一種霸凌，以前不知道，可是我也很感謝我父親，可是他對我姐姐跟我兩個弟弟都不會這樣，然後他特別對我嘛，我仔細去分析，應該是我比較維護媽媽，然後我也很感謝爸爸這樣對我，是因為我跟我媽媽很像，然後我也是一個很反骨的人，就是我比較固執，然後很有想法，然後每次我爸爸罵我的時候，我就告訴自己，我一定會比你好，所以我現在能夠走到現在，也是因為爸爸的關係，然後也是因為媽媽的關係，因為媽媽一直用正向的觀念一直支持著我，那我父親是用一種很負面的力量一直推著我走，所以有一個拉力，一個推力，所以其實我對我爸其實到現在還是還有很大進步的空間

R: 你有提到說，你總是可以知道在怎樣的一個時刻…知道媽媽的想法，然後你也會在那個moment的時候，去問一些重要的問題，為什麼您會知道說這個時候就是時候了，可以問媽媽一些重要的問題？

P: 其實我也不知道，我總是會去觀察當下的氣氛嘛，或者是說，在哪個點，我必須要做個提問， 因為我跟媽媽講說，因為媽媽一直知道善終這件事情，然後我也跟媽媽講說，其實那時候媽媽剛開完刀沒多久的時候，其實我有個想法，是不是可以幫她做一個生前告別式，那其實這個告別式其實不是一個很正式的，因為其實我媽媽人緣很好，所以當她生病開始，一直到她開完刀，這當中有很多

CODE STRIPES

- 討論生命末期醫療決策或照護 – Discussion about end-of-life medical decisions or care
- 協助或相信死後去更好的地方，安頓靈魂 – Help go to a better place; Believe in going to a better place after death, settle the soul
- 說最後的話 – Say the last words
- 以準備食物表達關愛 – Showing love by preparing food
- 完成心願是重要的 – Fulfilling wishes is important
- 意識到死亡臨近 – Aware of the impending death
- 遵從孝順理念是重要的 – Following the opinion of filial piety is important
- 討論或準備安葬地點(E.g, 塔位, 長眠之處) – Discuss about (or prepare) burial place (resting place)
- 討論或準備衣物(壽衣) – Discuss about or preparing burial clothes
- 執行宗教相關儀式, 宗教力量, 宗教支持協助 – Conducting religious rituals; Religious support
- 接受(需要)專業協助 – Professional helps (Need professional helps)
- 未改善且不能這樣繼續 – Not improving and can't continue
- 家屬採取前瞻性照護 – Proactive care by family
- 不強迫, 尊重自主與意願是重要的 – Important to not force or respect automony, preference
- 處理好後事是重要的 – Addressing the funeral well is important
    - 想起或談論過去 – Thanking or talking about the past
- 沒有遺憾是重要的 – No pity is important
- 注意到惡化 – Noticing deterioration
- 做有幫助的or對的事情是重要的 – Doing something helpful, right is important
- 陪伴是重要的 – Accompanying is important
- 盡力做, 不遺餘力 – Trying to do the best

Appendix 2: The nominal group technique guide

- Two research questions will be addressed in the second phase of the study:
  1) What are the barriers to the implementation of preparing family members for death and bereavement from the perspective of specialist palliative care professionals?
  2) What are feasible strategies to address the barriers to providing such care for family members?

The procedures of the NGT, described below, will be applied respectively to answer two research questions. The questions may be adjusted based on findings of the first phase of the study.

NOTE: The producers of the NGT may be adjusted after the pre-test NGT.

Step 1: Introduction

- The facilitator will explain the purposes and process to the group and invite participants to introduce themselves briefly.

Step 2: Presentation

- The facilitator will present the current state of the science related to preparedness for death and bereavement, as well as the research question for the second phase of this study.

Step 3: Generating ideas

- Participants will silently write down their thoughts about the question on paper (e.g., post-it notes).

Step 4: Listing ideas and clarification

- Participants will share their ideas without judgment.
- Those ideas will be listed on a board or typed on a computer and projected onto a screen.
- Clarify and discuss the ideas and add new ones if needed.

Step 5: Ranking/Voting and discussion

- Participants will privately rank, and the ranking will be presented and discussed.
- More than one round for the same question may be conducted if necessary.

Sept 6: Conclusion

- The facilitator will summarise the discussions, thank participants, explain what will happen next, remind them about confidentiality (e.g., not share details of the discussion outside the group), and answer final questions.

Appendix 3: Participant characteristics form for specialist palliative care professionals

Name:

Age (years):

Gender

☐ Male

☐ Female

☐ Prefer not to say

What is your profession?

☐ Physician ϒ Nurse ☐ Social worker ϒ Psychologist ϒ Chaplain ϒ Other

(________)

What type of specialist palliative cares do you provide now? *(Multiple choice)*

☐ Inpatient care

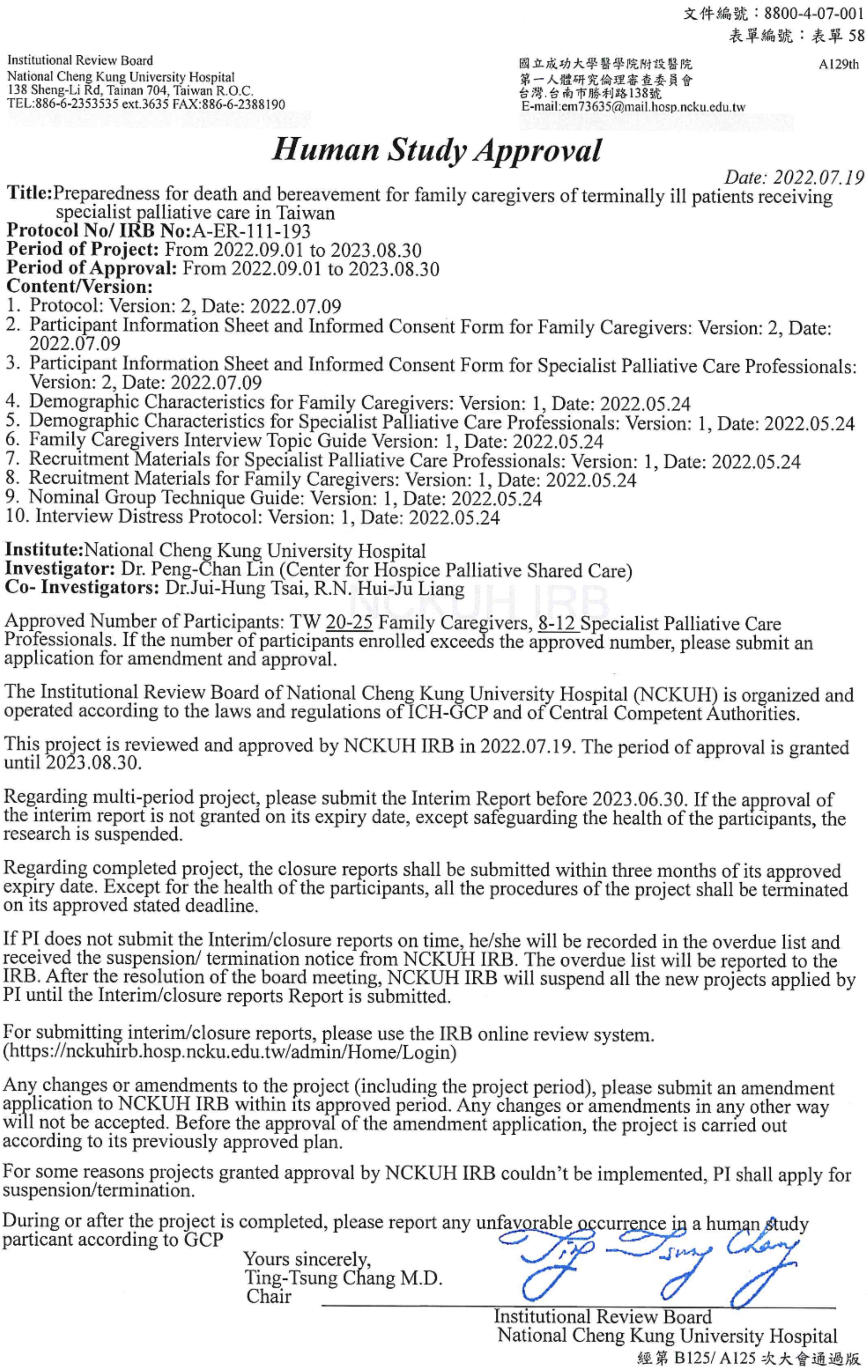
☐ Consultation or combined care

☐ Home care

Clinical Work Experience in Palliative Care

________years ________ month(s)

Appendix 4: Ethical approval documents



文件編號：8800-4-07-001
表單編號：表單 58

Institutional Review Board
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A129th

Human Study Approval

Date: 2022.07.19

Title: Preparedness for death and bereavement for family caregivers of terminally ill patients receiving specialist palliative care in Taiwan
Protocol No/ IRB No: A-ER-111-193
Period of Project: From 2022.09.01 to 2023.08.30
Period of Approval: From 2022.09.01 to 2023.08.30
Content/Version:

1. Protocol: Version: 2, Date: 2022.07.09
2. Participant Information Sheet and Informed Consent Form for Family Caregivers: Version: 2, Date: 2022.07.09
3. Participant Information Sheet and Informed Consent Form for Specialist Palliative Care Professionals: Version: 2, Date: 2022.07.09
4. Demographic Characteristics for Family Caregivers: Version: 1, Date: 2022.05.24
5. Demographic Characteristics for Specialist Palliative Care Professionals: Version: 1, Date: 2022.05.24
6. Family Caregivers Interview Topic Guide Version: 1, Date: 2022.05.24
7. Recruitment Materials for Specialist Palliative Care Professionals: Version: 1, Date: 2022.05.24
8. Recruitment Materials for Family Caregivers: Version: 1, Date: 2022.05.24
9. Nominal Group Technique Guide: Version: 1, Date: 2022.05.24
10. Interview Distress Protocol: Version: 1, Date: 2022.05.24

Institute: National Cheng Kung University Hospital
Investigator: Dr. Peng-Chan Lin (Center for Hospice Palliative Shared Care)
Co- Investigators: Dr.Jui-Hung Tsai, R.N. Hui-Ju Liang

Approved Number of Participants: TW 20-25 Family Caregivers, 8-12 Specialist Palliative Care Professionals. If the number of participants enrolled exceeds the approved number, please submit an application for amendment and approval.

The Institutional Review Board of National Cheng Kung University Hospital (NCKUH) is organized and operated according to the laws and regulations of ICH-GCP and of Central Competent Authorities.

This project is reviewed and approved by NCKUH IRB in 2022.07.19. The period of approval is granted until 2023.08.30.

Regarding multi-period project, please submit the Interim Report before 2023.06.30. If the approval of the interim report is not granted on its expiry date, except safeguarding the health of the participants, the research is suspended.

Regarding completed project, the closure reports shall be submitted within three months of its approved expiry date. Except for the health of the participants, all the procedures of the project shall be terminated on its approved stated deadline.

If PI does not submit the Interim/closure reports on time, he/she will be recorded in the overdue list and received the suspension/ termination notice from NCKUH IRB. The overdue list will be reported to the IRB. After the resolution of the board meeting, NCKUH IRB will suspend all the new projects applied by PI until the Interim/closure reports Report is submitted.

For submitting interim/closure reports, please use the IRB online review system.
(https://nckuhirb.hosp.ncku.edu.tw/admin/Home/Login)

Any changes or amendments to the project (including the project period), please submit an amendment application to NCKUH IRB within its approved period. Any changes or amendments in any other way will not be accepted. Before the approval of the amendment application, the project is carried out according to its previously approved plan.

For some reasons projects granted approval by NCKUH IRB couldn't be implemented, PI shall apply for suspension/termination.

During or after the project is completed, please report any unfavorable occurrence in a human study particant according to GCP

Yours sincerely,
Ting-Tsung Chang M.D.
Chair

Institutional Review Board
National Cheng Kung University Hospital

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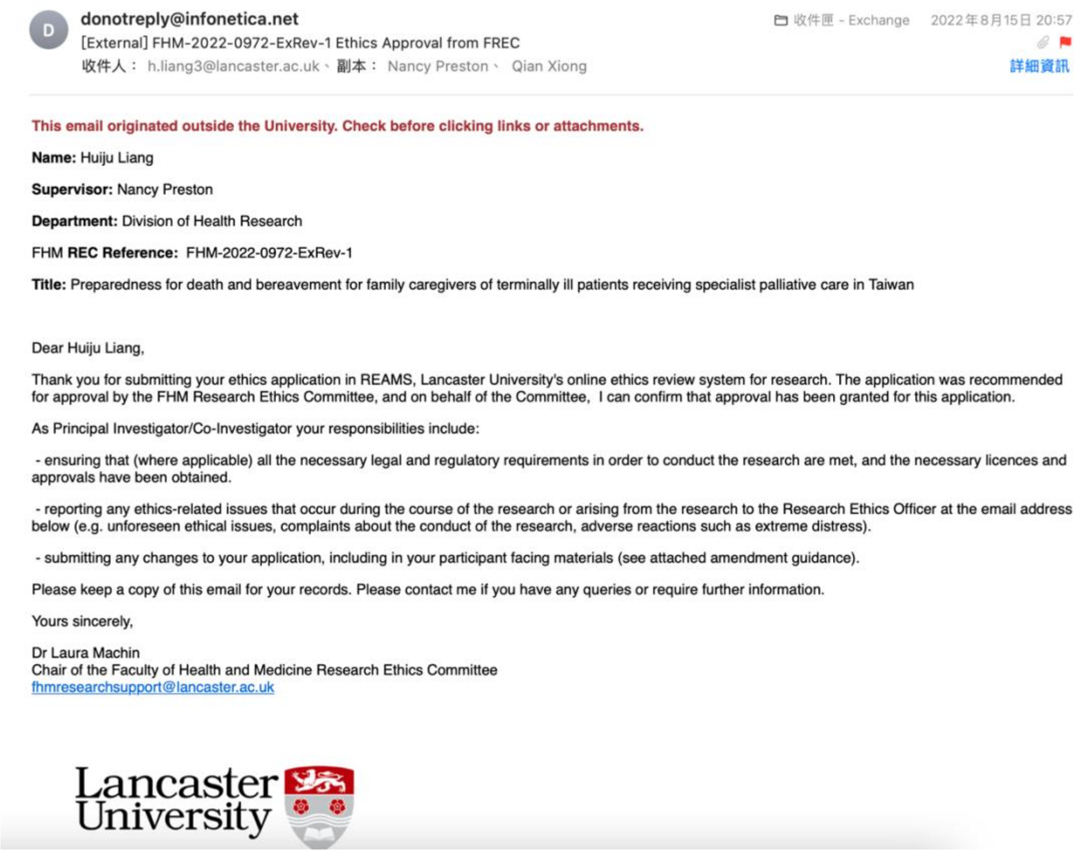


donotreply@infonetica.net
[External] FHM-2022-0972-ExRev-1 Ethics Approval from FREC
收件人： h.liang3@lancaster.ac.uk、副本： Nancy Preston、 Qian Xiong

2022年8月15日 20:57

This email originated outside the University. Check before clicking links or attachments.

Name: Huiju Liang

Supervisor: Nancy Preston

Department: Division of Health Research

FHM **REC Reference:** FHM-2022-0972-ExRev-1

Title: Preparedness for death and bereavement for family caregivers of terminally ill patients receiving specialist palliative care in Taiwan

Dear Huiju Liang,

Thank you for submitting your ethics application in REAMS, Lancaster University's online ethics review system for research. The application was recommended for approval by the FHM Research Ethics Committee, and on behalf of the Committee, I can confirm that approval has been granted for this application.

As Principal Investigator/Co-Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licences and approvals have been obtained.

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress).

- submitting any changes to your application, including in your participant facing materials (see attached amendment guidance).

Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
fhmresearchsupport@lancaster.ac.uk

Appendix 5: The 42 modified recommendations corresponding to the four finalised recommendations

The modified recommendations corresponding to each finalised recommendation

Finalised recommendation 1: Providing appropriate end-of-life care to patients and their families necessitates that healthcare professionals possess competencies in this field, which should be cultivated through adequate professional education

1: HCPs should possess the capability to recognise the needs of family members facing the impending death of a relative
2: HCPs should possess the capability to recognise and address the needs of family members facing the impending death of a relative (e.g., emotional needs, the need to address relational issues between the patient and families)
3: HCPs should be competent in predicting the patient’s life expectancy and communicating this information with family members to assist them in making realistic medical decisions and setting attainable care goals
4: HCPs should demonstrate competence in delivering appropriate end-of-life care, tailored to the various stages of their life expectancy
5: HCPs could assist patients in creating a legacy during the preparation for death, providing a means of connecting with their families after death (e.g. writing letters, audio recordings)
7: HCPs should be competent in conducting family meetings with family members to assist them in preparing for a relative’s death
8: HCPs could encourage and guide family members to participate in the physical care of the patient during the end-of-life stage
10: HCPs should be competent in recognising dying signs and delivering appropriate care (e.g., alerting families that death is near)
11: HCPs should be competent in facilitating end-of-life communication between patients and their families, including understanding the patient’s preferences
12: HCPs should facilitate family members' participation in the patient’s end-of-life decision-making process to achieve family consensus and alleviate the potential for regrets
13: HCPs should be competent in end-of-life communication with patients, families, and other healthcare staff through education and training programmes (e.g., facilitating discussions about death, dying, and loss and providing appropriate support)
14: HCPs could assist family members in fulfilling the patient’s last wishes and completing their unfinished business during the death preparation process
15: HCPs, especially psychosocial and spiritual care professionals, could facilitate communication between family members by conducting family-centred groups to address psychosocial and spiritual concerns and promote mutual support in preparation for the death
16: The need to assist patients in life review and fulfilling their last wishes during end-of-life care by asking two questions: “How would you describe your life in a sentence?” & “Do you have any unfinished wishes?”
26: The need to employ experiential teaching methods in end-of-life care education (e.g., using real case studies, bedside teaching & hands-on practice)

27: End-of-life care should be compulsory in all healthcare professional development curricula to ensure that all healthcare professionals have a basic understanding of it

35: HCPs could possess knowledge about the religious and cultural customs related to funeral arrangements and rituals

37: HCPs could be competent in assisting patients and families in reaching a consensus on funeral arrangements, especially funeral religious rituals

39: HCPs in primary care could initiate advance care planning discussions with patients and the public in community settings

Finalised recommendation 2: The significance of active government involvement and research is needed to support the delivery of appropriate palliative and end-of-life care

25: Death education should be compulsory in all general education curricula through government policy

30: Involving the government and using a top-down policy approach is crucial in organising, auditing, and monitoring palliative and end-of-life care systems

31: The need to conduct good quality research on palliative and end-of-life care to inform policy making and clinical practice through the government agencies' support

32: The need to make an unpaid leave policy through engagement with government agencies to encourage family members' participation in the patient's end-of-life discussions (e.g., attending family meetings)

33: Prognostic tools for estimating survival time should be developed and optimised in future research to help HCPs predict life expectancy more accurately and meet families' expectations

34: Further research in end-of-life care is needed, including understanding the end-of-life and dying experience of patients in the context of communities, determining if national healthcare policies (e.g., National Healthcare Insurance in Taiwan) can adequately meet dying patients' needs, and exploring how policies and legal provisions in Taiwan (e.g., the Patient Right to Autonomy Act), affect the willingness of HCPs to engage in advance care planning discussions

42: It is necessary to develop a national clinical audit programme to monitor and evaluate the quality of palliative and end-of-life care across the country

Finalised recommendation 3: Strengthening palliative and end-of-life care services within the healthcare system is essential, with particular emphasis on further developing generalist palliative care and integrating these services into non-specialist care units

6: The necessity to provide integrated and continuous palliative care services across the healthcare system, including the development of generalist palliative care services

9: HCPs should be competent in the early identification of patients with palliative care needs and discuss their future care plans, particularly in long-term care institutions

17: HCPs should possess both moral sensitivity and legal knowledge to provide appropriate end-of-life care for significant others who have unspeakable relationships with the patient, including providing anticipatory grief support and facilitating communication between them and the families of patients

18: HCPs should offer anticipatory grief support to significant others of the patient during end-of-life care, encompassing individuals who have live-in relationships without legal status with patients

19: The necessity to provide appropriate end-of-life care, including anticipatory grief support, for family members of a foetus diagnosed with life-limiting conditions

20: The need to deliver appropriate end-of-life care for a specific group, namely, family members with new immigrant status

21: The necessity of delivering appropriate end-of-life care for individuals of all ages facing life-limiting conditions, as well as their families and significant others

28: An effective way to improve family members' death preparation should start in intensive care units, including enhancing end-of-life care competencies of HCPs in intensive care units

40: The need to strengthen the capacity of primary care networks to deliver appropriate palliative and end-of-life care

Finalised recommendation 4: It is essential to increase the public's death literacy and awareness of issues surrounding death, alongside encouraging a shift in societal attitudes towards death-related topics through targeted and culturally sensitive public education initiatives

22: The need to deliver tailored death education to individuals in the community and long-term care institutions through employing various education methods and utilising diverse education content that covers a wide range of relevant topics

23: The need to educate the public about death preparation by creating and distributing films that cover various topics, including guidance on engaging in end-of-life discussions, such as understanding the patient's preferences for medical treatments and funeral arrangements, along with providing direction on expressing gratitude, love, apologies, and farewells

24: The need to educate the public about death and dying through a variety of ways, such as the Death Café

29: The need to enhance the public's death literacy and health literacy at the end of life through public education

36: Religious groups and organisations should actively provide the public with death education and consultation services

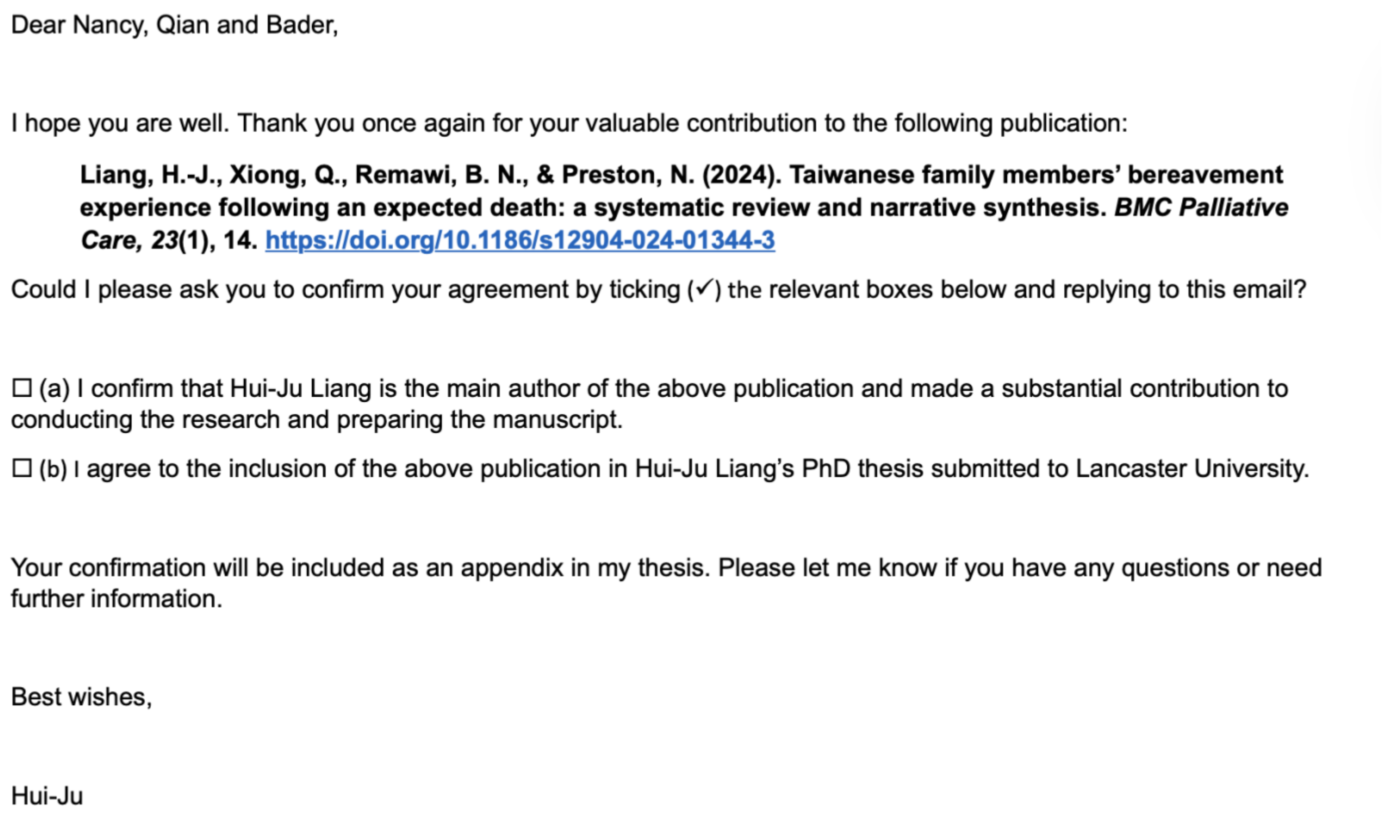
38: There is a need to promote death preparation, including the topics of death, dying, and bereavement, as a social issue through various approaches (e.g., collaborating with advocacy groups and nonprofit organisations, using social media & organising events such as death festivals)

41: It is necessary to develop in-person and online channels by non-profit organisations outside of hospitals to provide medical consultation to patients, families, and the public, including assisting in decision-making

HCPs: Healthcare professionals.

Appendix 6: Statement of authorship

Paper 1



Dear Nancy, Qian and Bader,

I hope you are well. Thank you once again for your valuable contribution to the following publication:

> **Liang, H.-J., Xiong, Q., Remawi, B. N., & Preston, N. (2024). Taiwanese family members' bereavement experience following an expected death: a systematic review and narrative synthesis. *BMC Palliative Care, 23*(1), 14. https://doi.org/10.1186/s12904-024-01344-3**

Could I please ask you to confirm your agreement by ticking (✓) the relevant boxes below and replying to this email?

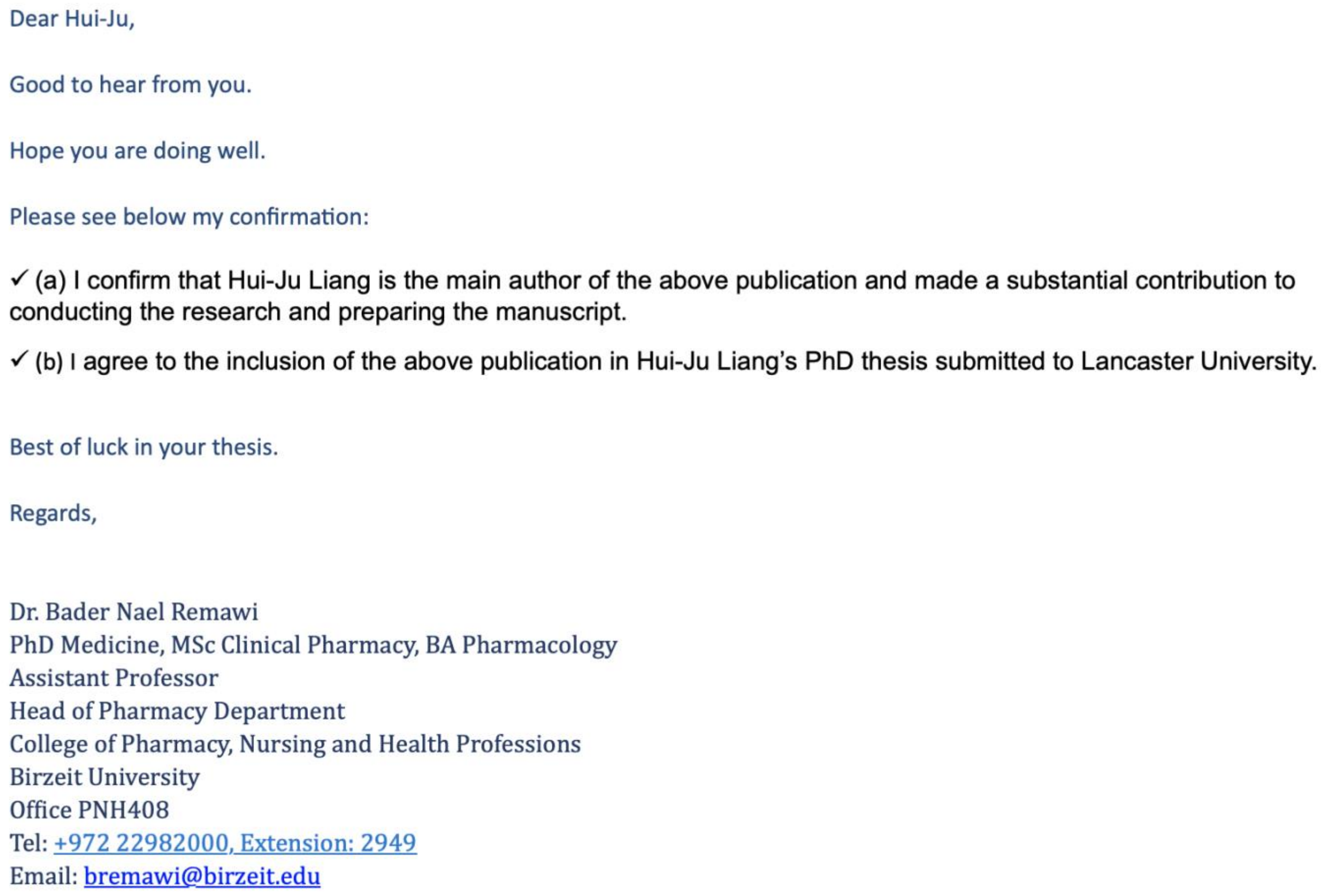
☐ (a) I confirm that Hui-Ju Liang is the main author of the above publication and made a substantial contribution to conducting the research and preparing the manuscript.

☐ (b) I agree to the inclusion of the above publication in Hui-Ju Liang's PhD thesis submitted to Lancaster University.

Your confirmation will be included as an appendix in my thesis. Please let me know if you have any questions or need further information.

Best wishes,

Hui-Ju



Dear Hui-Ju,

Good to hear from you.

Hope you are doing well.

Please see below my confirmation:

✓ (a) I confirm that Hui-Ju Liang is the main author of the above publication and made a substantial contribution to conducting the research and preparing the manuscript.

✓ (b) I agree to the inclusion of the above publication in Hui-Ju Liang's PhD thesis submitted to Lancaster University.

Best of luck in your thesis.

Regards,

Dr. Bader Nael Remawi
PhD Medicine, MSc Clinical Pharmacy, BA Pharmacology
Assistant Professor
Head of Pharmacy Department
College of Pharmacy, Nursing and Health Professions
Birzeit University
Office PNH408
Tel: +972 22982000, Extension: 2949
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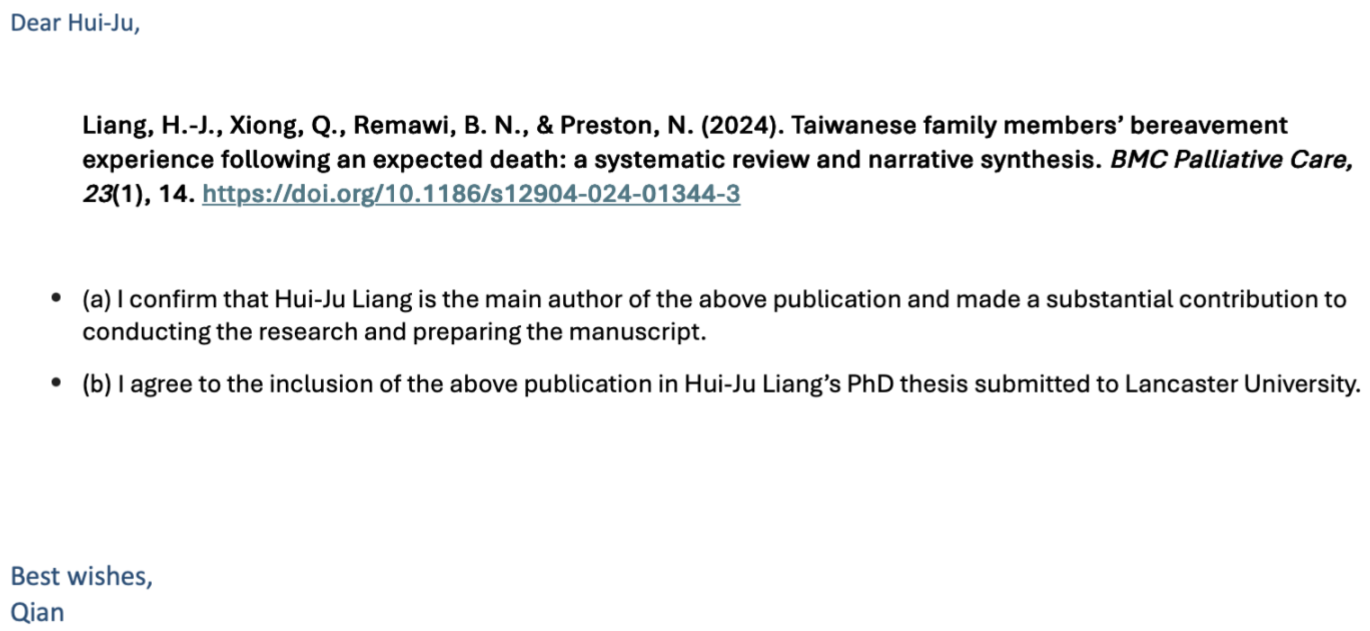

Dear Hui-Ju,

Liang, H.-J., Xiong, Q., Remawi, B. N., & Preston, N. (2024). Taiwanese family members' bereavement experience following an expected death: a systematic review and narrative synthesis. *BMC Palliative Care, 23*(1), 14. https://doi.org/10.1186/s12904-024-01344-3

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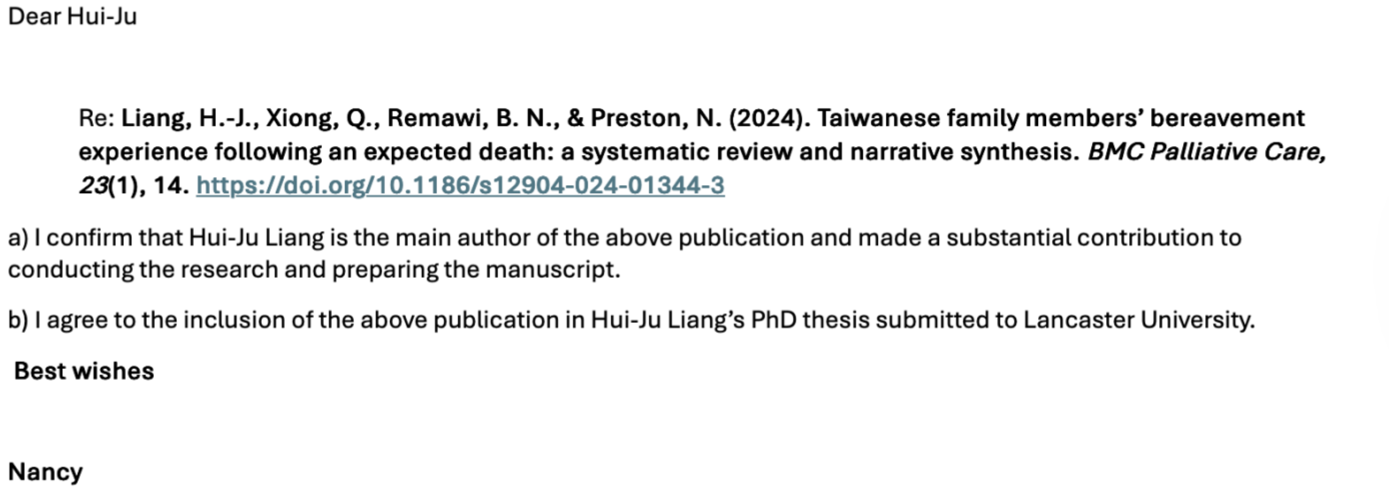
- (b) I agree to the inclusion of the above publication in Hui-Ju Liang's PhD thesis submitted to Lancaster University.

Best wishes,
Qian



Dear Hui-Ju

Re: **Liang, H.-J., Xiong, Q., Remawi, B. N., & Preston, N. (2024). Taiwanese family members' bereavement experience following an expected death: a systematic review and narrative synthesis. *BMC Palliative Care, 23*(1), 14. https://doi.org/10.1186/s12904-024-01344-3**

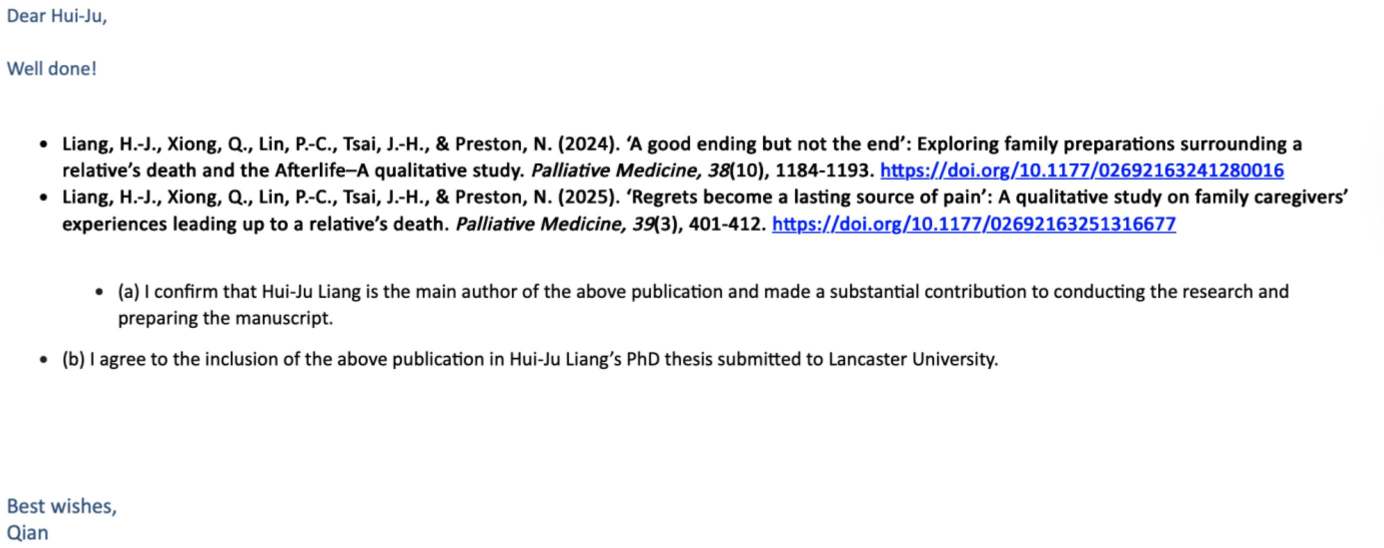
a) I confirm that Hui-Ju Liang is the main author of the above publication and made a substantial contribution to conducting the research and preparing the manuscript.

b) I agree to the inclusion of the above publication in Hui-Ju Liang's PhD thesis submitted to Lancaster University.

Best wishes

Nancy

Paper 2 and 3



Dear Hui-Ju,

Well done!

- **Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2024). 'A good ending but not the end': Exploring family preparations surrounding a relative's death and the Afterlife–A qualitative study. *Palliative Medicine, 38*(10), 1184-1193.** https://doi.org/10.1177/02692163241280016
- **Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2025). 'Regrets become a lasting source of pain': A qualitative study on family caregivers' experiences leading up to a relative's death. *Palliative Medicine, 39*(3), 401-412.** https://doi.org/10.1177/02692163251316677
    - (a) I confirm that Hui-Ju Liang is the main author of the above publication and made a substantial contribution to conducting the research and preparing the manuscript.
- (b) I agree to the inclusion of the above publication in Hui-Ju Liang's PhD thesis submitted to Lancaster University.

Best wishes,
Qian

Dear Hui-Ju,

I confirm the following regarding the above publication:

V (a) I confirm that Hui-Ju Liang is the main author of the above publication and made a substantial contribution to conducting the research and preparing the manuscript.

V (b) I agree to the inclusion of the above publication in Hui-Ju Liang's PhD thesis submitted to Lancaster University.

Please let me know if you require any additional information.

Best regards,

Peng-Chan

Liang, Hui-Ju (Postgraduate Researcher) <h.liang3@lancaster.ac.uk> 於 2025年11月13日 週四 上午7:25寫道：

> Dear Nancy, Qian, Dr Lin, and Dr Tsai,
>
> I hope you are well. Thank you once again for your valuable contribution to the following publication:
>
> - **Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2024). 'A good ending but not the end': Exploring family preparations surrounding a relative's death and the Afterlife–A qualitative study. *Palliative Medicine, 38*(10), 1184-1193.** https://doi.org/10.1177/02692163241280016
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Dear Hui-Ju:
I have check the two itemss. Please see the reply.

Best regards

Jui-Hung Tsai

Liang, Hui-Ju (Postgraduate Researcher) <h.liang3@lancaster.ac.uk> 於 2025年11月13日 週四 上午12:25寫道：

> Dear Nancy, Qian, Dr Lin, and Dr Tsai,
>
> I hope you are well. Thank you once again for your valuable contribution to the following publication:
>
> - **Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2024). 'A good ending but not the end': Exploring family preparations surrounding a relative's death and the Afterlife–A qualitative study. *Palliative Medicine, 38*(10), 1184-1193.** https://doi.org/10.1177/02692163241280016
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>
> Could I please ask you to confirm your agreement by ticking (✓) the relevant boxes below and replying to this email?
>
> ◆ (a) I confirm that Hui-Ju Liang is the main author of the above publication and made a substantial contribution to conducting the research and preparing the manuscript.
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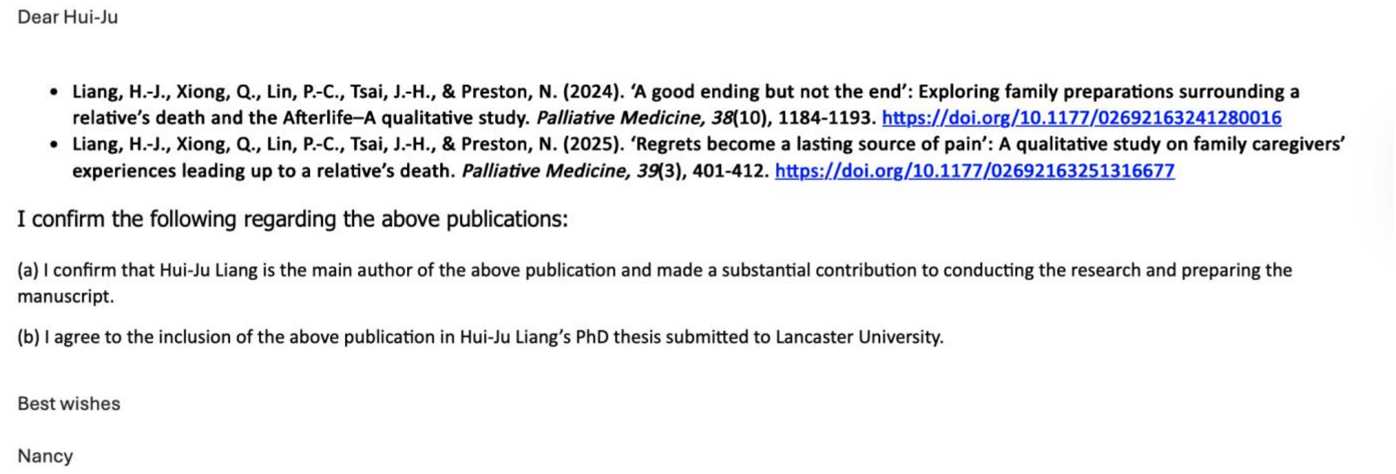
> ◆ (b) I agree to the inclusion of the above publication in Hui-Ju Liang's PhD thesis submitted to Lancaster University.



Dear Hui-Ju

- **Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2024). 'A good ending but not the end': Exploring family preparations surrounding a relative's death and the Afterlife–A qualitative study. *Palliative Medicine, 38*(10), 1184-1193.** https://doi.org/10.1177/02692163241280016
- **Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2025). 'Regrets become a lasting source of pain': A qualitative study on family caregivers' experiences leading up to a relative's death. *Palliative Medicine, 39*(3), 401-412.** https://doi.org/10.1177/02692163251316677

I confirm the following regarding the above publications:

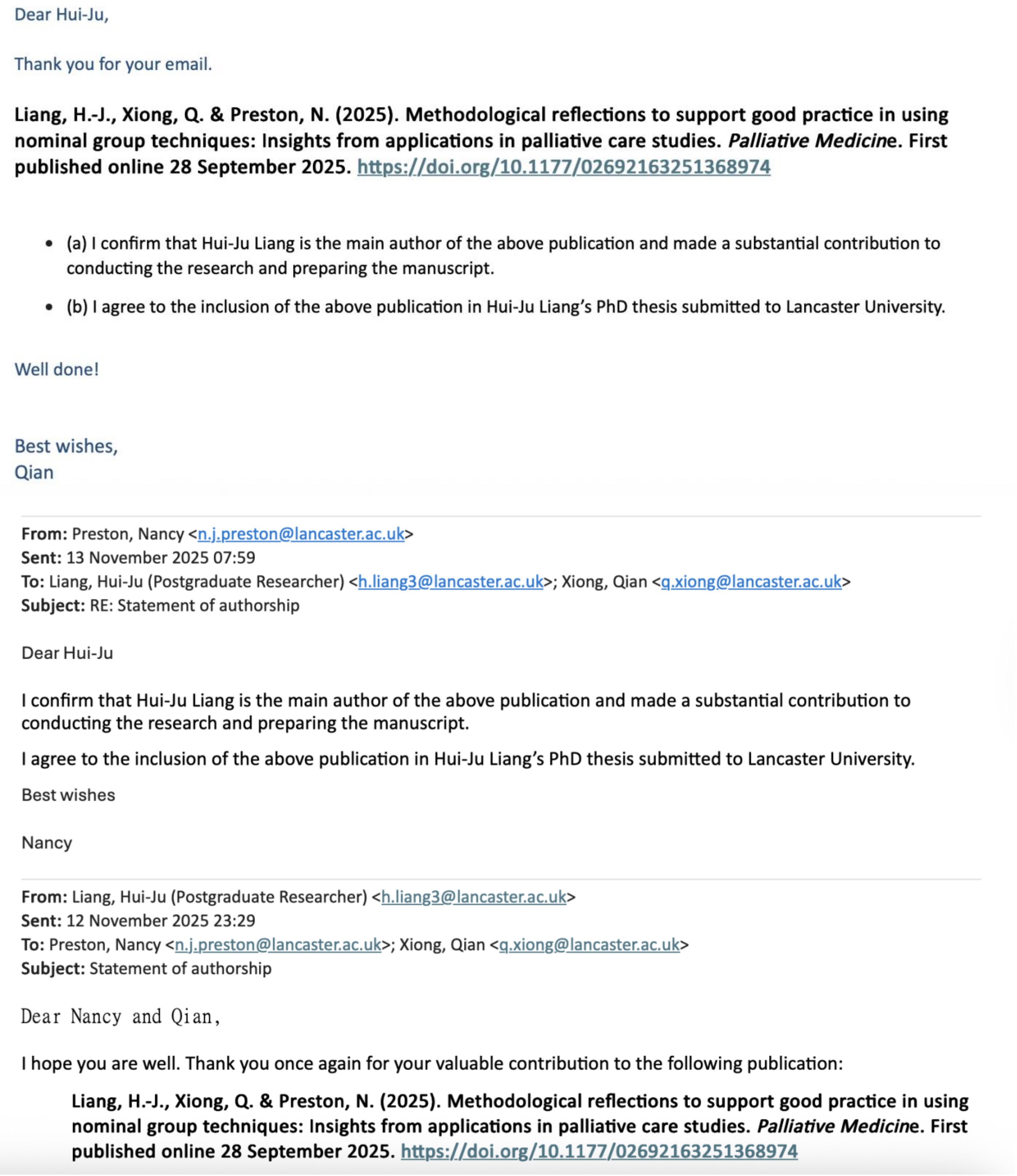
(a) I confirm that Hui-Ju Liang is the main author of the above publication and made a substantial contribution to conducting the research and preparing the manuscript.

(b) I agree to the inclusion of the above publication in Hui-Ju Liang's PhD thesis submitted to Lancaster University.

Best wishes

Nancy

Paper 4



Dear Hui-Ju,

Thank you for your email.

Liang, H.-J., Xiong, Q. & Preston, N. (2025). Methodological reflections to support good practice in using nominal group techniques: Insights from applications in palliative care studies. *Palliative Medicin*e. First published online 28 September 2025. https://doi.org/10.1177/02692163251368974

- (a) I confirm that Hui-Ju Liang is the main author of the above publication and made a substantial contribution to conducting the research and preparing the manuscript.
- (b) I agree to the inclusion of the above publication in Hui-Ju Liang’s PhD thesis submitted to Lancaster University.

Well done!

Best wishes,
Qian

From: Preston, Nancy <n.j.preston@lancaster.ac.uk>
Sent: 13 November 2025 07:59
To: Liang, Hui-Ju (Postgraduate Researcher) <h.liang3@lancaster.ac.uk>; Xiong, Qian <q.xiong@lancaster.ac.uk>
Subject: RE: Statement of authorship

Dear Hui-Ju

I confirm that Hui-Ju Liang is the main author of the above publication and made a substantial contribution to conducting the research and preparing the manuscript.

I agree to the inclusion of the above publication in Hui-Ju Liang’s PhD thesis submitted to Lancaster University.

Best wishes

Nancy

From: Liang, Hui-Ju (Postgraduate Researcher) <h.liang3@lancaster.ac.uk>
Sent: 12 November 2025 23:29
To: Preston, Nancy <n.j.preston@lancaster.ac.uk>; Xiong, Qian <q.xiong@lancaster.ac.uk>
Subject: Statement of authorship

Dear Nancy and Qian,

I hope you are well. Thank you once again for your valuable contribution to the following publication:

> **Liang, H.-J., Xiong, Q. & Preston, N. (2025). Methodological reflections to support good practice in using nominal group techniques: Insights from applications in palliative care studies. *Palliative Medicin*e. First published online 28 September 2025. https://doi.org/10.1177/02692163251368974**

References

Aeschlimann, A., Heim, E., Killikelly, C., Arafa, M., & Maercker, A. (2024). Culturally sensitive grief treatment and support: A scoping review. *SSM-Mental Health*, *5*, 100325. https://doi.org/10.1016/j.ssmmh.2024.100325

Alvariza, A., Hager-Tibell, L., Holm, M., Steineck, G., & Kreicbergs, U. (2020). Increasing preparedness for caregiving and death in family caregivers of patients with severe illness who are cared for at home - study protocol for a web-based intervention. *BMC palliative care*, *19*(1), 33. https://doi.org/10.1186/s12904-020-0530-6

Angelo, J. K., Egan, R., & Reid, K. (2013). Essential knowledge for family caregivers: a qualitative study. *International journal of palliative nursing*, *19*(8), 383-388. https://doi.org/10.12968/ijpn.2013.19.8.383

Asagumo, A. (2022). Relational autonomy, the right to reject treatment, and advance directives in Japan. *Asian Bioethics Review*, *14*(1), 57-69. https://doi.org/10.1007/s41649-021-00191-1

Asgeirsdottir, H. G., Valdimarsdottir, U., Furst, C. J., Steineck, G., & Hauksdottir, A. (2013). Low preparedness before the loss of a wife to cancer and the widower's chronic pain 4-5 years later-a population-based study. *Psychooncology*, *22*(12), 2763-2770. https://doi.org/10.1002/pon.3345

Badanta, B., González-Cano-Caballero, M., Suárez-Reina, P., Lucchetti, G., & de Diego-Cordero, R. (2022). How does confucianism influence health behaviors, health outcomes and medical decisions? A scoping review. *Journal of Religion and Health*, *61*(4), 2679-2725. https://doi.org/10.1007/s10943-022-01506-8

Baker, J., Lovell, K., & Harris, N. (2006). How expert are the experts? An exploration of the concept of 'expert' within Delphi panel techniques. *Nurse researcher*, *14*(1), 59-70. https://doi.org/10.7748/nr2006.10.14.1.59.c6010

Barry, L. C., Kasl, S. V., & Prigerson, H. G. (2002). Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *The American Journal of Geriatric Psychiatry*, *10*(4), 447-457.

Bennett, K. M., Chao, Q., Roper, L., & Lowers, V. (2018). “The deceased has left; the alive has to move on”: Experiences of Chinese Widows in the UK. *Death studies*, *42*(8), 498-507.

Benore, E. R., & Park, C. L. (2004). INVITED ESSAY: Death-Specific Religious Beliefs and Bereavement: Belief in an Afterlife and Continued Attachment. *International Journal for the Psychology of Religion*, *14*(1), 1-22. https://doi.org/10.1207/s15327582ijpr1401_1

Bhaskar, R. (2008). *A Realist Theory of Science*. Taylor & Francis Group.

Black, N., Murphy, M., Lamping, D., McKee, M., Sanderson, C., Askham, J., & Marteau, T. (1999). Consensus development methods: a review of best practice in creating clinical guidelines. *Journal of health services research & policy*, *4*(4), 236-248. https://doi.org/10.1177/135581969900400410

Boelen, P. A., Stroebe, M. S., Schut, H. A., & Zijerveld, A. M. (2006). Continuing bonds and grief: a prospective analysis. *Death studies*, *30*(8), 767-776. https://doi.org/10.1080/07481180600852936

Bonanno, G. A., Papa, A., Lalande, K., Westphal, M., & Coifman, K. (2004). The importance of being flexible: The ability to both enhance and suppress emotional expression predicts long-term adjustment. *Psychological science*, *15*(7), 482-487. https://doi.org/10.1111/j.0956-7976.2004.00705.x

Bond, M. H. (1993). Emotions and their expression in Chinese culture. *Journal of Nonverbal Behavior*, *17*(4), 245-262. https://doi.org/10.1007/BF00987240

Bourke, B. (2014). Positionality: Reflecting on the research process. *The qualitative report*, *19*(33), 1-9. https://doi.org/10.46743/2160-3715/2014.1026

Bowlby, J. (1961). Processes of mourning. *The International journal of psycho-analysis*, *42*, 317.

Bowlby, J. (1977). The making and breaking of affectional bonds: I. Aetiology and psychopathology in the light of attachment theory. *The British Journal of Psychiatry*, *130*(3), 201-210. https://doi.org/10.1192/bjp.130.3.201

Bowman, K. W., & Singer, P. A. (2001). Chinese seniors' perspectives on end-of-life decisions. *Social Science & Medicine*, *53*(4), 455-464. https://doi.org/10.1016/s0277-9536(00)00348-8

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

Braun, V., & Clarke, V. (2020). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37-47. https://doi.org/10.1002/capr.12360

Braun, V., & Clarke, V. (2022a). Conceptual and design thinking for thematic analysis. *Qualitative psychology*, *9*(1), 3-26. https://doi.org/10.1037/qup0000196

Braun, V., & Clarke, V. (2022b). *Thematic analysis : a practical guide* (1st ed.). Sage Publications.

Braun, V., & Clarke, V. (2023). Toward good practice in thematic analysis: Avoiding common problems and be (com) ing a knowing researcher. *International journal of transgender health*, *24*(1), 1-6. https://doi.org/10.1080/26895269.2022.2129597

Braun, V., & Clarke, V. (2024). Supporting best practice in reflexive thematic analysis reporting in Palliative Medicine: A review of published research and introduction to the Reflexive Thematic Analysis Reporting Guidelines (RTARG). *Palliative medicine*, *38*(6), 608-616. https://doi.org/10.1177/02692163241234800

Braun, V., & Clarke, V. (2025). Reporting guidelines for qualitative research: A values-based approach. *Qualitative Research in Psychology*, *22*(2), 399-438. https://doi.org/10.1080/14780887.2024.2382244

Breen, L. J., Aoun, S. M., O'Connor, M., Howting, D., & Halkett, G. K. B. (2018). Family Caregivers' Preparations for Death: A Qualitative Analysis. *Journal of pain and symptom management*, *55*(6), 1473-1479. https://doi.org/10.1016/j.jpainsymman.2018.02.018

Breen, L. J., Kawashima, D., Joy, K., Cadell, S., Roth, D., Chow, A., & Macdonald, M. E. (2022). Grief literacy: A call to action for compassionate communities. *Death studies*, *46*(2), 425-433. https://doi.org/10.1080/07481187.2020.1739780

Brewer, M. B., & Chen, Y.-R. (2007). Where (who) are collectives in collectivism? Toward conceptual clarification of individualism and collectivism. *Psychological review*, *114*(1), 133-151. https://doi.org/10.1037/0033-295X.114.1.133

Broom, A., & Kirby, E. (2013). The end of life and the family: hospice patients' views on dying as relational. *Sociology of health & illness*, *35*(4), 499-513. https://doi.org/10.1111/j.1467-9566.2012.01497.x

Callaway, M. V., Connor, S. R., & Foley, K. M. (2018). World Health Organization public health model: a roadmap for palliative care development. *Journal of pain and symptom management*, *55*(2), S6-S13. https://doi.org/10.1016/j.jpainsymman.2017.03.030

Caplan, G. A., Meller, A., Squires, B., Chan, S., & Willett, W. (2006). Advance care planning and hospital in the nursing home. *Age and ageing*, *35*(6), 581-585. https://doi.org/10.1093/ageing/afl063

Carr, D., & Sharp, S. (2014). Do afterlife beliefs affect psychological adjustment to late-life spousal loss? *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *69*(1), 103-112. https://doi.org/10.1093/geronb/gbt063

Carter, S., & Henderson, L. (2005). *Approaches to qualitative data collection in social science* (A. Bowling & S. Ebrahim, Eds. Vol. 1). Open University Press.

Caserta, M., Utz, R., Lund, D., Supiano, K., & Donaldson, G. (2019). Cancer Caregivers' Preparedness for Loss and Bereavement Outcomes: Do Preloss Caregiver Attributes Matter? *Omega (Westport)*, *80*(2), 224-244. https://doi.org/10.1177/0030222817729610

Centeno, C., Garralda, E., Carrasco, J. M., den Herder-van der Eerden, M., Aldridge, M., Stevenson, D., Meier, D. E., & Hasselaar, J. (2017). The palliative care challenge: analysis of barriers and opportunities to integrate palliative care in Europe in the view of national associations. *Journal of palliative medicine*, *20*(11), 1195-1204. https://doi.org/10.1089/jpm.2017.0039

Chan, C. L. W., Chow, A. Y. M., Ho, S. M. Y., Tsui, Y. K. Y., Tin, A. F., Koo, B. W. K., & Koo, E. W. K. (2005). The experience of Chinese bereaved persons: a preliminary study of meaning making and continuing bonds. *Death studies*, *29*(10), 923-947. https://doi.org/10.1080/07481180500299287

Chao, C.-S. C. (2000a). *Guideline of home hospice and palliative care*. Department of Health, Executive Yuan

Chao, C.-S. C. (2000b). *Guideline of Inpatient hospice and palliative care*. Department of Health, Executive Yuan

Chao, C.-S. C. (2015). Hospice palliative care is a universal value and the essence of nursing. *Hu Li Za Zhi*, *62*(2), 5-12. https://doi.org/10.6224/JN.62.2.5

Chen, X., & Fan, R. (2010). The family and harmonious medical decision making: cherishing an appropriate Confucian moral balance. *Journal of Medicine and Philosophy*, *35*(5), 573-586. https://doi.org/10.1093/jmp/jhq046

Cheng, M., Luo, Q., Fang, C., Comery, A., & Troyer, J. (2025). Exploring good death in China: A qualitative study from the perspectives of family members. *Social Science & Medicine*, *367*, 117727. https://doi.org/10.1016/j.socscimed.2025.117727

Cheng, S.-Y., Chen, C.-Y., & Chiu, T.-Y. (2016). Advances of hospice palliative care in Taiwan. *The Korean Journal of Hospice and Palliative Care*, *19*(4), 292-295. https://doi.org/10.14475/kjhpc.2016.19.4.292

Cheng, S.-Y., Hu, W.-Y., Liu, W.-J., Yao, C.-A., Chen, C.-Y., & Chiu, T.-Y. (2008). Good death study of elderly patients with terminal cancer in Taiwan. *Palliative medicine*, *22*(5), 626-632. https://doi.org/10.1177/0269216307087142

Chiang, J.-K., & Kao, Y.-H. (2021). Changes in the place of natural death in Taiwan. *Taiwan Journal of Family Medicine*, *31*(1), 13-25. https://doi.org/10.3966/168232812021033101003

Chow, A. Y. M., Chan, C. L. W., Ho, S. M. Y., Tse, D. M. W., Suen, M. H. P., & Yuen, K. F. K. (2006). Qualitative study of Chinese widows in Hong Kong: insights for psycho-social care in hospice settings. *Palliative medicine*, *20*(5), 513-520. https://doi.org/10.1191/0269216306pm1168oa

Chu, D., Yen, Y.-F., Hu, H.-Y., Lai, Y.-J., Sun, W.-J., Ko, M.-C., Huang, L.-Y., Chen, C.-C., Curtis, J.-R., Lee, Y.-L., & Huang, S.-J. (2018). Factors associated with advance directives completion among patients with advance care planning communication in Taipei, Taiwan. *PLoS One*, *13*(7), e0197552. https://doi.org/10.1371/journal.pone.0197552

Clark, A. M., Lissel, S. L., & Davis, C. (2008). Complex critical realism: tenets and application in nursing research. *Advances in Nursing Science*, *31*(4), E67-E79. https://doi.org/10.1097/01.ANS.0000341421.34457.2a

Clarke, S. M., Hayslip, B., Edmondson, R., & Guarnaccia, C. A. (2003). Religiosity, Afterlife Beliefs, and Bereavement Adjustment in Adulthood. *Journal of Religious Gerontology*, *14*(2-3), 207-224. https://doi.org/10.1300/J078v14n02_08

Collins, M., & Halliday, E. (2020). Public engagement in health research. In C. Walshe & S. Brearley (Eds.), *Handbook of Theory and Methods in Applied Health Research: Questions, Methods and Choices* (pp. 323-340). Edward Elgar Publishing.

Control Yuan of Republic of China/Taiwan. (2019, November 22). *The report of the challenges of providing palliative care in Taiwan*. https://www.cy.gov.tw/News_Content.aspx?n=528&s=14922

Davison, S. N., & Simpson, C. (2006). Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ*, *333*(7574), 886. https://doi.org/doi.org/10.1136/bmj.38965.626250.55

De Roo, M. L., Leemans, K., Claessen, S. J., Cohen, J., Pasman, H. R. W., Deliens, L., Francke, A. L., & EURO IMPACT. (2013). Quality indicators for palliative care: update of a systematic review. *Journal of pain and symptom management*, *46*(4), 556-572. https://doi.org/10.1016/j.jpainsymman.2012.09.013

Dixon, J., Karagiannidou, M., & Knapp, M. (2018). The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers: A Systematic Review and Critical Discussion. *Journal of* *pain and symptom management*, *55*(1), 132-150. https://doi.org/10.1016/j.jpainsymman.2017.04.009

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R., & Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC medical research methodology*, *6*, 35. https://doi.org/10.1186/1471-2288-6-35

Djelantik, A. A. A. M. J., Smid, G. E., Mroz, A., Kleber, R. J., & Boelen, P. A. (2020). The prevalence of prolonged grief disorder in bereaved individuals following unnatural losses: Systematic review and meta regression analysis. *Journal of affective disorders*, *265*, 146-156. https://doi.org/10.1016/j.jad.2020.01.034

Donchin, A. (2001). Understanding autonomy relationally: toward a reconfiguration of bioethical principles. *The Journal of medicine and philosophy*, *26*(4), 365-386. https://doi.org/10.1076/jmep.26.4.365.3012

Durepos, P., Akhtar-Danesh, N., Ploeg, J., Sussman, T., & Kaasalainen, S. (2021). Caring ahead: Mixed methods development of a questionnaire to measure caregiver preparedness for end-of-life with dementia. *Palliative medicine*, *35*(4), 768-784. https://doi.org/10.1177/0269216321994732

Durepos, P., Ploeg, J., Akhtar-Danesh, N., Sussman, T., Orr, E., & Kaasalainen, S. (2020). Caregiver preparedness for death in dementia: an evaluation of existing tools. *Aging & mental health*, *24*(10), 1671-1680. https://doi.org/10.1080/13607863.2019.1622074

Durepos, P., Ploeg, J., Sussman, T., Akhtar-Danesh, N., & Kaasalainen, S. (2020). "A Crazy Roller Coaster at the End": A Qualitative Study of Death Preparedness With Caregivers of Persons With Dementia. *SAGE open nursing*, *6*, 2377960820949111. https://doi.org/0.1177/2377960820949111

Durepos, P., Sussman, T., Ploeg, J., Akhtar-Danesh, N., Punia, H., & Kaasalainen, S. (2019). What Does Death Preparedness Mean for Family Caregivers of Persons With Dementia? *The American journal of hospice & palliative care*, *36*(5), 436-446. https://doi.org/10.1177/1049909118814240

Esposito, J., & Evans-Winters, V. (2021). *Introduction to intersectional qualitative research*. SAGE Publications.

Ewing, G., Brundle, C., Payne, S., Grande, G., & National Association for Hospice at Home. (2013). The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *Journal of pain and symptom management*, *46*(3), 395-405. https://doi.org/10.1016/j.jpainsymman.2012.09.008

Ewing, G., Grande, G., & National Association for Hospice at Home. (2013). Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliative medicine*, *27*(3), 244-256. https://doi.org/10.1177/0269216312440607

Fang, M. L., Malcoe, L. H., Sixsmith, J., Wong, L. Y. M., & Callender, M. (2015). Exploring traditional end-of-life beliefs, values, expectations, and practices among Chinese women living in England: Informing culturally safe care. *Palliative & supportive care*, *13*(5), 1261-1274. https://doi.org/10.1017/S1478951514001126

Fernando, G. V. M. C., & Hughes, S. (2019). Team approaches in palliative care: a review of the literature. *International journal of palliative nursing*, *25*(9), 444-451. https://doi.org/10.12968/ijpn.2019.25.9.444

Ferrell, B. R., Twaddle, M. L., Melnick, A., & Meier, D. E. (2018). National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *Journal of palliative medicine*, *21*(12), 1684-1689. https://doi.org/10.1089/jpm.2018.0431

Field, N. P., & Friedrichs, M. (2004). Continuing bonds in coping with the death of a husband. *Death studies*, *28*(7), 597-620. https://doi.org/10.1080/07481180490476425

Fink, A., Kosecoff, J., Chassin, M., & Brook, R. H. (1984). Consensus methods: characteristics and guidelines for use. *American journal of public health*, *74*(9), 979-983. https://doi.org/10.2105/ajph.74.9.979

Finkelstein, E. A., Bhadelia, A., Goh, C., Baid, D., Singh, R., Bhatnagar, S., & Connor, S. R. (2022). Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021. *Journal of pain and symptom management*, *63*(4), e419-e429. https://doi.org/10.1016/j.jpainsymman.2021.12.015

Foronda, C., Baptiste, D.-L., Reinholdt, M. M., & Ousman, K. (2016). Cultural humility: A concept analysis. *Journal of Transcultural Nursing*, *27*(3), 210-217. https://doi.org/10.1177/1043659615592677

Foth, T., Efstathiou, N., Vanderspank-Wright, B., Ufholz, L.-A., Dütthorn, N., Zimansky, M., & Humphrey-Murto, S. (2016). The use of Delphi and Nominal Group Technique in nursing education: A review. *International journal of nursing studies*, *60*, 112-120. https://doi.org/10.1016/j.ijnurstu.2016.04.015

Freud, S. (1917). Mourning and melancholia. *The standard edition of the complete psychological works of Sigmund Freud*, *14*(1914-1916), 237-258.

Fukui, M., Iwase, S., Sakata, N., Kuroda, Y., Yoshiuchi, K., Nakagawa, K., Quinn, K., & Hudson, P. L. (2013). Effectiveness of using clinical guidelines for conducting palliative care family meetings in Japan. *Supportive Care in Cancer*, *21*(1), 53-58. https://doi.org/10.1007/s00520-012-1491-y

Gallagher, R., & Krawczyk, M. (2013). Family members' perceptions of end-of-life care across diverse locations of care. *BMC palliative care*, *12*(1), 25. https://doi.org/10.1186/1472-684X-12-25

Garden, G., Green, S., Pieniak, S., & Gladman, J. (2016). The Bromhead Care Home Service: the impact of a service for care home residents with dementia on hospital admission and dying in preferred place of care. *Clinical Medicine*, *16*(2), 114-118. https://doi.org/10.7861/clinmedicine.16-2-114

Gillies, J., & Neimeyer, R. A. (2006). Loss, grief, and the search for significance: Toward a model of meaning reconstruction in bereavement. *Journal of Constructivist Psychology*, *19*(1), 31-65. https://doi.org/10.1080/10720530500311182

Gire, J. (2014). How death imitates life: Cultural influences on conceptions of death and dying. *Online Readings in Psychology and Culture*, *6*(2), 3.

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of Dying* (1st ed.). Taylor & Francis Group.

Gómez-Batiste, X., Murray, S. A., Thomas, K., Blay, C., Boyd, K., Moine, S., Gignon, M., Van den Eynden, B., Leysen, B., Wens, J., Engels, Y., Dees, M., & Costantini, M. (2017). Comprehensive and integrated palliative care for people with advanced chronic conditions: an update from several European initiatives and recommendations for policy. *Journal of pain and symptom management*, *53*(3), 509-517. https://doi.org/10.1016/j.jpainsymman.2016.10.361

Gómez-Vírseda, C., de Maeseneer, Y., & Gastmans, C. (2019). Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC medical ethics*, *20*(1), 76. https://doi.org/10.1186/s12910-019-0417-3

Gómez-Vírseda, C., de Maeseneer, Y., & Gastmans, C. (2020). Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities. *BMC medical ethics*, *21*(1), 50. https://doi.org/10.1186/s12910-020-00495-1

Grignoli, N., Di Bernardo, V., & Malacrida, R. (2018). New perspectives on substituted relational autonomy for shared decision-making in critical care. *Critical Care*, *22*(1), 260. https://doi.org/10.1186/s13054-018-2187-6

Hamilton, S., Golding, B., & McCarthy, J. R. (2022). Do we need to decolonise bereavement studies? *Bereavement*, *1*. https://doi.org/10.54210/bj.2022.20

Hauksdóttir, A., Steineck, G., Fürst, C. J., & Valdimarsdóttir, U. (2010). Long-term harm of low preparedness for a wife's death from cancer--a population-based study of widowers 4-5 years after the loss. *American journal of epidemiology*, *172*(4), 389-396. https://doi.org/10.1093/aje/kwq147

Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: reviewing disparate data systematically. *Qualitative health research*, *12*(9), 1284-1299. https://doi.org/10.1177/1049732302238251

Hebert, R. S., Prigerson, H. G., Schulz, R., & Arnold, R. M. (2006). Preparing Caregivers for the Death of a Loved One: A Theoretical Framework and Suggestions for Future Research. *Journal of palliative medicine*, *9*(5), 1164-1171. https://doi.org/10.1089/jpm.2006.9.1164

Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *Journal of pain and symptom management*, *37*(1), 3-12. https://doi.org/10.1016/j.jpainsymman.2007.12.010

Hedtke, L., & Winslade, J. (2004). *Remembering Lives : Conversations with the Dying and the Bereaved*. Taylor & Francis Group.

Hilgeman, M. M., Allen, R. S., Snow, A. L., Durkin, D. W., DeCoster, J., & Burgio, L. (2014). Preserving Identity and Planning for Advance Care (PIPAC): preliminary outcomes from a patient-centered intervention for individuals with mild dementia. *Aging & mental health*, *18*(4), 411-424. https://doi.org/10.1080/13607863.2013.868403

Hirai, K., Miyashita, M., Morita, T., Sanjo, M., & Uchitomi, Y. (2006). Good death in Japanese cancer care: a qualitative study. *Journal of pain and symptom management*, *31*(2), 140-147. https://doi.org/10.1016/j.jpainsymman.2005.06.012

Hofstede, G. H. (1984). *Culture's consequences: International differences in work-related values*. Sage Publications.

Hofstede, G. H. (2001). *Culture's consequences : comparing values, behaviors, institutions, and organizations across nations* (2nd ed.). Sage Publications.

Holland, J. M., Thompson, K. L., Rozalski, V., & Lichtenthal, W. G. (2014). Bereavement-related regret trajectories among widowed older adults. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *69*(1), 40-47. https://doi.org/10.1093/geronb/gbt050

Holtslander, L., Baxter, S., Mills, K., Bocking, S., Dadgostari, T., Duggleby, W., Duncan, V., Hudson, P., Ogunkorode, A., & Peacock, S. (2017). Honoring the voices of bereaved caregivers: a Metasummary of qualitative research. *BMC palliative care*, *16*(1), 48. https://doi.org/10.1186/s12904-017-0231-y

Hovland, C. A., & Fuller, K. A. (2022). African American Family Caregivers Share How they Prepared for the Death of an Older Adult with Dementia: A Pilot Study of Hospice Care in A Nursing Home. *Journal of social work in end-of-life & palliative care*, *18*(2), 129-145. https://doi.org/10.1080/15524256.2022.2042458

Hovland, C. A., & Kramer, B. J. (2019). Barriers and Facilitators to Preparedness for Death: Experiences of Family Caregivers of Elders with Dementia. *Journal of social work in end-of-life & palliative care*, *15*(1), 55-74. https://doi.org/10.1080/15524256.2019.1595811

Hovland-Scafe, C. A., & Kramer, B. J. (2017). Preparedness for Death: How Caregivers of Elders With Dementia Define and Perceive its Value. *The Gerontologist*, *57*(6), 1093-1102. https://doi.org/10.1093/geront/gnw092

Howarth, G. (2007). *Death and dying: A sociological introduction*. Polity.

Hsiung, N.-H., Ni, C.-F., Silber, C., Jacques, J., & Dykeman, C. (2025). Filial Care in Transition: Linguistic and Emotional Patterns in Online Discourse Among Emerging Adults in Taiwan. *Behavioral Sciences*, *15*(10), 1417. https://doi.org/10.3390/bs15101417

Hsu, C.-y., O'Connor, M., & Lee, S. (2009). Understandings of death and dying for people of Chinese origin. *Death studies*, *33*(2), 153-174. https://doi.org/10.1080/07481180802440431

Hu, W.-Y., Chiu, T.-Y., Chuang, R.-B., & Chen, C.-Y. (2002). Solving family-related barriers to truthfulness in cases of terminal cancer in Taiwan: a professional perspective. *Cancer nursing*, *25*(6), 486-492. https://doi.org/10.1097/00002820-200212000-00014

Hudson, P., Girgis, A., Thomas, K., Philip, J., Currow, D. C., Mitchell, G., Parker, D., Liew, D., Brand, C., Le, B., & Moran, J. (2021). Do family meetings for hospitalised palliative care patients improve outcomes and reduce health care costs? A cluster randomised trial. *Palliative medicine*, *35*(1), 188-199. https://doi.org/10.1177/0269216320967282

Hudson, P., Quinn, K., O'Hanlon, B., & Aranda, S. (2008). Family meetings in palliative care: multidisciplinary clinical practice guidelines. *BMC palliative care*, *7*, 12. https://doi.org/10.1186/1472-684X-7-12

Hudson, P., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M., Hall, C., Trauer, T., Bolleter, A., Clarke, D. M., & Bauld, C. (2012). Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *Journal of palliative medicine*, *15*(6), 696-702. https://doi.org/10.1089/jpm.2011.0466

Hui, C. H., & Triandis, H. C. (1986). Individualism-collectivism: A study of cross-cultural researchers. *Journal of cross-cultural psychology*, *17*(2), 225-248. https://doi.org/10.1177/0022002186017002006

Hung, Y. C. (2013). The analysis of mourning experiences in traditional funeral rituals: from death to encoffining ceremony. *Chinese Journal of Guidance and Counselling*(37), 55-88.

Hunt, K. J., Richardson, A., Darlington, A.-S. E., & Addington-Hall, J. M. (2019). Developing the methods and questionnaire (VOICES-SF) for a national retrospective mortality follow-back survey of palliative and end-of-life care in England. *BMJ Supportive & Palliative Care*, *9*(1), e5. https://doi.org/10.1136/bmjspcare-2016-001288

Hwang, K.-K. (1999). Filial piety and loyalty: Two types of social identification in Confucianism. *Asian Journal of Social Psychology*, *2*(1), 163-183. https://doi.org//10.1111/1467-839X.00031

Ikari, T., Hiratsuka, Y., Cheng, S.-Y., Miyashita, M., Morita, T., Mori, M., Uneno, Y., Amano, K., Uehara, Y., Yamaguchi, T., Maeda, I., & Inoue, A. (2022). Factors associated with good death of patients with advanced cancer: A prospective study in Japan. *Supportive Care in Cancer*, *30*(11), 9577-9586. https://doi.org/10.1007/s00520-022-07363-1

Inglehart, R., & Baker, W. E. (2000). Modernization, cultural change, and the persistence of traditional values. *American sociological review*, *65*(1), 19-51. https://doi.org/10.2307/2657288

Inglehart, R. F. (2008). Changing values among western publics from 1970 to 2006. *West european politics*, *31*(1-2), 130-146. https://doi.org/10.1080/01402380701834747

Ishida, M., Onishi, H., Matsubara, M., Tada, Y., Ito, H., Narabayashi, M., Sasaki, Y., Nomura, S., & Uchitomi, Y. (2012). Psychological distress of the bereaved seeking medical counseling at a cancer center. *Japanese journal of clinical oncology*, *42*(6), 506-512. https://doi.org/10.1093/jjco/hys051

Ito, M., Tanida, N., & Turale, S. (2010). Perceptions of Japanese patients and their family about medical treatment decisions. *Nursing & health sciences*, *12*(3), 314-321. https://doi.org/10.1111/j.1442-2018.2010.00532.x

Jeon, E. D., & Jing, J. (2023). A study of end-of-life care communication and decision-making in China by exploring filial piety and medical information concealment. *Asian Journal of Medical Humanities*, *2*(1), 20230006. https://doi.org/10.1515/ajmedh-2023-0006

Jeong-ho, J., & Naehui, K. (2022). Introduction: Theory of Postmodernism. *Art in translation*, *14*(4), 381-391. https://doi.org/10.1080/17561310.2022.2163084

Jiang, J., & May, P. (2021). Proportion of deaths in hospital in European countries: trends and associations from panel data (2005–2017). *European journal of public health*, *31*(6), 1176-1183. https://doi.org/10.1093/eurpub/ckab169

Jones, J., & Hunter, D. (1995). Consensus methods for medical and health services research. *BMJ*, *311*(7001), 376-380. https://doi.org/10.1136/bmj.311.7001.376

Jung, Y., Yeom, H.-E., & Lee, N.-R. (2021). The Effects of Counseling about Death and Dying on Perceptions, Preparedness, and Anxiety Regarding Death among Family Caregivers Caring for Hospice Patients: A Pilot Study. *Journal of hospice and palliative care*, *24*(1), 46-55. https://doi.org/10.14475/jhpc.2021.24.1.46

Jung, Y.-Y., & Hung, C.-H. (2017). The grief process of middle-adulthood which facing father's death of cancer. *Guidance Quarterly*, *53*(1), 25-34.

Jünger, S., & Payne, S. (2020). The crossover artist: consensus methods in health research. In C. Walshe & S. Brearley (Eds.), *Handbook of Theory and Methods in Applied Health Research: Questions, Methods and Choices* (pp. 199-213). Edward Elgar.

Kaltman, S., & Bonanno, G. A. (2003). Trauma and bereavement: examining the impact of sudden and violent deaths. *Journal of anxiety disorders*, *17*(2), 131-147. https://doi.org/10.1016/s0887-6185(02)00184-6

Kasai, H. (2022). Taiwanese multiculturalism and the political appropriation of new immigrants' languages. *Comparative Education*, *58*(4), 509-525. https://doi.org/10.1080/03050068.2022.2099657

Kawashima, D., Kempe, T., & Koga, Y. (2023). "I want my loved one back virtually": Exploring the desire of bereaved people to create and maintain digital bonds with their deceased loved ones. *OMEGA-Journal of Death and Dying*, *92*(2), 1049–1065. https://doi.org/10.1177/00302228231194857

Ke, L.-S., Hu, W.-Y., Chen, M.-J., Cheng, H.-C., & Lin, L.-H. (2020). Advance Care Planning to Improve End-of-Life Decision-Making Consistency between Older People and Their Surrogates in Taiwan. *Journal of palliative medicine*, *23*(3), 325-336. https://doi.org/10.1089/jpm.2019.0277

Keegan, O., Murphy, I., Benkel, I., Limonero, J. T., Relf, M., & Guldin, M.-B. (2021). Using the Delphi technique to achieve consensus on bereavement care in palliative care in Europe: An EAPC White Paper. *Palliative medicine*, *35*(10), 1908-1922. https://doi.org/10.1177/02692163211043000

Kehl, K. A. (2006). Moving toward peace: an analysis of the concept of a good death. *American Journal of Hospice and Palliative Medicine*, *23*(4), 277-286. https://doi.org/10.1177/1049909106290380

Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine*, *106*(12), 1071-1075. https://doi.org/10.1093/qjmed/hct200

Kim, Y., Carver, C. S., Spiegel, D., Mitchell, H. R., & Cannady, R. S. (2017). Role of family caregivers' self-perceived preparedness for the death of the cancer patient in long-term adjustment to bereavement. *Psycho-oncology*, *26*(4), 484-492. https://doi.org/10.1002/pon.4042

Kishino, M., Ellis-Smith, C., Afolabi, O., & Koffman, J. (2022). Family involvement in advance care planning for people living with advanced cancer: a systematic mixed-methods review. *Palliative medicine*, *36*(3), 462-477. https://doi.org/10.1177/02692163211068282

Klass, D. (1996). Grief in an Eastern culture: Japanese ancestor worship. In D. Klass, P. R. Silverman, & S. L. Nickman (Eds.), *Continuing Bonds: New Understandings of Grief* (pp. 59-70). Taylor & Francis.

Klass, D., & Silverman, P. R. (1996). Introduction: what's the problem? In D. Klass, P. R. Silverman, & S. L. Nickman (Eds.), *Continuing Bonds: New Understandings of Grief* (pp. 3-27). Taylor & Francis.

Klass, D., Silverman, P. R., & Nickman, S. L. (1996). *Continuing bonds: New understandings of grief*. Taylor & Francis.

Kodba-Čeh, H., Lunder, U., Bulli, F., Caswell, G., van Delden, J. J. M., Kars, M. C., Korfage, I. J., Miccinesi, G., Rietjens, J. A. C., Seymour, J., Toccafondi, A., Zwakman, M., Pollock, K., & ACTION Consortium. (2022). How can advance care planning support hope in patients with advanced cancer and their families: A qualitative study as part of the international ACTION trial. *European Journal of Cancer Care*, *31*(6), e13719. https://doi.org/10.1111/ecc.13719

Koo, B. W. S., Tin, A. F., Koo, E. W. K., & Lee, S. M. (2006). When east meets west: Implications for bereavement counseling. In C. L. W. Chan & A. Y. M. Chow (Eds.), *Death, dying and bereavement: A Hong Kong Chinese experience* (pp. 261–271). Hong Kong University Press.

Korfage, I. J., Carreras, G., Arnfeldt Christensen, C. M., Billekens, P., Bramley, L., Briggs, L., Bulli, F., Caswell, G., Červ, B., van Delden, J. J. M., Deliens, L., Dunleavy, L., Eecloo, K., Gorini, G., Groenvold, M., Hammes, B., Ingravallo, F., Jabbarian, L. J., Kars, M. C., . . . Rietjens, J. A. C. (2020). Advance care planning in patients with advanced cancer: a 6-country, cluster-randomised clinical trial. *PLoS medicine*, *17*(11), e1003422. https://doi.org/10.1371/journal.pmed.1003422

Krishna, L. K. R., Watkinson, D. S., & Beng, N. L. (2015). Limits to relational autonomy—the Singaporean experience. *Nursing ethics*, *22*(3), 331-340. https://doi.org/10.1177/0969733014533239

Kristensen, P., Weisaeth, L., & Heir, T. (2012). Bereavement and mental health after sudden and violent losses: a review. *Psychiatry*, *75*(1), 76-97. https://doi.org/10.1521/psyc.2012.75.1.76

Krychiw, J. K., James, R., & Ward-Ciesielski, E. F. (2018). Suddenness of death as a determinant of differential grief experiences. *Bereavement Care*, *37*(3), 92-100. https://doi.org/10.1080/02682621.2018.1539312

Krys, K., de Almeida, I., Wasiel, A., & Vignoles, V. L. (2025). WEIRD–Confucian comparisons: Ongoing cultural biases in psychology's evidence base and some recommendations for improving global representation. *American psychologist*, *80*(2), 247–263. https://doi.org/10.1037/amp0001298

Lai, C., Luciani, M., Morelli, E., Galli, F., Cappelluti, R., Penco, I., Aceto, P., & Lombardo, L. (2014). Predictive role of different dimensions of burden for risk of complicated grief in caregivers of terminally ill patients. *American Journal of Hospice and Palliative Medicine*, *31*(2), 189-193. https://doi.org/10.1177/1049909113490227

Lai, W.-S., Li, W.-W., & Chiu, W.-H. (2021). Grieving in silence: Experiences of bereaved Taiwanese family members whose loved ones died from cancer. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*, *52*, 101967. https://doi.org/10.1016/j.ejon.2021.101967

Laws & Regulations Database of The Republic of China/Taiwan. (2000). *Natural Death Act (Hospice Palliative Care Act)*. Retrieved 01 August from https://law.moj.gov.tw/ENG/LawClass/LawAll.aspx?pcode=L0020066

Laws & Regulations Database of The Republic of China/Taiwan. (2019). *The Patient Right to Autonomy Act*. Retrieved 01 August from https://law.moj.gov.tw/ENG/LawClass/LawAll.aspx?pcode=L0020189

Le, H., Zhou, N., Ogrodniczuk, J., & Killikelly, C. (2025). Mourning rituals impact grief outcomes in East and Southeast Asia: A mixed-methods review. *Death studies*, 1-12. https://doi.org/10.1080/07481187.2025.2561079

Lee, M.-h. (2010). Confucian traditions in modern East Asia: Their destinies and prospects. *Oriens Extremus*, *49*, 237-247.

Lee, S.-C., Shih, C.-Y., Chen, S.-T., Lee, C.-Y., Li, S.-R., Tang, C.-C., Tsai, J.-S., Cheng, S.-Y., & Huang, H.-L. (2024). Factors Contributing to Non-Concordance Between End-of-Life Care and Advance Care Planning. *Journal of pain and symptom management*, *67*(6), 544-553. https://doi.org/10.1016/j.jpainsymman.2024.03.004

Lee, W.-L., Hou, Y.-C., & Lin, Y.-S. (2017). Revisiting the Continuing Bonds Theory: The Cultural Uniqueness of the Bei Dao Phenomenon in Taiwanese Widows/Widowers. *Qualitative health research*, *27*(12), 1892-1904. https://doi.org/10.1177/1049732317697097

Lewis, M. J. (2007). *Medicine and care of the dying: a modern history*. Oxford University Press.

Li, Y., Chan, W. C. H., & Marrable, T. (2024). “I never told my family I was grieving for my mom”: The not-disclosing-grief experiences of parentally bereaved adolescents and young adults in Chinese families. *Family process*, *63*(1), 379-391. https://doi.org/10.1111/famp.12865

Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2024). ‘A good ending but not the end’: Exploring family preparations surrounding a relative’s death and the Afterlife–A qualitative study. *Palliative medicine*, *38*(10), 1184–1193. https://doi.org/10.1177/02692163241280016

Liang, H.-J., Xiong, Q., Lin, P.-C., Tsai, J.-H., & Preston, N. (2025). ‘Regrets become a lasting source of pain’: A qualitative study on family caregivers’ experiences leading up to a relative’s death. *Palliative medicine*, *39*(3), 401–412. https://doi.org/10.1177/02692163251316677

Liang, H.-J., Xiong, Q., & Preston, N. (2025). Methodological reflections to support good practice in using nominal group techniques: Insights from applications in palliative care studies. *Palliative medicine*, *39*(10), 1099-1108.

Liang, H.-J., Xiong, Q., Remawi, B. N., & Preston, N. (2024). Taiwanese family members’ bereavement experience following an expected death: a systematic review and narrative synthesis. *BMC palliative care*, *23*(1), 14. https://doi.org/10.1186/s12904-024-01344-3

Lichtenthal, W. G., Roberts, K. E., Donovan, L. A., Breen, L. J., Aoun, S. M., Connor, S. R., & Rosa, W. E. (2024). Investing in bereavement care as a public health priority. *The Lancet Public Health*, *9*(4), e270-e274. https://doi.org/10.1016/S2468-2667(24)00030-6

Lin, M.-H., & Chou, Y.-J. (2024). Exploring the influence of the impending death discharge tradition on home death rate in Taiwan. *Journal of the Chinese Medical Association*, *87*(8), 746-753. https://doi.org/10.1097/JCMA.0000000000001125

Lin, M.-L., Huang, C.-T., & Chen, C.-H. (2017). Reasons for family involvement in elective surgical decision-making in Taiwan: a qualitative study. *Journal of clinical nursing*, *26*(13-14), 1969-1977. https://doi.org/10.1111/jocn.13600

Lindemann, E. (1963). Symptomatology and management of acute grief. *Pastoral psychology*, *14*(6), 8-18. https://doi.org/10.1007/BF01770375

Livingston, G., Lewis-Holmes, E., Pitfield, C., Manela, M., Chan, D., Constant, E., Jacobs, H., Wills, G., Carson, N., & Morris, J. (2013). Improving the end-of-life for people with dementia living in a care home: an intervention study. *International psychogeriatrics*, *25*(11), 1849-1858. https://doi.org/10.1017/S1041610213001221

Lowers, J., Scardaville, M., Hughes, S., & Preston, N. J. (2020). Comparison of the experience of caregiving at end of life or in hastened death: a narrative synthesis review. *BMC Palliat Care*, *19*(1), 154. https://doi.org/10.1186/s12904-020-00660-8

Mackenzie, C., & Stoljar, N. (2000). *Relational autonomy: Feminist perspectives on automony, agency, and the social self*. Oxford University Press.

Malhotra, C., Shafiq, M., & Batcagan-Abueg, A. P. M. (2022). What is the evidence for efficacy of advance care planning in improving patient outcomes? A systematic review of randomised controlled trials. *BMJ open*, *12*(7), e060201. https://doi.org/10.1136/bmjopen-2021-060201

Manevich, A., & Aluma, S. (2025). Artificial Continuing Bonds: A Proposed Framework for Responsible Integration of Generative AI in Clinical Thanatology. *OMEGA-Journal of Death and Dying*, 00302228251372418. https://doi.org/10.1177/00302228251372418

Martina, D., Lin, C.-P., Kristanti, M. S., Bramer, W. M., Mori, M., Korfage, I. J., van der Heide, A., van der Rijt, C. C. D., & Rietjens, J. A. C. (2021). Advance care planning in Asia: a systematic narrative review of healthcare professionals' knowledge, attitude, and experience. *Journal of the American Medical Directors Association*, *22*(2), 349.e341–349.e328. https://doi.org/10.1016/j.jamda.2020.12.018

Matsumura, S., Bito, S., Liu, H., Kahn, K., Fukuhara, S., Kagawa-Singer, M., & Wenger, N. (2002). Acculturation of attitudes toward end-of-life care: a cross-cultural survey of Japanese Americans and Japanese. *Journal of General Internal Medicine*, *17*(7), 531-539. https://doi.org/10.1046/j.1525-1497.2002.10734.x

Matsuzaka, S., Ohba, A., Masukawa, K., Aoyama, M., Morita, T., Kizawa, Y., Tsuneto, S., Shima, Y., & Miyashita, M. (2024). Factors associated with the preparedness for bereavement in families of patients with cancer: A secondary analysis of a nationwide bereaved family survey. *Psycho-oncology*, *33*(1), e6276. https://doi.org/10.1002/pon.6276

McEvoy, P., & Richards, D. (2016). A critical realist rationale for using a combination of quantitative and qualitative methods. *Journal of Research in Nursing*, *11*(1), 66-78. https://doi.org/10.1177/1744987106060192

McNamara, B. (2001). *Fragile lives: death, dying and care.* Open University Press.

Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry*, *24*(4), 261-271. https://doi.org/10.1016/j.jagp.2016.01.135

Milberg, A., Olsson, E.-C., Jakobsson, M., Olsson, M., & Friedrichsen, M. (2008). Family members' perceived needs for bereavement follow-up. *Journal of pain and symptom management*, *35*(1), 58-69. https://doi.org/10.1016/j.jpainsymman.2007.02.039

Ministry of Health and Welfare. (2020, June 16). *2019 Statistics of death of populaion in Taiwan*. Retrieved February 8 from https://www.mohw.gov.tw/cp-16-54482-1.html

Ministry of Health and Welfare of the Republic of China/Taiwan. (2021). *Statistics of death of population in Taiwan*. Retrieved June 30 from https://dep.mohw.gov.tw/dos/lp-5069-113.html

Ministry of Health and Welfare of the Republic of China/Taiwan. (2022). *Statistics of population in 2021 in Taiwan*. Retrieved April 13 from https://dep.mohw.gov.tw/DOS/cp-5083-55377-113.html

Ministry of Health and Welfare of the Republic of China/Taiwan. (2024). *Life expectancy and mortality rate in Taiwan*. Retrieved April 13 from https://dep.mohw.gov.tw/DOS/cp-5083-55378-113.html

Miyashita, M., Morita, T., Sato, K., Hirai, K., Shima, Y., & Uchitomi, Y. (2008a). Factors contributing to evaluation of a good death from the bereaved family member's perspective. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *17*(6), 612-620. https://doi.org/10.1002/pon.1283

Miyashita, M., Morita, T., Sato, K., Hirai, K., Shima, Y., & Uchitomi, Y. (2008b). Good death inventory: a measure for evaluating good death from the bereaved family member's perspective. *Journal of pain and symptom management*, *35*(5), 486-498. https://doi.org/10.1016/j.jpainsymman.2007.07.009

Miyashita, M., Sanjo, M., Morita, T., Hirai, K., & Uchitomi, Y. (2007). Good death in cancer care: a nationwide quantitative study. *Annals of Oncology*, *18*(6), 1090-1097. https://doi.org/10.1093/annonc/mdm068

Mo, H. N., Shin, D. W., Woo, J. H., Choi, J. Y., Kang, J., Baik, Y. J., Huh, Y. R., Won, J. H., Park, M. H., & Cho, S. H. (2012). Is patient autonomy a critical determinant of quality of life in Korea? End-of-life decision making from the perspective of the patient. *Palliative medicine*, *26*(3), 222-231. https://doi.org/10.1177/0269216311405089

Morrison, R. S., Meier, D. E., & Arnold, R. M. (2021). What’s wrong with advance care planning? *JAMA*, *326*(16), 1575-1576. https://doi.org/10.1001/jama.2021.16430

Murray, S. A., Firth, A., Schneider, N., Van den Eynden, B., Gomez-Batiste, X., Brogaard, T., Villanueva, T., Abela, J., Eychmuller, S., Mitchell, G., Downing, J., Sallnow, L., van Rijswijk, E., Barnard, A., Lynch, M., Fogen, F., & Monine, S. (2015). Promoting palliative care in the community: production of the primary palliative care toolkit by the European Association of Palliative Care

Taskforce in primary palliative care. *Palliative medicine*, *29*(2), 101-111. https://doi.org/10.1177/0269216314545006

National Health Insurance Administration. (2021, October 15). *The palliative care services in Taiwan*. Retrieved February 03 from https://www.nhi.gov.tw/Content_List.aspx?n=D8386FD9AD1B49D3&topn=D39E2B72B0BDFA15

National Health Insurance Administration, T. (2024, 05 February 2025). *National health insurance home-based acute care pilot program*. Retrieved 06 October from https://www.nhi.gov.tw/ch/lp-3660-1.html

Neimeyer, R. A. (2000). Searching for the meaning of meaning: Grief therapy and the process of reconstruction. *Death studies*, *24*(6), 541-558. https://doi.org/10.1080/07481180050121480

Neimeyer, R. A. (2019). Meaning reconstruction in bereavement: Development of a research program. *Death studies*, *43*(2), 79-91. https://doi.org/10.1080/07481187.2018.1456620

NICE guideline [NG150]. (2020). *Supporting adult carers*. Retrieved 28 February from https://www.nice.org.uk/guidance/ng150

NICE guidline [NG142]. (2019). *End of life care for adults: service delivery*. Retrieved 28 February from https://www.nice.org.uk/guidance/ng142

Nicholas, L. H., Bynum, J. P., Iwashyna, T. J., Weir, D. R., & Langa, K. M. (2014). Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Affairs*, *33*(4), 667-674. https://doi.org/10.1377/hlthaff.2013.1258

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M. B. (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical psychology review*, *44*, 75-93. https://doi.org/10.1016/j.cpr.2016.01.002

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Vedsted, P., Bro, F., & Guldin, M. B. (2017). Preloss grief in family caregivers during end-of-life cancer care: A nationwide population-based cohort study. *Psycho-oncology*, *26*(12), 2048-2056. https://doi.org/10.1002/pon.4416

Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2016). Developing death literacy. *Progress in Palliative Care*, *24*(1), 31-35. https://doi.org/10.1080/09699260.2015.1103498

Ntini, E. (2016). Today's world: Can modernisation theory still explain it convincingly? *Journal of Sociology and Social Anthropology*, *7*(1), 56-67. https://doi.org/10.1080/09766634.2016.11885702

Ntizimira, C. R., Dunne, M., Rana, S., & Birindabagabo, P. (2024). End-of-life care needs decolonising. *BMJ*, *387*. https://doi.org/10.1136/bmj.q2810

Park, C. L. (2005). Religion as a meaning-making framework in coping with life stress. *Journal of social issues*, *61*(4), 707-729. https://doi.org/10.1111/j.1540-4560.2005.00428.x

Park, S.-Y., Lee, B., Seon, J. Y., & Oh, I.-H. (2021). A national study of life-sustaining treatments in South Korea: what factors affect decision-making? *Cancer research and treatment*, *53*(2), 593-600. https://doi.org/10.4143/crt.2020.803

Parker, S. M., Clayton, J. M., Hancock, K., Walder, S., Butow, P. N., Carrick, S., Currow, D., Ghersi, D., Glare, P., Hagerty, R., & Tattersall, M. H. (2007). A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management*, *34*(1), 81-93. https://doi.org/10.1016/j.jpainsymman.2006.09.035

Parkes, C. M. (1970). The first year of bereavement: A longitudinal study of the reaction of London widows to the death of their husbands. *Psychiatry*, *33*(4), 444-467. https://doi.org/10.1080/00332747.1970.11023644

Parkes, C. M. (1985). Bereavement. *The British Journal of Psychiatry*, *146*(1), 11-17. https://doi.org/10.1192/bjp.146.1.11

Parkinson, S., Eatough, V., Holmes, J., Stapley, E., & Midgley, N. (2016). Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qualitative Research in Psychology*, *13*(2), 109-129. https://doi.org/10.1080/14780887.2015.1119228

Pasman, H. R. W., Brandt, H. E., Deliens, L., & Francke, A. L. (2009). Quality indicators for palliative care: a systematic review. *Journal of pain and symptom management*, *38*(1), 145-156. https://doi.org/10.1016/j.jpainsymman.2008.07.008

Pastrana, T., Vallath, N., Mastrojohn, J., Namukwaya, E., Kumar, S., Radbruch, L., & Clark, D. (2010). Disparities in the contribution of low-and middle-income countries to palliative care research. *Journal of pain and symptom management*, *39*(1), 54-68. https://doi.org/10.1016/j.jpainsymman.2009.05.023

Penson, R. T. (2004). Bereavement across Cultures. In R. J. Moore & D. Spiegel (Eds.), *Cultures. Cancer, culture, and communication* (pp. 241-279). Kluwer Academic/Plenum Publishers.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version*, *1*(1), b92.

Quill, T. E., & Abernethy, A. P. (2013). Generalist plus specialist palliative care—creating a more sustainable model. *New England Journal of Medicine*, *368*(13), 1173-1175. https://doi.org/10.1056/NEJMp1215620

Radbruch, L., De Lima, L., Knaul, F., Wenk, R., Ali, Z., Bhatnaghar, S., Blanchard, C., Bruera, E., Buitrago, R., Burla, C., Callaway, M., Munyoro, E. C., Centeno, C., Cleary, J., Connor, S., Davaasuren, O., Downing, J., Foley, K., Goh, C., . . . Pastrana, T. (2020). Redefining Palliative Care-A New Consensus-Based Definition. *Journal of pain and symptom management*, *60*(4), 754-764. https://doi.org/10.1016/j.jpainsymman.2020.04.027

Redman, S., Carrick, S., Cockburn, J., & Hirst, S. (1997). Consulting about priorities for the NHMRC National Breast Cancer Centre: how good is the nominal group technique. *Australian and New Zealand journal of public health*, *21*(3), 250-256. https://doi.org/10.1111/j.1467-842x.1997.tb01695.x

Rehman, A. A., & Alharthi, K. (2016). An introduction to research paradigms. *International journal of educational investigations*, *3*(8), 51-59.

Reigada, C., Pais-Ribeiro, J. L., Novella, A., & Gonçalves, E. (2015). The caregiver role in palliative care: a systematic review of the literature. *Health Care Current Reviews*, *3*(2), 1000143. https://doi.org/10.4172/2375-4273.1000143

Riegel, M., Buckley, T., & Randall, S. (2023). Family's experience of memory making in adult intensive care and its use in early bereavement: A descriptive qualitative study. *Journal of clinical nursing*, *32*(17-18), 6648-6661. https://doi.org/10.1111/jocn.16725

Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., van der Heide, A., Heyland, D. K., Houttekier, D., Janssen, D. J. A., Orsi, L., Payne, S., Seymour, J., Jox, R. J., Korfage, I. J., & European Association for Palliative Care. (2017). Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *The Lancet Oncology*, *18*(9), e543-e551. https://doi.org/10.1016/S1470-2045(17)30582-X

Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. In *Analyzing qualitative data* (pp. 173-194). Routledge.

Root, B. L., & Exline, J. J. (2014). The role of continuing bonds in coping with grief: overview and future directions. *Death studies*, *38*(1-5), 1-8. https://doi.org/10.1080/07481187.2012.712608

Rosa, W. E., Ahmed, E., Chaila, M. J., Chansa, A., Cordoba, M. A., Dowla, R., Gafer, N., Khan, F., Namisango, E., Rodriguez, L., Knaul, F. M., & Pettus, K. I. (2022). Can you hear us now? Equity in global advocacy for palliative care. *Journal of pain and symptom management*, *64*(4), e217-e226. https://doi.org/10.1016/j.jpainsymman.2022.07.004

Rothaupt, J. W., & Becker, K. (2007). A literature review of Western bereavement theory: From decathecting to continuing bonds. *The Family Journal*, *15*(1), 6-15. https://doi.org/10.1177/1066480706294031

Salifu, Y. (2025). Ethical challenges in sensitive research: a reflective narrative on managing the clinician-researcher dual role. *BMC palliative care*, *24*(1), 205.

Sallnow, L., Smith, R., Ahmedzai, S. H., Bhadelia, A., Chamberlain, C., Cong, Y., Doble, B., Dullie, L., Durie, R., Finkelstein, E. A., Guglani, S., Hodson, M., Husebø, B. S., Kellehear, A., Kitzinger, C., Knaul, F. M., Murray, S. A., Neuberger, J., O'Mahony, S., . . . Lancet Commission on the Value of Death. (2022). Report of the Lancet Commission on the Value of Death: bringing death back into life. *The Lancet*, *399*(10327), 837-884. https://doi.org/10.1016/S0140-6736(21)02314-X

Schulz, R., Boerner, K., Klinger, J., & Rosen, J. (2015). Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *Journal of palliative medicine*, *18*(2), 127-133. https://doi.org/10.1089/jpm.2014.0309

Schuster-Wallace, C., Nouvet, E., Rigby, I., Krishnaraj, G., de Laat, S., Schwartz, L., & Hunt, M. (2022). Culturally sensitive palliative care in humanitarian action: Lessons from a critical interpretive synthesis of culture in palliative care literature. *Palliative & supportive care*, *20*(4), 582-592. https://doi.org/10.1017/S1478951521000894

Sellars, M., Chung, O., Nolte, L., Tong, A., Pond, D., Fetherstonhaugh, D., McInerney, F., Sinclair, C., & Detering, K. M. (2019). Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies. *Palliative medicine*, *33*(3), 274-290. https://doi.org/10.1177/0269216318809571

Selman, L. (2024). Facing death differently: revolutionising our approach to death and grief. *BMJ*, *387*, q2815. https://doi.org/10.1136/bmj.q2815

Selman, L. E., Turner, N., Dawson, L., Chamberlain, C., Mustan, A., Rivett, A., & Fox, F. (2023). Engaging and supporting the public on the topic of grief and bereavement: an evaluation of Good Grief Festival. *Palliative Care and Social Practice*, *17*, 26323524231189523. https://doi.org/10.1177/26323524231189523

Shih, F.-J., Lin, H.-R., Gau, M.-L., Chen, C.-H., Hsiao, S.-M., Shih, S.-N., & Sheu, S.-J. (2009). Spiritual needs of Taiwan's older patients with terminal cancer. *Oncology nursing forum*, *36*(1), E31–E38. https://doi.org/10.1188/09.ONF.E31-E38

Shih, F.-L. (2010). Chinese ‘bad death’practices in Taiwan: Maidens and modernity. *Mortality*, *15*(2), 122-137. https://doi.org/10.1080/13576275.2010.482770

Shih, S.-Y. (1982). Religious Behavior and Religious Phenomena (Part I). *Chinese Buddhism Monthly*, *26*(5), 3-10.

Steffen, E. M., & Klass, D. (2018). Culture, contexts and connections: a conversation with Dennis Klass about his life and work as a bereavement scholar. *Mortality*, *23*(3), 203-214. https://doi.org/10.1080/13576275.2018.1469481

Steinhauser, K. E., Bosworth, H. B., Clipp, E. C., McNeilly, M., Christakis, N. A., Parker, J., & Tulsky, J. A. (2002). Initial assessment of a new instrument to measure quality of life at the end of life. *Journal of palliative medicine*, *5*(6), 829-841. https://doi.org/10.1089/10966210260499014

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*, *284*(19), 2476-2482. https://doi.org/10.1001/jama.284.19.2476

Steinhauser, K. E., Clipp, E. C., Bosworth, H. B., McNeilly, M., Christakis, N. A., Voils, C. I., & Tulsky, J. A. (2004). Measuring quality of life at the end of life: validation of the QUAL-E. *Palliative & supportive care*, *2*(1), 3-14. https://doi.org/10.1017/s1478951504040027

Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: observations of patients, families, and providers. *Annals of internal medicine,*, *132*(10), 825-832. https://doi.org/10.7326/0003-4819-132-10-200005160-00011

Stjernswärd, J., Foley, K. M., & Ferris, F. D. (2007a). Integrating palliative care into national policies. *Journal of pain and symptom management*, *33*(5), 514-520. https://doi.org/10.1016/j.jpainsymman.2007.02.031

Stjernswärd, J., Foley, K. M., & Ferris, F. D. (2007b). The public health strategy for palliative care. *Journal of pain and symptom management*, *33*(5), 486-493. https://doi.org/10.1016/j.jpainsymman.2007.02.016

Stroebe, M., & Schut, H. (1998). Culture and grief. *Bereavement Care*, *17*(1), 7-11. https://doi.org/10.1080/02682629808657425

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: rationale and description. *Death studies*, *23*(3), 197-224. https://doi.org/10.1080/074811899201046

Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *OMEGA-Journal of Death and Dying*, *61*(4), 273-289. https://doi.org/10.2190/OM.61.4.b

Stroebe, M., Schut, H., & Boerner, K. (2010). Continuing bonds in adaptation to bereavement: Toward theoretical integration. *Clinical psychology review*, *30*(2), 259-268. https://doi.org/10.1016/j.cpr.2009.11.007

Stroebe, M., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *The Lancet*, *370*(9603), 1960-1973. https://doi.org/10.1016/S0140-6736(07)61816-9

Stroebe, M., Stroebe, W., Van De Schoot, R., Schut, H., Abakoumkin, G., & Li, J. (2014). Guilt in bereavement: The role of self-blame and regret in coping with loss. *PLoS One*, *9*(5), e96606. https://doi.org/10.1371/journal.pone.0096606

Supiano, K. P., Luptak, M., Andersen, T., Beynon, C., Iacob, E., & Wong, B. (2020). If we knew then what we know now: The preparedness experience of pre-loss and post-loss dementia caregivers. *Death studies*, *46*(2), 369–380. https://doi.org/10.1080/07481187.2020.1731014

Tan Kiak Min, M. (2017). Beyond a Western bioethics in Asia and its implication on autonomy. *The New Bioethics*, *23*(2), 154-164. https://doi.org/10.1080/20502877.2017.1345091

Tanaka, M., Ohnishi, K., Enzo, A., Okita, T., & Asai, A. (2021). Grounds for surrogate decision-making in Japanese clinical practice: a qualitative survey. *BMC medical ethics*, *22*(1), 5. https://doi.org/10.1186/s12910-020-00573-4

Tang, S.-T., Chang, W.-C., Chou, W.-C., Hsieh, C.-H., Chen, J.-S., & Wen, F.-H. (2021). Family Caregivers' Emotional Preparedness for Death is Distinct from Their Cognitive Prognostic Awareness for Cancer Patients. *Journal of palliative medicine*, *24*(3), 405-412. https://doi.org/10.1089/jpm.2020.0264

Tang, S.-T., Chen, J.-S., Wen, F.-H., Chou, W.-C., Chang, J.-W., Hsieh, C.-H., & Chen, C.-H. (2019). Advance Care Planning Improves Psychological Symptoms But Not Quality of Life and Preferred End-of-Life Care of Patients With Cancer. *Journal of the National Comprehensive Cancer Network*, *17*(4), 311-320. https://doi.org/10.6004/jnccn.2018.7106

Tang, S.-T., Hsieh, C.-H., Chou, W.-C., Chang, W.-C., Chen, J.-S., & Wen, F.-H. (2021). Course of Changes in Emotional Preparedness for Death and Its Associations With Caregiving Outcomes for Family Caregivers of Terminally Ill Cancer Patients Over Their Last Year of Life. *Journal of pain and symptom management*, *61*(5), 974-982. https://doi.org/10.1016/j.jpainsymman.2020.09.033

Tang, Y. (2019). Caregiver burden and bereavement among family caregivers who lost terminally ill cancer patients. *Palliative & supportive care*, *17*(5), 515-522. https://doi.org/10.1017/S1478951518001025

Tey, M. Q., & Lee, G. L. (2025). Understanding Bereavement Experiences and Coping Among Bereaved Family Caregivers in Singapore: Positive Meaning Reconstruction in the Dual Process Model. *OMEGA-Journal of Death and Dying*, *91*(1), 263-280. https://doi.org/10.1177/00302228221133584

Tipps, D. C. (1973). Modernization Theory and the Comparative Study of National Societies: A Critical Perspective. *Comparative Studies in Society and History*, *15*(2), 199-226. https://doi.org/10.1017/S0010417500007039

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC medical research methodology*, *12*, 181. https://doi.org/10.1186/1471-2288-12-181

Treml, J., Schmidt, V., Nagl, M., & Kersting, A. (2021). Pre-loss grief and preparedness for death among caregivers of terminally ill cancer patients: A systematic review. *Social Science & Medicine*, *284*, 114240. https://doi.org/10.1016/j.socscimed.2021.114240

Umubyeyi, B., Leboul, D., & Bagaragaza, E. (2024). “You close the door, wipe your sadness and put on a smiling face”: a qualitative study of the emotional labour of healthcare professionals providing palliative care in nursing homes in France. *BMC health services research*, *24*(1), 1070. https://doi.org/10.1186/s12913-024-11550-7

van Nes, F., Abma, T., Jonsson, H., & Deeg, D. (2010). Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing*, *7*(4), 313-316. https://doi.org/10.1007/s10433-010-0168-y

Varpio, L., & Ellaway, R. H. (2021). Shaping our worldviews: a conversation about and of theory. *Advances in Health Sciences Education*, *26*(1), 339-345. https://doi.org/10.1007/s10459-021-10033-2

Varpio, L., Paradis, E., Uijtdehaage, S., & Young, M. (2020). The distinctions between theory, theoretical framework, and conceptual framework. *Academic Medicine*, *95*(7), 989-994. https://doi.org/10.1097/ACM.0000000000003075

Virdun, C., Luckett, T., Lorenz, K., Davidson, P. M., & Phillips, J. (2017). Dying in the hospital setting: a meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliative medicine*, *31*(7), 587-601. https://doi.org/10.1177/0269216316673547

Wang, Y. (2023). Advance care planning in Taiwan. *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen*, *180*, 107-110. https://doi.org/10.1016/j.zefq.2023.06.002

Weller, R. P. (2020). Identity and social change in Taiwanese religion. In *Taiwan: A New History* (pp. 339-365). Routledge.

Wen, F.-H., Chou, W.-C., Hou, M.-M., Su, P.-J., Shen, W.-C., Chen, J.-S., Chang, W.-C., Hsu, M.-H., & Tang, S.-T. (2022a). Associations of death-preparedness states with bereavement outcomes for family caregivers of terminally ill cancer patients. *Psycho-oncology*, *31*(3), 450-459. https://doi.org/10.1002/pon.5827

Wen, F.-H., Chou, W.-C., Hou, M.-M., Su, P.-J., Shen, W.-C., Chen, J.-S., Chang, W.-C., Hsu, M.-H., & Tang, S.-T. (2022b). Caregivers' Death-Preparedness States Impact Caregiving Outcomes and Patients' End-of-Life Care. *Journal* *of pain and symptom management*, *63*(2), 199-209. https://doi.org/10.1016/j.jpainsymman.2021.09.012

Westphal, M., Seivert, N. H., & Bonanno, G. A. (2010). Expressive flexibility. *Emotion*, *10*(1), 92-100. https://doi.org/10.1037/a0018420

Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of advanced nursing*, *52*(5), 546-553. https://doi.org/10.1111/j.1365-2648.2005.03621.x

Wilson, D. M., & Hewitt, J. A. (2018). A scoping research literature review to assess the state of existing evidence on the “bad” death. *Palliative & supportive care*, *16*(1), 90-106. https://doi.org/10.1017/S1478951517000530

Worden, J. W. (2018). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. Springer Publishing.

World Health Organisation. (2002). National cancer control programmes : policies and managerial guidelines. In (2nd ed.). Geneva: World Health Organisation.

World Health Organisation. (2014). Strengthening of palliative care as a component of comprehensive care throughout the life course. *Journal of pain & palliative care pharmacotherapy*, *28*(2), 130–134. https://doi.org/10.3109/15360288.2014.911801

World Values Survey. (2023). *The Inglehart-Welzel World Cultural Map*. Retrieved 28, February from https://www.worldvaluessurvey.org/WVSContents.jsp

Wu, M. (2006). Hofstede's cultural dimensions 30 years later: A study of Taiwan and the United States. *Intercultural communication studies*, *15*(1), 33.

Yao, X. (2000). *An introduction to Confucianism*. Cambridge University Press.

Yeh, K.-H., Yi, C.-C., Tsao, W.-C., & Wan, P.-S. (2013). Filial piety in contemporary Chinese societies: A comparative study of Taiwan, Hong Kong, and China. *International Sociology*, *28*(3), 277-296. https://doi.org/10.1177/0268580913484345

Yen, C.-C., Lin, C.-P., Su, Y.-T., Tsu, C.-H., Chang, L.-M., Sun, Z.-J., Lin, B.-S., & Wu, J.-S. (2021). The Characteristics and Motivations of Taiwanese People toward Advance Care Planning in Outpatient Clinics at a Community Hospital. *International journal of environmental research and public health*, *18*(6), 2821. https://doi.org/10.3390/ijerph18062821

Yen, Y.-F., Huang, L.-Y., Hu, H.-Y., Sun, W.-J., Ko, M.-C., Lee, Y.-L., Huang, S.-J., & Chu, D. (2018). Association of Advance Directives Completion With the Utilization of Life-Sustaining Treatments During the End-of-Life Care in Older Patients. *Journal of pain and symptom management*, *55*(2), 265-271. https://doi.org/10.1016/j.jpainsymman.2017.08.031

Yen, Y.-F., Lee, Y.-L., Hu, H.-Y., Sun, W.-J., Ko, M.-C., Chang, S.-S., Chen, C.-C., Huang, S.-J., & Chu, D. (2022). Association of advance care planning with place of death and utilisation of life-sustaining treatments in deceased patients at Taipei City Hospital in Taiwan. *BMJ Supportive & Palliative Care*, *12*, e311-e318. https://doi.org/10.1136/bmjspcare-2020-002520

Yick, A. G., & Gupta, R. (2002). Chinese cultural dimensions of death, dying, and bereavement: focus group findings. *Journal of cultural diversity*, *9*(2), 32-42.

Young, A. J., Rogers, A., Dent, L., & Addington-Hall, J. M. (2009). Experiences of hospital care reported by bereaved relatives of patients after a stroke: a retrospective survey using the VOICES questionnaire. *Journal of advanced nursing*, *65*(10), 2161-2174. https://doi.org/10.1111/j.1365-2648.2009.05081.x

Yu, T.-H., Wei, C.-J., Wu, W.-W., & Lu, F.-L. (2024). Does the role of family meetings important at the end-of-life? A retrospective national study in Taiwan. *BMC palliative care*, *23*(1), 286. https://doi.org/10.1186/s12904-024-01613-1

Yu, W., Lu, Q., Lu, Y., Yang, H., Zhang, L., Guo, R., & Hou, X. (2021). Anticipatory Grief among Chinese Family Caregivers of Patients with Advanced Cancer: A Cross-Sectional Study. *Asia-Pacific journal of oncology nursing*, *8*(4), 369-376. https://doi.org/10.4103/apjon.apjon-214

Yum, J. O. (1988). The impact of Confucianism on interpersonal relationships and communication patterns in East Asia. *Communications Monographs*, *55*(4), 374-388. https://doi.org/10.1080/03637758809376178

Zaman, S. (2025). Cultural assumptions and the good death: rethinking global frameworks. *Medical Humanities*, *51*(2), 296–300. https://doi.org/10.1136/medhum-2024-013062

Zaman, S., Inbadas, H., Whitelaw, A., & Clark, D. (2017). Common or multiple futures for end of life care around the world? Ideas from the ‘waiting room of history’. *Social Science & Medicine*, *172*, 72-79. https://doi.org/10.1016/j.socscimed.2016.11.012

Zwakman, M., Milota, M. M., Van der Heide, A., Jabbarian, L. J., Korfage, I. J., Rietjens, J. A. C., van Delden, J. J. M., & Kars, M. C. (2021). Unraveling patients’ readiness in advance care planning conversations: a qualitative study as part of the ACTION Study. *Supportive Care in Cancer*, *29*(6), 2917-2929. https://doi.org/10.1007/s00520-020-05799-x