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DEVELOPMENT AND EVALUATION OF A CULTURALLY SPECIFIC END-OF-
LIFE COMMUNICATION SKILLS TRAINING FOR CHINESE ONCOLOGY
NURSES

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PhD

The Hong Kong Polytechnic University

2024

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Development and Evaluation of a Culturally Specific End-of-life Communication
Skills Training for Chinese Oncology Nurses

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of
Philosophy

July 2024

CERTIFICATE OF ORIGINALITY

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_____ (Signed)

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ABSTRACT

Background: End-of-life communication is fundamental for providing goal-concordant care and improving patient outcomes and experience. Nurses play a crucial role in facilitating such communication but often lack the necessary training. Moreover, the influence of culture presents unique challenges that add complexity to end-of-life communication in the Chinese context.

Aim: To develop and evaluate a culturally specific end-of-life CST for Chinese oncology nurses.

Methods: The development phase consists of two studies, including (1) a scoping review capturing the board knowledge of available end-of-life communication strategies and (2) a qualitative descriptive study with semi-structured in-depth interviews and focus group discussions to explore stakeholders' experiences, perceptions, suggestions and preferred end-of-life communication strategies. A randomised controlled trial (RCT) embedded with a process evaluation was conducted in the evaluation phase. One hundred and fifty-nine oncology nurses were randomly assigned to an 8-session communication skills training (n = 79) or a wait-list control group (n = 80). The training curriculum covered four modules: responding to patient cues, negotiating with the family, nurturing hope, and bereavement support. A combination of lectures, videos, and simulations were used. Data collection was conducted for both groups before (T0), immediately after (T1) and one month after the intervention group received the training (T2) on nurses' communication skills, self-efficacy and outcome expectancy belief. Process evaluation included assessments of acceptability, satisfaction, and experiences. Generalised estimating equations (GEE) were utilised in data analysis.

Results: The scoping review found seven themes of available end-of-life communication strategies, including (a) preparation, (b) exploration and assessment, (c) family involvement, (d) provision and tailoring of information, (e) empathic emotional responses, (f) reframing and revisiting the goals of care, and (g) conversation closure. The qualitative study involved 19 patients, 22 family caregivers, and 25 healthcare

providers. It identified protective and open states of end-of-life communication and several factors affecting it. Participants suggested communication strategies were arranged into an acronym, IGNITE, i.e., a) **Identify** the primary communicator(s) and prepare the family if necessary; b) Initiate end-of-life communication in a **Gradual** and **Natural** manner; c) **Navigate** realistic expectations; d) **Inner** healing with emotional support and meaning reconstruction; and e) **Timing** and **Environment**. In the RCT, participants had a mean age of 31.36 years, and 94.30% were female. The intervention group showed significant improvements compared to controls in communication skills ($p < .05$), self-efficacy ($p < .001$) and outcome expectancy beliefs ($p < .001$). The training program demonstrated good acceptability and satisfaction. Participants identified facilitators and barriers during the learning process.

Conclusion: A culturally specific end-of-life communication skills training program incorporating stakeholders' views is well developed. The program's effectiveness has been demonstrated in improving communication skills, self-efficacy, and outcome expectancy beliefs among Chinese oncology nurses. The findings of this research can inform the development of contextual end-of-life communication guidelines tailored to Chinese clinical practice and those countries or regions with a similar cultural background. Further research is warranted to investigate the transfer of nurses' communication skills in practical settings.

RESEARCH OUTPUT ARISING FROM THE THESIS

Journal publications:

1. **Chen, W.**, Chung, J. O. K., Lam, K. K. W., & Molassiotis, A. (2023). End-of-life communication strategies for healthcare professionals: A scoping review. *Palliat Med*, 37(1), 61-74. <https://doi.org/10.1177/02692163221133670>
2. **Chen, W.**, Chung, J. O. K., Lam, K. K. W., & Molassiotis, A. (2023). Patients', families' and healthcare providers' perspectives on end-of-life communication in Chinese hospital settings: A qualitative study protocol. *PLoS One*, 18(12), Article e0296342. <https://doi.org/10.1371/journal.pone.0296342>

Conference presentations:

1. **Chen, W.**, Chung, J. O. K., Lam, K. K. W., & Molassiotis, A. Strategies for healthcare professionals to initiate and facilitate end-of-life communication with terminally ill patients and families: a scoping review. 22nd Annual Research Postgraduate Conference. Hong Kong, China. June 2022. Oral presentation.
2. **Chen, W.**, Chung, J. O. K., Lam, K. K. W., & Molassiotis, A. Talking about end-of-life topics with terminally ill patients and their families: a scoping review of communication strategies. 26th East Asian Forum of Nursing Scholars (EAFONS). Tokyo, Japan. March 2023. Poster presentation.

Awards:

1. **Chen, W.**, Outstanding Poster Presentation Award, 26th East Asian Forum of Nursing Scholars (EAFONS). Tokyo, Japan. March 2023.
2. **Chen, W.**, Second Runner-up, Three Minute Thesis (3MT[®]) competition, Faculty of Health and Social Sciences, The Hong Kong Polytechnic University, June 2024.

ACKNOWLEDGEMENTS

First, I would like to express my heartfelt gratitude to the Hong Kong Polytechnic University and the School of Nursing for providing me with the opportunity and financial support three years ago, which enabled me to continue pursuing my academic aspirations. I have gained immense strength and support within this vibrant and youthful campus.

I want to convey my most profound appreciation to my chief supervisor, Dr Joyce Chung and co-supervisors, Dr Katherine Lam and Prof. Alex Molassiotis. They have offered me unwavering encouragement, patience, guidance, and support. I am incredibly fortunate to have had them alongside me throughout this doctoral journey.

I also sincerely thank the expert advisory group members, patients, family caregivers, and healthcare professionals who participated in this research. Thank them for generously sharing their experiences and insights with me. Additionally, I am grateful for the support provided by the hospital administrators who facilitated the implementation of the research.

Lastly, I would like to thank my family and friends. They have made me feel loved and cherished at all times. This thesis is dedicated to my paternal and maternal grandfathers, who exemplified kindness and gentleness throughout their lives. The sudden accidents that took them from us have left me without the opportunity to understand their deepest wishes. Though life is short and unpredictable, I will continue with the abundance of love they have all provided.

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LIST OF ABBREVIATIONS

ACP	Advance care planning
CG	Control group
CI	Confidence interval
CONSORT	Consolidated Standards of Reporting Trials
COQ	Communication Outcomes Questionnaire
CST	Communication skills training
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
ELNEC	End-of-Life Nursing Education Consortium
GEE	Generalised estimating equation
GOC	Goals of care
GP	General practitioner
HSESC	Human Subjects Ethics Sub-Committee
IG	Intervention group
ITT	Intention to Treat
KS	Kolmogorov-Smirnov
M	Mean
MCAR	Missing Completely at Random
MD	Mean difference
MERSQI	Medical Education Research Study Quality Instrument
MRC	Medical Research Council
OR	Odds ratio
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
RCT	Randomised controlled trial
SD	Standard deviation
SE	Standard error
SICG	Serious Illness Conversation Guide
SP	Standardised patient

SRQR	Standards for Reporting Qualitative Research
UK	United Kingdom
US	United States (of America)
WHO	World Health Organization

Chapter 1: Introduction

1.1 Introduction

This chapter provides an introduction to the doctoral thesis, including the research background (Section 1.2) and the thesis organisation (Section 1.3).

1.2 Background

The importance of timely and efficient communication regarding end-of-life matters, such as discussions on prognosis and care objectives, is widely acknowledged as highly advantageous for individuals facing terminal illnesses and their families (Scholz et al., 2020). Despite the acknowledged value and advantages of end-of-life communication, these dialogues are not frequently conducted during medical consultations (Knutzen et al., 2021; Qama et al., 2021). It has often been neglected in acute care settings, partly due to the popular curative culture (Olsson et al., 2021). Numerous terminally ill patients continue to receive treatment in acute hospital settings, despite studies showing that these settings are typically not thought to be optimal for end-of-life care (Robertson et al., 2022). There have been serious concerns raised regarding the lack of end-of-life communication in acute hospital settings and its consequences because the underlying model of care emphasises treatment and cure rather than the comfort and dignity care that end-of-life care advocates (Virdun et al., 2015; Cotogni et al., 2018; Vanderhaeghen et al., 2018). During clinical contacts, several possibilities for end-of-life communication were lost (Knutzen et al., 2021). The majority of end-of-life communication take place during hospital stays very near to the patient's death and are brought on by sudden medical decline (Mack et al., 2012). This kind of communication puts less emphasis on the opinions and desires of patients and their families, which might have a negative impact on grief, care satisfaction, and end-of-life decisions (Bergenholtz et al., 2019; Fenton et al., 2023).

Due to variances in national legislation, cultural, social, and political contexts, and the duties of healthcare personnel, end-of-life communication in acute care settings may vary from one country to another (Olsson et al., 2021). End-of-life communication in the Chinese context is strongly influenced by Chinese culture and philosophy, especially Confucianism (Turnbull et al., 2023). Although fear of death is a global phenomenon, Chinese culture and philosophy still have a unique influence on attitudes towards death and dying (Hsu et al., 2009). Confucianism is mainly concerned with the value of life, fostering virtues, and maintaining social peace (Bedford and Yeh, 2019). Death is frequently seen as a disruption of the ideal family structure and societal order. This emphasis on increasing life may make people reluctant to have candid conversations about death (Bowman and Singer, 2001). Family-oriented decision-making styles compromise the patient's own perspective and autonomy. It is common for family members to ask medical staff to conceal their condition from the patient (Lin et al., 2019). The idea of filial piety, which emphasises respect and care for one's parents and ancestors, is fundamental to Confucian principles (Bedford and Yeh, 2019). Death can be interpreted as a failure to meet these responsibilities, which makes talking about or getting ready for death unpleasant (Dong et al., 2016).

Hospital-based healthcare providers may not have adequate training regarding end-of-life communication, which might lead to late end-of-life communication, associated with many adverse outcomes (e.g., poor quality of end-of-life care and bereavement experience) (Im et al., 2019). Nurses are most frequently in direct contact with patients during clinical care, allowing them to establish close relationships with patients (Kerr et al., 2020; Smith et al., 2018). They are a crucial and reliable nexus in end-of-life communication (Bennett & O'Conner-Von, 2020). Patients in the terminal stages of cancer have a growing need for nursing care and less need for medical treatment, requiring oncology nurses to have a higher level of clinical ability to ensure quality end-of-life care (Reblin et al., 2014; Zheng et al., 2015). Nevertheless, oncology nurses reported low self-efficacy and a lack of communication skills on a series of end-of-life

topics (e.g., life-sustaining treatments, death and dying, bereavement support) (Huang, 2021). Further training is needed to enhance oncology nurses' end-of-life communication skills.

Several end-of-life communication skills training (CST) programs have been developed for healthcare providers. The specific contents, delivery methods, duration, participants and training settings differed greatly between research (Brighton et al., 2017; Lord et al., 2016; Pulsford et al., 2013; Walczak et al., 2016). More importantly, many methodological problems were apparent and should be noted, including (1) few efficacy trials; frequent use of less robust study designs to examine the effect of CST; (2) wide use of outcome measures; most communication outcome measures were unvalidated or self-reported; and (3) inadequate reporting of evaluation studies (Bos-van den Hoek et al., 2019; Brighton et al., 2017; Chan et al., 2019; Lord et al., 2016; Selman et al., 2017; Walczak et al., 2016). The quality of end-of-life CST should be further enhanced.

To date, end-of-life CST is scant in Mainland China, and only a few programs exist. Western-based end-of-life communication strategies were taught without socio-cultural adaptations. However, China has significantly different beliefs and practices surrounding end-of-life communication compared to Western societies. These significant sociocultural differences are bound to contribute to differences in the end-of-life communication process and related training (Pace & Lunsford, 2011). Culturally specific end-of-life communication strategies are urged to address local needs.

Two main research gaps have been identified through literature reviews. Firstly, no empirical evidence on end-of-life communication strategies from a Chinese perspective has been found. Secondly, there is a lack of culturally specific CST regarding end-of-life issues for Chinese oncology nurses. Therefore, this project aims to develop and evaluate a culturally specific end-of-life CST for Chinese oncology nurses. This project consists of two phases. The first study in phase one is a scoping review aiming to

capture broad knowledge of healthcare providers' existing end-of-life communication strategies. The findings provide a basis for the development of the training content. Besides, it also identified the research gap in available end-of-life communication strategies in the Chinese context, which informed the next study. The second study in phase one will use a qualitative approach to explore the experiences and suggestions of Chinese patients with advanced illnesses, their families and healthcare providers. The anticipated findings will benefit the understanding of culturally appropriate end-of-life communication strategies in the Chinese context, which will extend the current knowledge and contribute to developing a culturally specific end-of-life CST program. Lastly, a randomized controlled trial design will be adopted in phase two to evaluate the effectiveness of culturally specific end-of-life CST among Chinese oncology nurses.

1.3 Thesis organisation

This thesis comprises nine chapters, including the current introductory chapter. Chapter 2 reviews the literature on end-of-life communication and its training while identifying research gaps. The third chapter presents a scoping review of the end-of-life communication strategy, a valuable reference for developing the training content. In Chapter 4, the conceptual framework of this study is thoroughly explained. Chapter 5 encompasses the aims and objectives of this study, along with an overview of the overall research design and ethical considerations. Chapter 6 elaborates on a qualitative study by discussing its objectives, methods, results, discussions, limitations, and implications. Chapter 7 describes the development of a Chinese culturally specific end-of-life CST. Chapter 8 reports details of a randomized controlled trial that evaluated the culturally specific end-of-life CST. Finally, Chapter 9 concludes the overall research.

Chapter 2: Literature Review

2.1 Introduction

The present chapter critically examines the relevant literature pertaining to this thesis, encompassing the concept of end-of-life communication and its significance; the current status of end-of-life CST; challenges associated with end-of-life communication in the Chinese context; and the end-of-life CST for nurses.

2.2 End-of-life communication

End-of-life communication refers to a clinical interaction involving conversations regarding various end-of-life matters. These discussions typically encompass topics such as death and the dying process, advance care planning (ACP), establishing goals of care (GOC) and decision-making, exploring palliative or hospice care alternatives and referrals, as well as providing support for bereavement (Brighton et al., 2017; Gonella et al., 2019; Pfeifer & Head, 2018; Sinuff et al., 2015). Ideally, it should be initiated and facilitated systematically by an interdisciplinary team involving physicians, nurses, chaplains and social workers (Martins et al., 2021; Pfeifer & Head, 2018).

Effective communication among terminally ill patients, their families, and healthcare providers is essential for providing high-quality end-of-life care (Brighton & Bristowe, 2016). Successful communication at the end of life can have positive outcomes for both patients and healthcare systems (Chan et al., 2022; Starr et al., 2019). It enables patients and their family members or significant others to understand the situation and have shared decision-making (Sinuff et al., 2015). It can also improve family members' bereavement experience (Yamaguchi et al., 2017). For healthcare providers, such conversations allow them to establish a relationship with patients and their families, acknowledge their concerns and wishes, align care with preferences and promote the

patient a good death (Keeley, 2016; Krikorian et al., 2020; Olsson et al., 2021). In addition, the outcomes of effective end-of-life communication are associated with better quality of life and quality of care (Chan et al., 2022; Wright et al., 2008; Yamaguchi et al., 2017). To be specific, better patient-provider end-of-life communication is associated with lower end-of-life care costs (median US\$1048 vs US\$23482; $p < .001$); less acute care near end-of-life (OR 0.43-0.69); less intensive care near end-of-life (ORs 0.26, 0.68); less emergency department visit ($p < .001$); shorter hospital length of stay; more likely to die outside the hospital; more hospice use (OR 1.79-6.88); and less chemotherapy use (ORs 0.41, 0.57) (Starr et al., 2019).

Even though there are strong arguments for end-of-life communication, these conversations are often delayed or do not occur in clinical practice (Im et al., 2019). Insufficient and inconsistent end-of-life communication results from various barriers from patients, healthcare providers and the healthcare system (Bernacki & Block, 2014). Patient-related factors include ambivalence, discomfort, or fear (Granek et al., 2013; Hadley, 2020; Jacobsen et al., 2018); misunderstandings or denial regarding the illness (Casarett & Quill, 2007; Coyle et al., 2015), misconceptions concerning end-of-life care (Casarett & Quill, 2007), and lack of transparent information sharing within the family (Hauser, 2017). Healthcare providers face barriers such as insufficient training, feeling unprepared and uncomfortable in addressing emotional issues, and difficulty in determining patient readiness and initiating end-of-life conversations routinely (Jiao & Hussin, 2020; ten Koppel et al., 2019; Toh et al., 2021; Zehm et al., 2020). Besides, several factors related to the healthcare system also contribute to difficulties in talking about end-of-life issues, which include the popular curative model in acute care settings and acquiescent life-sustaining treatments (Bernacki & Block, 2014; Olsson et al., 2021); lack of a systematic approach to organizing a series of end-of-life conversations (Granek et al., 2013); and cultural and ethical issues (e.g., nondisclosure of bad news is considered protective in some cultures) (Barclay et al., 2007; Glare et al., 2008; Granek et al., 2013; Hauser, 2017; Smith et al., 2009).

A number of interventions have been developed to remove these barriers to end-of-life communication. Among them, patient-focussed interventions have attempted to improve communication by enhancing patient-held medical records (Cornbleet et al., 2002), providing patient education (Walczak et al., 2016), and consultation audio recordings (Uitdehaag et al., 2012). Family caregiver–focused communication systems (Chih et al., 2013) and family meetings (Fukui et al., 2013) are set up to meet their information needs. The most common form of healthcare provider intervention is CST (Walczak et al., 2016). Some interventions are multifocal, targeting two or more stakeholder groups, such as communication tools (e.g., the question prompt list) (Clayton et al., 2007), structured advance care planning program (Lillie et al., 2020; Song et al., 2009), and combined interventions that included physician training, patient coaching and tool utilization (Epstein et al., 2017; Rodenbach et al., 2017). Bernacki and Block (Bernacki & Block, 2014) proposed several steps to systematize end-of-life communication, including training for healthcare providers; identifying patients at risk and triggering early discussion; patient and family education; structured conversation guidance and documentation; and measurement of communication performance.

2.3 End-of-life CST

2.3.1 Current status of end-of-life CST

Healthcare providers play essential roles in end-of-life communication with life-limiting patients and their families (Anderson et al., 2019). Healthcare professionals are expected to consider and respect patients' preferences for information and involve them in decision-making processes, while also being mindful of their emotional needs and vulnerabilities (Bos-van den Hoek et al., 2019). This complex situation places increased emphasis on their communication abilities. Additionally, initiating discussions about end-of-life care early on is widely recommended in the context of a severe illness, indicating that these conversations should commence once a patient has been identified as approaching the end of life (Bernacki & Block, 2014; National Consensus Project

for Quality Palliative Care, 2018; National Institute for Health and Excellence, 2015; Olsson et al., 2021; Starr et al., 2019). Given this, the primary care providers who care for patients with advanced, progressive and incurable illnesses should initiate such conversations (Buss et al., 2017; Ferrell et al., 2017). Examples of such healthcare providers include oncologists and nurses in inpatient settings (Selman et al., 2017).

End-of-life communication is frequently overlooked in acute care environments, primarily as a result of the prevailing curative-oriented approach. The significance of end-of-life care is increasing in various healthcare settings, including acute care. However, challenges arise in acute care environments as the original palliative care models were primarily designed for hospice settings, focusing on comfort rather than cure (Olsson et al., 2021). It is important to note that palliative care encompasses a broader scope than end-of-life care, as it can be provided over an extended period, including years, and may involve curative treatments for individuals with progressive severe illnesses (Krau, 2016). Hospice care, on the other hand, is specifically tailored for individuals nearing the end of life, with healthcare professionals and volunteers offering support when death is anticipated within a short timeframe, emphasizing a peaceful, comfortable, and dignified passing (National Institute on Aging, 2021). The concept of end-of-life care often differs significantly from the curative approach that typically characterizes hospital care. Hospital-based healthcare providers may not have adequate training regarding end-of-life communication (Olsson et al., 2021). This might lead to late end-of-life communication, which is associated with many adverse outcomes (e.g., poor quality of end-of-life care and bereavement experience) (Im et al., 2019). Therefore, there is an urgent need to improve hospital-based healthcare providers' communication skills on end-of-life issues.

Several end-of-life CST programs have been developed for healthcare providers. The specific contents, delivery methods, duration, participants and training settings varied widely across studies (Brighton et al., 2017; Lord et al., 2016; Pulsford et al., 2013;

Walczak et al., 2016). The training contents covered breaking bad news; talking about death and dying; discussing treatment uncertainties and limitations; symptom management; advance care planning; family conflict and supporting shared decision-making; local referral procedures; spiritual care; ethical principles, and medical and legal issues (e.g., organ donation); and bereavement support (Chung et al., 2016; Lord et al., 2016; Olsson et al., 2021; Pulsford et al., 2013; Smith et al., 2018). Various methods were used to deliver the training, including didactics (lectures and presentations); reflection and discussion; simulations (e.g., role play); case studies; self-study; clinical visits; and individualized feedback (Brighton et al., 2017; Lord et al., 2016; Pulsford et al., 2013; Smith et al., 2018).

The developments of current training mainly referred to literature, theories, experts or healthcare providers' views, and needs assessments (Brighton et al., 2017). It is uncommon to involve patients and families in developing the CST (Brighton et al., 2017). In addition, many methodological problems were apparent and should be noted, including (1) efficacy trials were rare; in testing the effect of CST, less robust study designs were common; (2) a substantial variety of outcome measures were used, and the majority of the communication outcome measures were unvalidated or self-reported; and (3) poor reporting of evaluation studies (Bos-van den Hoek et al., 2019; Brighton et al., 2017; Lord et al., 2016; Selman et al., 2017; Walczak et al., 2016).

2.3.2 End-of-life CST in Chinese context

So far, end-of-life CST is scant in Mainland China, and only a few programs exist. Wuensch et al. (Wuensch et al., 2013) attempted to conduct a CST for oncologists on breaking bad news in China. Yet the training was developed based on a Western communication strategy – the SPIKES model. The authors also found that Asian cultures do not readily adapt to Western ideas of breaking bad news since they are based on the patient's autonomy. Further socio-cultural adaptations are necessary. Cheng et al. (Q. Cheng et al., 2021) reported a training with a 'communication and truth disclosure' module for palliative care specialist nurses, developed by referring to the End-of-Life

Nursing Education Consortium (ELNEC). The development of ELNEC was based on Western practice. It is still unknown whether these communication strategies taught in this course can be accepted by Chinese patients and families or not. Another study in Mainland China aimed to train nurses in ACP communication (Chen, 2020). It was reported that Chinese cultural background was considered in the development of the training. However, the specific details were not shown, such as the language used in the booklet and which cultural characteristics that have been considered. Although the results of this study showed that training effectively improved nurses' cognition, attitude and self-efficacy of ACP, the mainland has not yet legislated to protect the implementation of ACP, and medical institutions have not formed operational practices for the implementation of ACP. Therefore, communication skills training for ACP is not enough and has limited practicability for nurses in clinical practice.

While healthcare providers may face the same challenges when communicating with patients approaching the end of life – such as uncertainties of prognosis; various information needs; complex attitudes towards death; inadequate training and personal limitation; maintaining hope while preparing for death; strong ambitious to offer quality end-of-life care versus sufferings from moral and emotional distress; and heavy workloads and time constraints – some challenges are distinct to specific sociocultural contexts (Bernacki & Block, 2014; Huang et al., 2018; Stocklassa et al., 2022; Zheng et al., 2015; Zhu et al., 2021). Compared to Western societies (refer to Anglo-Saxon countries and English-dominant contexts, i.e., UK, US, Canada, and Australia, in this report) (Louviot, 2020; Pun et al., 2018), China has significantly different beliefs and practices surrounding end-of-life communication. The first difference, individualism vs collectivism, influences patient autonomy and decision-making style (Pun et al., 2018). Western cultures stress individuals' rights and protect them by laws, while Chinese favour a family-driven decision (Deng et al., 2019). The second difference is high-context vs low-context cultures in terms of how explicit communication is (Pun et al., 2018). In low-context cultures, patients expect to be fully informed of their situation.

In contrast, in high-context cultures, like China, indirect and nonverbal manners regarding truth disclosure are appreciated (Barclay et al., 2007). The third difference refers to Christianity vs Confucianism (Pun et al., 2018). The Western idea of patient-centred care is an expression of the Western Christian tradition's advocacy for egalitarian relationships between individuals. While the Confucian tradition emphasizes harmony and obedience, reflecting a power differential between patients and physicians (Pun et al., 2020). Besides, many westerners have religious beliefs, such as Christians who do not fear to talk about death. However, influenced by traditional Chinese culture, including Confucianism, many Chinese people have negative attitudes towards death and are reluctant to discuss end-of-life issues (Deng et al., 2019). These significant sociocultural differences are bound to contribute to differences in end-of-life communication process and related training (Pace & Lunsford, 2011).

2.3.3 End-of-life CST for nurses

In 2020, the World Health Organization (WHO) reported that there were 27.9 million nurses globally, representing approximately 60% of the health professions and the largest occupational group within the health sector (WHO., 2020). Nurses are most frequently in direct contact with patients during clinical care, allowing them to establish close relationships with patients (Kerr et al., 2020; Smith et al., 2018). They are a crucial and reliable nexus in end-of-life communication (Bennett & O'Conner-Von, 2020). Research indicates that healthcare professionals who maintain a consistent and trustworthy rapport with patients and their families are more effective in facilitating end-of-life discussions (Reblin et al., 2014). Many studies had nurses facilitate or support various communication interventions, which may improve clinical outcomes and patient experience (Bennett & O'Conner-Von, 2020; Iglesias et al., 2020). Moreover, multiple roles in end-of-life communication are perceived by nurses, including setting up healthcare team meetings on patients' end-of-life issues; informing team members about perceived medical conditions, family relations, and emotional changes; supplementing explanations for patients and their families on treatments and options in plain languages; verifying patients and families understanding; providing mental and

emotional support; and assisting patients and their families to cope with social hardships (Kimura et al., 2020). Nurses reported stronger awareness of their own roles ($p < .001$), and higher need for end-of-life communication training (54.7%) than other healthcare providers (Kimura et al., 2020).

One in six deaths, or around 10 million deaths, is due to cancer in 2020, making it the leading cause of death globally (WHO., 2022). Cancer mortality in Mainland China has been predicted to rise gradually in the next 20 years (Sun et al., 2020). Patients in the terminal stages of cancer have a growing need for nursing care and less need for medical treatment, requiring oncology nurses to have a higher level of clinical ability to ensure quality end-of-life care (Reblin et al., 2014; Zheng et al., 2015). Nevertheless, oncology nurses reported low self-efficacy and a lack of communication skills on a series of end-of-life topics (e.g., life-sustaining treatments, death and dying, bereavement support) (Huang, 2021). Further training is needed to enhance oncology nurses' end-of-life communication skills.

2.4 Chapter summary

This chapter reviews the literature on end-of-life communication and its training, highlighting the challenges of end-of-life communication in the Chinese context and identifying limitations within the relevant CST programs. The following chapter presents an original research study conducted by the author, which focuses on end-of-life communication strategies, identifies gaps in current research, and lays the groundwork for future training development.

Chapter 3: End-of-life Communication Strategies for Healthcare Professionals: A Scoping Review

3.1 Introduction

This chapter presents a scoping review focusing on end-of-life communication strategies. It includes the study background (Section 3.2), methods (Section 3.3), results (Section 3.4), discussion (Section 3.5) and conclusion (Section 3.6). This study has already been published in an international peer-reviewed journal (Chen et al., 2023). Modest modifications were made to the reference lists and citation styles to conform to the structure and specifications of this PhD thesis. Permission to use the published study has been granted by the publisher (Chen, W., Chung, J. O. K., Lam, K. K. W., & Molassiotis, A. (2023). End-of-life communication strategies for healthcare professionals: A scoping review. *Palliat Med*, 37(1), 61-74. <https://doi.org/10.1177/02692163221133670>) following “Sage’s Author Archiving and Re-Use Guidelines”.

3.2 Background

Effective communication is essential in delivering high-quality care to individuals facing terminal illness and their families (Scholz et al., 2020). As the disease progresses beyond curative measures, the focus shifts towards enhancing the patient's quality of life and ensuring a peaceful and dignified end-of-life experience (Krau, 2016; Rosenberg et al., 2013). This transition poses challenges for both patients and families as they grapple with the limitations of medical interventions and the reality of mortality, leading to emotional distress and shattered hopes (Wright et al., 2008). Effective communication at the end of life is essential for healthcare providers to understand the wishes, requirements, and choices of patients and their families. This enables the establishment of achievable care objectives and the provision of holistic care to support a respectful end-of-life experience (Keeley, 2016; Olsson et al., 2021).

Studies have shown that successful communication at the end of life can lead to a decrease in the utilization of aggressive and expensive medical treatments, an improvement in the quality of life for patients, a better experience during the bereavement period, and an overall higher satisfaction with the care received (Bernacki & Block, 2014; Brighton & Bristowe, 2016; Pun et al., 2020). Despite the recognized importance and benefits of end-of-life discussions, such conversations are not commonplace during interactions among terminally ill patients, their families, and healthcare providers (Knutzen et al., 2021; Qama et al., 2021). Obstacles to successful communication with patients can arise from various factors such as hesitancy, unease, or apprehension in discussing future issues, misinterpretations or refusal to acknowledge the illness, misunderstandings regarding end-of-life treatment, and insufficient clarity in information dissemination among family members (Granek et al., 2013; Hadley, 2020; Jacobsen et al., 2018).

Healthcare providers may encounter obstacles such as apprehension about causing discomfort, difficulties in evaluating patient readiness and information preferences, and insufficient training (Jiao & Hussin, 2020; ten Koppel et al., 2019; Toh et al., 2021; Zehm et al., 2020). Additionally, uncertainty about disease progression, lack of standardized protocols for end-of-life care, and cultural and ethical considerations further complicate effective communication (Trankle et al., 2020; Granek et al., 2013; Barclay et al., 2007; Glare et al., 2008; Smith et al., 2009). Nevertheless, it is the responsibility of healthcare professionals to engage in end-of-life conversations with terminally ill patients and their families (Brighton & Bristowe, 2016). In light of the aforementioned obstacles, it is crucial to furnish healthcare practitioners with proficient communication tactics for addressing end-of-life matters and offer assistance to guarantee that such dialogues are carried out with professionalism, sensitivity, and propriety (Courteau et al., 2018; Scholz et al., 2020).

Scholz et al. (2020) and Jain and Bernacki (2020) identified strategies primarily from clinicians' perspectives, while Anderson et al.'s systematic review (Anderson et al., 2019) incorporated insights from nurses, social workers, and relatives in addition to clinicians, although most studies were conducted in intensive care settings. A systematic review conducted by Parker and colleagues in 2007 consolidated the preferences of patients and caregivers concerning the content, manner, and timing of end-of-life communication (Parker et al., 2007). This review has since provided a basis for the formulation of successful approaches for healthcare practitioners in this context. Some studies have focused on specific end-of-life communication topics such as prognosis (van der Velden et al., 2020), advance care planning (Barclay et al., 2007) and goals of care (Bernacki & Block, 2014), potentially resulting in fragmented evidence on communication strategies. Nonetheless, there is a notable absence of a thorough examination that encompasses a range of end-of-life issues, taking into account the viewpoints of diverse stakeholders such as patients, families, and healthcare professionals in palliative and hospice care environments.

The definition of end-of-life communication is not universally agreed upon and exhibits variability among various research studies (Gonella et al., 2019). This review opts for a comprehensive interpretation that encompasses conversations surrounding diverse end-of-life topics such as death and dying, advance care planning, care goals, palliative or hospice care alternatives, referral procedures, and bereavement assistance (Brighton et al., 2017; Gonella et al., 2019; Pfeifer & Head, 2018; Sinuff et al., 2015). The term 'communication strategy' is inconsistently defined in the literature, with different terms such as process (Glare et al., 2008), step (Courteau et al., 2018), tactic (Broom et al., 2014), skill (Buckman, 2001), technique (Isaacson & Minton, 2018) and approach (Thomas et al., 2020) used to describe communication strategies. In order to encompass the various nuances of this concept, the definition proposed in the Comskil model by Brown and Bylund (2008) was utilized. Within this conceptual framework, a communication strategy is categorized as a higher-level concept and is explicitly

defined as a collection of plans that guide communication behaviors towards achieving communication objectives (Brown & Bylund, 2008). The model further elucidates that a communication strategy is executed through a sequence of distinct verbal utterances (communication skills) and nonverbal actions (process tasks) (Brown & Bylund, 2008; Kissane et al., 2012). Both communication skills and process tasks are tangible components. For instance, the strategy of 'tailoring the consultation to the patient's needs' can be realized by employing communication skills such as assessing patient comprehension and information preferences, in conjunction with implementing process tasks like minimizing interruptions and involving third parties (Brown & Bylund, 2008). Researchers can utilize the Comskil model to identify a specific communication strategy and differentiate it from communication skills and process tasks found in current literature. For instance, despite the use of the term 'communication strategy' by certain authors, the actual content may align more closely with a 'communication skill' or 'process task' depending on contextual analysis and the model's delineation (de Araujo & da Silva, 2012; Shannon et al., 2011).

The primary aim of this research was to provide a comprehensive overview and analysis of communication strategies utilized by healthcare professionals when discussing end-of-life matters with terminally ill patients and their families. To achieve this goal, a scoping review was conducted to synthesize the extensive body of knowledge available on this topic (Peters MDJ et al., 2020). The study focused on terminally ill adult patients, their families, and healthcare providers, with a specific emphasis on end-of-life communication strategies within various healthcare settings catering to adult patients nearing the end of life. The key objectives of the study were twofold: (a) to delineate the existing end-of-life communication strategies employed by healthcare professionals and (b) to pinpoint any gaps in the current literature, thereby guiding future research endeavors in this area.

3.3 Methods

This research conducted a scoping review following the framework established by Arksey and O'Malley (2005). The framework outlines five key stages for conducting a scoping review, which include identifying the research question, locating relevant studies, selecting pertinent studies, organizing the data, and synthesizing and reporting the findings. It is noted that the review protocol was not publicly available, and the study was not registered with PROSPERO, as recommended by scoping review guidelines (Arksey & O'Malley, 2005). Additionally, the study adhered to the PRISMA Extension for Scoping Reviews (PRISMA-ScR) guidelines for comprehensive reporting (Tricco et al., 2018).

3.3.1 Review question

What communication strategies are available for healthcare professionals to initiate and facilitate end-of-life communication with terminally ill adult patients and their families?

3.3.2 Data sources and search strategy

The author systematically searched for relevant studies from December 2021 to January 2022 to answer the research question. The search included published and unpublished studies between January 1990 and January 2022. The start date of 1990 was selected because the World Health Organization (WHO) released an initial international guideline for palliative care that year (WHO., 1990). No language restrictions were applied to the included studies, in order to obtain a comprehensive understanding of end-of-life communication strategies used globally across different countries and cultural environments. Given the review's aim to capture a wide range of knowledge on communication strategies, there were no restrictions on study design or type of evidence source.

The search was conducted across eight databases: PubMed, CINAHL, Embase, PsycINFO, Web of Science, Scopus, Cochrane Library, and China National Knowledge Infrastructure. Grey (unpublished) literature was searched through Google, Google

Scholar, and ProQuest Dissertations & Theses. The Google search process involved reviewing links from consecutive pages until the information was considered saturated, as per the Kelly et al. (2019) method.

Additionally, the authors hand-searched the websites of seven specific journals known to have a higher frequency of relevant literature based on an initial limited search. These journals were: *Journal of Palliative Medicine*, *American Journal of Hospice and Palliative Medicine*, *Palliative Medicine*, *Current Opinion in Supportive and Palliative Care*, *Journal of Pain and Symptom Management*, *BMC Palliative Care*, and *Patient Education and Counseling*.

The bibliographies of all included systematic and traditional literature reviews were checked to ensure relevant studies were not missed. Citation searches were also performed to identify new studies. Finally, a librarian was consulted to refine the overall search strategy.

3.3.3 Eligibility criteria

Two reviewers applied the following inclusion and exclusion criteria to identify the relevant studies:

3.3.3.1 Inclusion criteria

(1) Studies focused on end-of-life communication. (2) Studies describing recommended communication strategies for healthcare professionals to use when discussing end-of-life issues with patients and their families. (3) Studies concerning adult patients approaching the end of life, defined as those with advanced, progressive, and incurable conditions whose likely life expectancy was fewer than 12 months (National Institute for Health and Care Excellence, 2021). Relevant life-limiting illnesses included advanced cancer, advanced heart failure, end-stage pulmonary disease, end-stage kidney disease, and motor neuron disease. (4) Studies involving the families (including bereaved relatives) and healthcare providers (doctors, nurses, social workers, allied health staff) of the patients nearing the end-of-life.

3.3.3.2 Exclusion criteria

(1) Adult patients with chronic diseases (e.g., diabetes, dementia, multiple sclerosis) whose illness trajectory was indeterminable or whose likely life expectancy was over 1 year. (2) Patients being treated with a curative intent. (3) Studies focused on euthanasia or assisted suicide.

3.3.4 Study selection

During the initial phase of study selection, two reviewers independently assessed the titles and abstracts of potentially relevant studies. In the subsequent phase, the same reviewers examined the full texts of the preliminarily selected studies. Any discrepancies were addressed through discussion with a third reviewer and resolved by consensus. All search results were organized and managed using Endnote 20 (Clarivate Analytics, Philadelphia, PA).

3.3.5 Data extraction

A data charting form, adapted from the Joanna Briggs Institute template data extraction instrument (Peters MDJ et al., 2020), was utilized for the extraction of data. One reviewer employed this form to gather the data, while a second reviewer independently verified the accuracy of the collected data. The recorded information for the included documents comprised: (a) author(s), year of publication, and country; (b) aims of the study; (c) article focus; (d) article type; (e) methodology, including study design, setting, and participants; and (f) key findings pertinent to the scoping review questions.

3.3.6 Data collection and analysis

A table presents the salient features and principal conclusions of the included documents. To get in-depth analyses, descriptive qualitative content analysis was used (Peters MDJ et al., 2020). Two reviewers performed this in the beginning. An additional reviewer verified the extraction and analysis of the data. The three reviewers spoke and worked out their differences. Reading each of the included documents several times to have a general sense of their contents was the first stage in the analytical process. Second, pertinent literature on end-of-life communication strategies was found. Next, strategies that conveyed a similar meaning were coded, such as 'Team meeting before

patient communication’, based on the context or explanation given by the document writers. Following that, codes that conveyed similar meanings were sorted and linkages between them were found to establish categories. Ultimately, a series of dominant themes emerged from the categories. Quality evaluation and synthesis of the research evidence were not carried out because this was a scoping review (Arksey & O'Malley, 2005).

3.4 Results

3.4.1 Study selection

The study selection process is depicted in Figure 3.1. The initial search across databases identified a total of 63,188 records. An additional 442 records were found through other methods like grey literature and hand-searching. After removing duplicates, 60,830 records remained. Based on title and abstract screening, 60,294 of those records were deemed irrelevant and excluded. The remaining 536 full-text articles were assessed for eligibility, and 477 of those were subsequently excluded because they did not meet the inclusion criteria. All included documents were published in English; initial screening was carried out on articles in Spanish, but after translating the title and abstract they were found to be irrelevant to the study and were therefore excluded. Finally, the study inclusion process resulted in 59 documents being included in the overall analysis.

3.4.2 Descriptive characteristics of the documents

The 59 included documents in the study were derived from 10 different countries, with the majority coming from the United States (31 documents), followed by the UK (8), Australia (7), Canada (5), Sweden (3), Switzerland (1), the Netherlands (1), Portugal (1), Korea (1), and Japan (1). In terms of document types, the 59 included items consisted of 31 journal articles, 14 reviews, and 7 conference abstracts. The study designs encompassed 26 qualitative studies, 11 literature reviews, 7 case studies, 2 pre-post quantitative studies, 2 mixed-method studies, 2 systematic reviews, and 1 cross-sectional study. There were also 2 special articles published in peer-reviewed journals, 2 guidelines, 2 web pages, and 1 quality improvement project.

The studies were conducted in a variety of settings, including 15 in a hospital setting, 6 in a community setting, 5 in a hospice care setting, and 7 that spanned multiple settings. The remaining studies did not focus on specific settings.

The data was collected from different sources, including 14 studies involving healthcare professionals, 4 with patients, and 4 with patient families. Six studies collected data from all three of these stakeholder groups. Some studies focused specifically on data from doctors (10 studies) or nurses (6 studies).

In terms of the topical focus, 24 of the included documents covered the entire process of end-of-life communication or multiple aspects of it. The remaining documents focused on specific components, such as prognosis (10), goals of care and/or decision-making (8), advance care planning (4), end-of-life care (3), palliative care referral (2), hospice care referral (1), life expectancy (1), do-not-attempt-resuscitation (1), existential issues (1), the day of patient death (1), and bereavement care (1). The key characteristics of the included documents are summarized in Table 3.1.

3.4.3 Thematic findings of communication strategies

The communication strategies identified from the documents included in this review were collated and grouped into seven themes: (a) preparation; (b) exploration and assessment; (c) family involvement; (d) provision and tailoring of information; (e) empathic emotional responses; (f) reframing and revisiting the goals of care; and (g) conversation closure. The analysis indicates that individual articles may have discussed communication approaches falling under multiple thematic categories. Figure 3.2 presents a visual representation mapping these emergent themes.

3.4.3.1 Preparation

The literature reviewed strongly emphasizes the importance of developing a thorough and multifaceted preparation strategy prior to engaging in end-of-life communication with terminally ill patients and their families (Barclay et al., 2007; Buckman, 2001;

Casarett & Quill, 2007; Clayton et al., 2007; Courteau et al., 2018; Coyle et al., 2015; Felber et al., 2021; Hauser, 2017; Hickman, 2002; Isaacson & Minton, 2018; Kehl, 2015; Khosla et al., 2017; Koh et al., 2016; Martins et al., 2021; McCormack et al., 2021; Schapira, 2015; Thomas et al., 2020). Some documents describe this strategy as ‘setting the stage’ (Casarett & Quill, 2007; Hauser, 2017; van Vliet & Epstein, 2014). This strategy may include the following.

(1) Reviewing the patient’s medical facts (Barclay et al., 2007; Casarett & Quill, 2007; Clayton et al., 2007; Hauser, 2017; Isaacson & Minton, 2018; Jain & Bernacki, 2020; Kehl, 2015; Pfeifer & Head, 2018). (2) Planning the communication agenda (Jain & Bernacki, 2020). End-of-life communication may need a family meeting and several follow-up conversations (Pfeifer & Head, 2018). The involved patient, significant others the patient wants to be present and the relevant healthcare professionals should be identified (Casarett & Quill, 2007; Hauser, 2017; Martins et al., 2021; van Vliet & Epstein, 2014). (3) Identifying the roles of team members in a team meeting and ensuring coordination of communication if a healthcare team is presented in the communication (Hadley, 2020; Hauser, 2017; Kehl, 2015; Martins et al., 2021; Reblin et al., 2014; Schapira, 2015; van der Velden et al., 2020; van Vliet et al., 2015). (4) Preparing the physical setting, including arranging the place and ensuring privacy and adequate seats (Barclay et al., 2007; Buckman, 2001; Casarett & Quill, 2007; Clayton, et al., 2007; Felber et al., 2021; Hauser, 2017; Hickman, 2002; Khosla et al., 2017; Koh et al., 2016; Oluya et al., 2021; Pfeifer & Head, 2018). (5) Setting ample and uninterrupted time for each conversation (Barclay et al., 2007; Buckman, 2001; Casarett & Quill, 2007; Clayton, et al., 2007; Felber et al., 2021; Hauser, 2017; Hickman, 2002; Khosla et al., 2017; Koh et al., 2016; Oluya et al., 2021; Pfeifer & Head, 2018).

3.4.3.1.1 Roles of healthcare professionals in end-of-life communication.

End-of-life communication ideally involves healthcare professionals from medicine, nursing, chaplaincy and social work (Kimura et al., 2020; Martins et al., 2021; Pfeifer & Head, 2018). Anderson et al. (2019) and Hauser (2017) reported that doctors are

responsible for discussing prognosis. Nurses provide care and prepare families by assessing their information needs (Anderson et al., 2019; Kehl, 2015). Social workers and chaplains attend to emotion management (Pfeifer & Head, 2018). When communicating with patients and families from different cultural backgrounds, the presence of professional medical interpreters is recommended (Barclay et al., 2007; Khosla et al., 2017). Some documents have suggested that the preference of the patients and their families should be considered when deciding who should deliver the information (Clayton et al., 2007; Pfeifer & Head, 2018). For instance, some patients prefer to receive information from an expert (Barclay et al., 2007), whereas others may wish to receive information from a familiar professional (Hadley, 2020; Isaacson & Minton, 2018). Reblin et al. (2014) found that healthcare professionals who have an established, trusting relationship with terminally ill patients and their families may be best suited to facilitate end-of-life conversations. Two other studies (Martins et al., 2021; van Vliet et al., 2015) corroborated this notion, suggesting that designating one primary point-of-contact professional to liaise between the patient, family, and other healthcare providers can be an effective strategy. This assigned professional can ensure consistent, up-to-date information sharing and maintain a continuous relational connection throughout the end-of-life communication process.

3.4.3.2 Exploration and assessment

The sources emphasize the importance of thoroughly understanding the patient's perspective, concerns, and goals of care prior to engaging in conversations about sensitive end-of-life topics (Ariadne Labs, 2021; Barclay et al., 2007; Buckman, 2001; Childers et al., 2017; Clayton et al., 2005; Clayton et al., 2007; Coyle et al., 2015; Felber et al., 2021; Friedrichsen & Strang, 2003; Hadley, 2020; Hauser, 2017; Herrmann et al., 2019; Hickman, 2002; Isaacson & Minton, 2018; Jacobsen et al., 2018; Jain & Bernacki, 2020; Khosla et al., 2017; Martins et al., 2021; Masterson et al., 2018; Ngo-Metzger et al., 2008; Ohlen et al., 2016; Oluya et al., 2021; Schapira, 2015; Shaw et al., 2020; van Vliet & Epstein, 2014; VitalTalk, 2022; Wittenberg, Reb, & Kanter, 2018). It is critical to consider the patient's perspective and tailor further communication accordingly

(Buckman, 2001; Clayton et al., 2007; Herrmann et al., 2019; Kehl, 2015; van der Velden et al., 2020; van Vliet et al., 2015). The sources indicate that healthcare professionals can effectively explore patients' thoughts, needs, and preferences by actively listening to their narratives, stories, and perspectives. This approach involves seeking to understand the patients' underlying logic, beliefs, and concerns, rather than immediately discussing clinical end-of-life details (Hadley, 2020; Ohlen et al., 2016; Schapira, 2015; van der Velden et al., 2020; Wittenberg, Reb, & Kanter, 2018). Healthcare providers should not rush into substantive end-of-life discussions, but rather take the time to thoroughly explore and understand the patient's mindset, concerns, and goals of care over multiple interactions (Clayton et al., 2007; Koh et al., 2016). It also prepares the patients and their families for subsequent communication (Beddard-Huber et al., 2021; O'Connor et al., 2020). These strategies may include the following:

(a) Assessing patients' perceptions and understanding their diagnoses and prognoses (Applebaum et al., 2018; Barclay et al., 2007; Clayton et al., 2005; Clayton et al., 2007; Hadley, 2020; Hauser, 2017; Hickman, 2002; Isaacson & Minton, 2018; Jain & Bernacki, 2020; Khosla et al., 2017; Koh et al., 2016; Martins et al., 2021; Masterson et al., 2018; Schapira, 2015; van der Velden et al., 2020; van Vliet & Epstein, 2014); (b) exploring and ascertaining the patients' and families' information preferences (e.g., details or summary, type of information) (Applebaum et al., 2018; Barclay et al., 2007; Clayton et al., 2005; Clayton et al., 2007; Hadley, 2020; Hauser, 2017; Hickman, 2002; Isaacson & Minton, 2018; Khosla et al., 2017; Koh et al., 2016; Martins et al., 2021; Pfeifer & Head, 2018; Quill et al., 2009; Schapira, 2015; van der Velden et al., 2020); (c) exploring patients' concerns and problems (Buckman, 2001; Ohlen et al., 2016; Shaw et al., 2020); addressing denials reflected as seeking out medically futile treatments, by exploring the reason for the requests before providing information (Clayton et al., 2007; Schapira, 2015); being aware of patient cues (e.g., 'I don't know what to do about this') and have deeper questioning (Clayton et al., 2007; Isaacson & Minton, 2018); (d) exploring patients' emotional issues (Barclay et al., 2007; Bernacki & Block, 2014; Buckman, 2001; Jacobsen et al., 2018; Martins et al., 2021; Masterson

et al., 2018; Strang et al., 2014) and attitudes towards death (Schapira, 2015; Strang et al., 2014); (e) exploring patients' concerns about cultural issues, such as asking questions about dignity (Beddard-Huber et al., 2021) and their preference regarding the provider's gender (Barclay et al., 2007; Khosla et al., 2017; Ngo-Metzger et al., 2008); and (f) assessing patients' readiness to talk about end-of-life topics by firing a warning shot, in which the negative news is mentioned briefly to prepare the patients before sharing the detailed news (Barclay et al., 2007; Hauser, 2017; Martins et al., 2021; van Vliet & Epstein, 2014).

3.4.3.3 Family involvement

Many publications have discussed communication strategies that involve including the family in end-of-life communications (Applebaum et al., 2018; Beddard-Huber et al., 2021; Thomas et al., 2020). Multiple roles of families, such as those of surrogate decision-makers and informants, should be considered (Anderson et al., 2019; Barclay et al., 2007; Clayton et al., 2007; Dalkin et al., 2018; Kane et al., 2020; Koh et al., 2016; Martins et al., 2021; Schapira, 2015; van Vliet et al., 2015; VitalTalk, 2022; Wittenberg, Reb, & Kanter, 2018). The related strategies are as follows:

(a) Exploring families' concerns and desires, such as withhold information from patients; clarifying the reasons and making necessary explanations (e.g., explain that patients are often aware of the situation) (Barclay et al., 2007; Clayton et al., 2007); (b) identifying decision-making dynamics (i.e., 'patient-centred' or family-centred', which stresses different levels of patient autonomy) (Barclay et al., 2007; Koh et al., 2016); (c) determining who is the right person to talk to about end-of-life issues (Barclay et al., 2007; Koh et al., 2016; Shaw et al., 2020); considering the patient's preference for family involvement (Bernacki & Block, 2014); assisting surrogate decision-making (e.g., explaining their responsibilities) (Barclay et al., 2007; van Vliet et al., 2015); (d) observing family communication patterns to select suitable communication strategies (Wittenberg, Reb, & Kanter, 2018); recognising family discord at an early stage, while recognising limitations to resolve family dysfunction (Clayton et al., 2007; Schapira, 2015); (e) getting patient-related information from families to promote communication

(Schapira, 2015); (f) eliciting and clarifying the families' information preferences and communication needs (Clayton et al., 2007; van Vliet et al., 2015; Wittenberg, Reb, & Kanter, 2018); if necessary, having separate discussions without patients but providing consistent information to each party (Barclay et al., 2007).

3.4.3.4 Provision and tailoring of information

The literature reviewed has highlighted the need for healthcare professionals to provide appropriate, tailored information to terminally ill patients and their families. This includes explaining medical facts, details about the diagnosis, and information about available treatment options (Buckman, 2001; Clayton et al., 2005; Clayton et al., 2007; Clayton et al., 2017; Courteau et al., 2018; Coyle et al., 2015; Granek et al., 2013; Hadley, 2020; Hauser, 2017; Herrmann et al., 2019; Hickman, 2002; Kehl, 2015; Martins et al., 2021; Oluya et al., 2021; Schapira, 2015; van der Velden et al., 2020). The provision should be made carefully, and communication should be tailored to the patient's wishes (Anderson et al., 2019; Clayton et al., 2007; Friedrichsen & Strang, 2003). Several possible strategies have been identified.

(1) Providing relevant information to ensure the patients understand their prognosis (Anderson et al., 2019; Granek et al., 2013; Isaacson & Minton, 2018; Shaw et al., 2020), such as by highlighting the patient's deteriorating condition (Anderson et al., 2019), explaining the uncertainty and limitations and the process involved with making survival predictions while avoiding being too exact (Anderson et al., 2020; Clayton et al., 2005; Clayton et al., 2007; Jain & Bernacki, 2020) and educating about possible outcomes of different treatments (Dressler et al., 2020). Some documents have also suggested specific strategies for explaining uncertainty by illustrating multiple cases: the best case, the worst case and the most likely case (Clayton et al., 2007; Herrmann et al., 2019; Jain & Bernacki, 2020; Masterson et al., 2018; Schapira, 2015; van der Velden et al., 2020). (2) Pacing information to the patient's understanding (Barclay et al., 2007; Buckman, 2001; Clayton et al., 2007), such as by providing information in small segments and checking patient understanding from time to time (Courteau et al., 2018) using clear, jargon-free language (Buckman, 2001; Clayton et al., 2007; Courteau

et al., 2018; Coyle et al., 2015; Hadley, 2020; Hauser, 2017; Hickman, 2002; Khosla et al., 2017; Norton & Talerico, 2000; Schapira, 2015; Smith et al., 2009; Wittenberg, Reb, & Kanter, 2018), employing graphic language (e.g., ‘break their ribs’) (Dressler et al., 2020), and providing written materials (Barclay et al., 2007; Collins et al., 2018; Smith et al., 2009). (3) Pacing information to the patient’s reaction and acceptance by starting conversations with weaker words or expressions (e.g., ‘thinking about the future’ is weaker than ‘thinking about dying’) (Jacobsen et al., 2018; Norton & Talerico, 2000; Schapira, 2015) and using visual metaphors (‘taking a road trip’ when talking about palliative care referral, ‘opening a box’ when talking about goals of care) (Courteau et al., 2018; Jacobsen et al., 2018). (4) Ensuring the consistency of the information (Hauser, 2017; Herrmann et al., 2019; Martins et al., 2021). (5) Involving healthcare professionals with significant health expertise and palliative knowledge and the capability to explain medical information in an understandable way to patients and their families (Dalkin et al., 2018; Wittenberg, Reb, & Kanter, 2018). (6) Tailoring the content, timing and provider of information delivery to the patient’s information preference and needs (Anderson et al., 2019; Collins et al., 2018; Friedrichsen & Strang, 2003; Masterson et al., 2018; Thomas et al., 2020) and offering patients the option to not discuss end-of-life topics (Clayton et al., 2007).

3.4.3.5 Empathic emotional responses

The literature highlights the importance of healthcare professionals adopting an empathetic, validating approach when patients and families express emotions like fear, grief, or anxiety around end-of-life issues. Specific strategies recommended include:

(a) Acknowledging emotional reactions and verbalising empathy (Buckman, 2001; Childers et al., 2017; Clayton et al., 2007; Clayton et al., 2014; Courteau et al., 2018; Coyle et al., 2015; Hauser, 2017; Kane et al., 2020; Kimura et al., 2020; Oluya et al., 2021; Pfeifer & Head, 2018; Strang et al., 2014; van der Velden et al., 2020; van Vliet & Epstein, 2014; van Vliet et al., 2015; VitalTalk, 2022), as in a case study by Back and Arnold that illustrates four types of verbal empathic statements (verbalise empathy, exchange information, containing emotional chaos and respect searching) in response

to different emotions (Back & Arnold, 2013); (b) showing understanding, respect and support (Back & Arnold, 2013; Barclay et al., 2007; Buckman, 2001; Courteau et al., 2018; Hauser, 2017; Hickman, 2002; van Vliet & Epstein, 2014; van Vliet et al., 2015); (c) exploring, validating and normalising patients' emotions (Barclay et al., 2007; Casarett & Quill, 2007; Clayton et al., 2017; Coyle et al., 2015; Hauser, 2017; Jain & Bernacki, 2020; van der Velden et al., 2020; van Vliet & Epstein, 2014); and (d) giving patients and their families time and space to process their feelings (Friedrichsen & Strang, 2003; Hickman, 2002; Reblin et al., 2014; Schapira, 2015; van Vliet et al., 2015).

3.4.3.6 Reframing and revisiting the goals of care

The literature emphasizes that framing the goals of care for end-of-life is an ongoing, iterative process that requires frequent meetings between healthcare professionals, patients, and their families (Barclay et al., 2007; Casarett & Quill, 2007; Collins et al., 2018; Dressler et al., 2020; Felber et al., 2021; Hauser, 2017; Hickman, 2002; Jain & Bernacki, 2020; Pfeifer & Head, 2018; Schapira, 2015; Wittenberg, Reb, & Kanter, 2018). Examples of strategies include the following:

(1) Expressing professional opinions and questioning a patient's care plans or expectations using a hypothetical scenario sequence (i.e., describing a hypothetical future scenario based on the patient's plan or expectations, pointing out potential problems and offering suggestions) (Jain & Bernacki, 2020; Land et al., 2019). (2) Modifying treatment expectations and redefining the notion of success (Childers et al., 2017; Granek et al., 2013; VitalTalk, 2022); for example, patients and their families should be brought to understand that cure is not a treatment goal in an advanced progressive life-limiting illness but should be informed that there are other care options to improve the length and quality of life (Clayton et al., 2007). Reblin (2014) described a strategy that reframes a tragic loss as a successful accomplishment of caring for bereaved families. (3) Focusing on life and living rather than on death and dying (Clayton et al., 2007; Jacobsen et al., 2018; Schapira, 2015; Wittenberg, Reb, & Kanter, 2018). (4) Laying out care options with possible outcomes and side effects, avoiding misleading (Pfeifer & Head, 2018). (5) Delaying the introduction of hospice care until

the patient's goals of care are consistent with a hospice approach, rather than introducing it right at the beginning (Casarett & Quill, 2007; van Vliet et al., 2015). The introduction should inform the patients and their families of the benefits of hospice care and address their misconceptions (Casarett & Quill, 2007; Clayton et al., 2007; Herrmann et al., 2019). (6) Articulating multiple survival scenarios and recommending hospice care to patients and their families to hope for the best while preparing for the worst (Clayton et al., 2007; Herrmann et al., 2019; Schapira, 2015; van der Velden et al., 2020). (7) Being patient, allowing the patients and their families to absorb the information and reflect on the trade-offs (Bernacki & Block, 2014; Casarett & Quill, 2007; Granek et al., 2013; Jacobsen et al., 2018; Khosla et al., 2017; Pfeifer & Head, 2018; Shaw et al., 2020). (8) Re-evaluating the goals of care when new information emerges (Hickman, 2002; Shaw et al., 2020).

3.4.3.7 Conversation closure

It is necessary to make an explicit closure at the end of each conversation (Ariadne Labs, 2021; Barclay et al., 2007; Beddard-Huber et al., 2021; Buckman, 2001; Coyle et al., 2015; Hauser, 2017; Oluya et al., 2021; van Vliet & Epstein, 2014; VitalTalk, 2022). Several strategies are recommended in the literature:

(a) Summarising what has been discussed and providing a contract for the next contact (Ariadne Labs, 2021; Barclay et al., 2007; Beddard-Huber et al., 2021; Buckman, 2001; Coyle et al., 2015; Felber et al., 2021; Hauser, 2017; Oluya et al., 2021; Shaw et al., 2020; VitalTalk, 2022); (b) checking in with the patient and confirming what has been said (Barclay et al., 2007; Buckman, 2001; Courteau et al., 2018; Coyle et al., 2015; Shaw et al., 2020); (c) emphasising care continuity and team availability (Hadley, 2020; Strang et al., 2014; van der Velden et al., 2020), making partnership statements and giving reassurance about non-abandonment (Barclay et al., 2007; Buckman, 2001; Casarett & Quill, 2007; Courteau et al., 2018; Coyle et al., 2015; Hadley, 2020; Kane et al., 2020; Strang et al., 2014; van der Velden et al., 2020); and (d) documenting discussions (Ariadne Labs, 2021; Clayton et al., 2007) and sharing information within the patient's healthcare team (Kimura et al., 2020; McCormack et al., 2021).

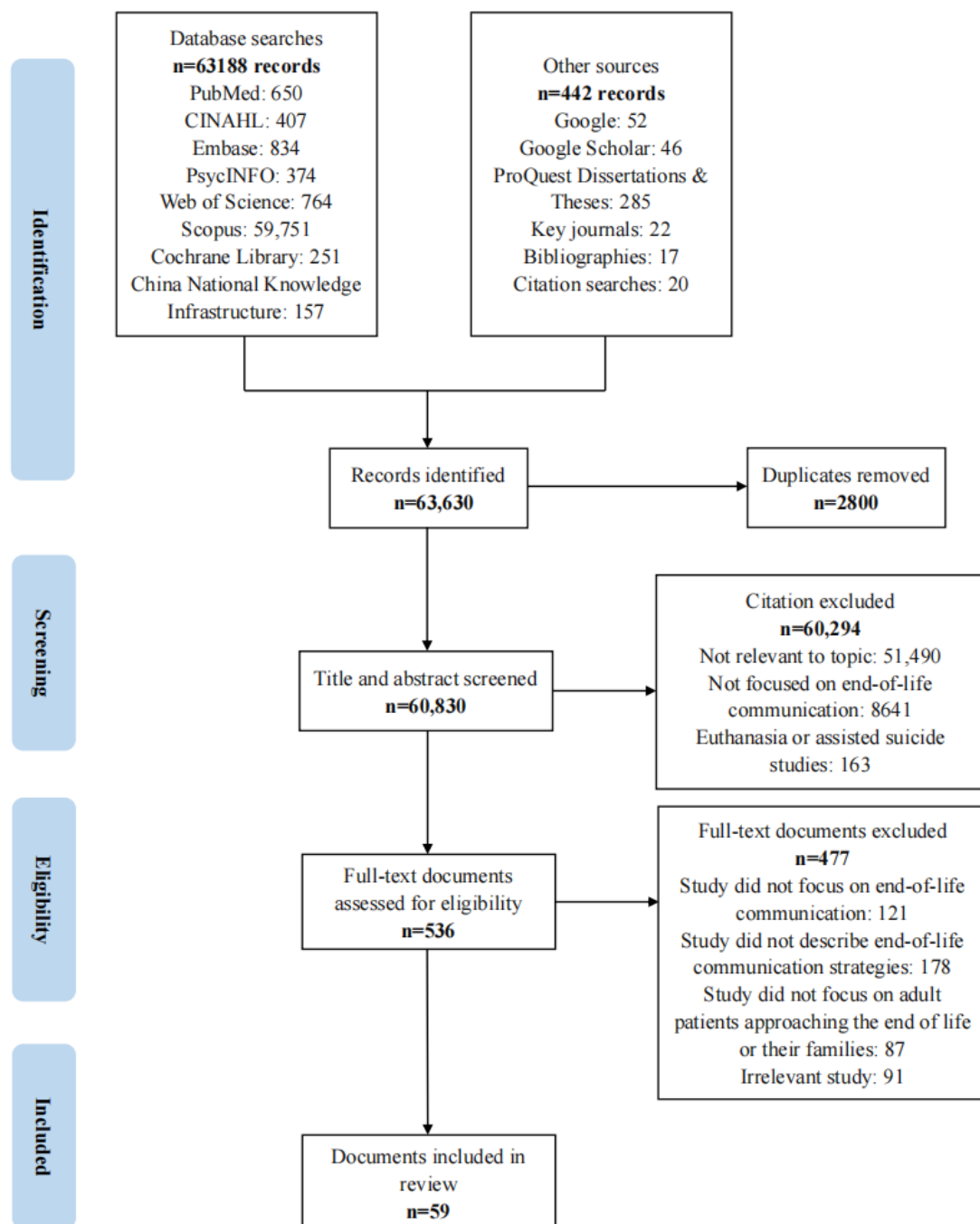


Figure 3.1 Flow Diagram of the Selection of Sources of Evidence

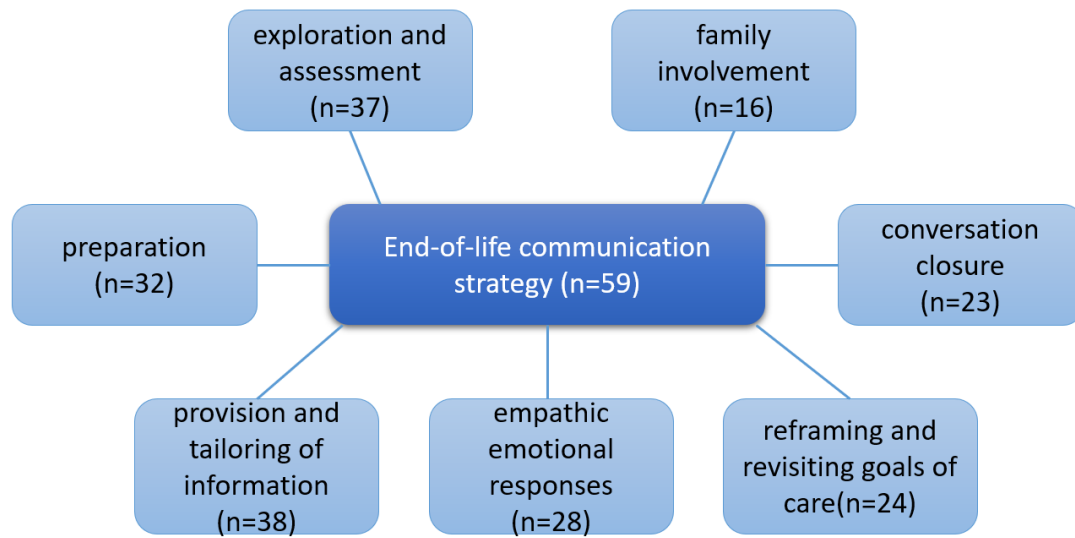


Figure 3.2 Map of scoping review results

Table 3.1 Main characteristics of the included documents

No.	Author(s), year of publication, country	Article Focus (related to this review)	Article type	Study design	Aim(s)	Setting(s)	Participants	Key findings of the article relevant to the review
1	Back & Arnold, 2013, US	Respond to emotional cues in the discussion of goals of care	Journal article	Case study	To discuss four different communication strategies for patients who ask, "Isn't there anything more you can do?"	Hospital	Patient with metastatic colon cancer; clinician	Four communication strategies—verbalise empathy; exchange information; contain the chaos; and respect searching
2	Barclay et al., 2007, US	Deliver bad news and discuss advance care planning	Review	Literature review	To provide an overview of the evidence for communication strategies in delivering bad news and discussing advance care planning	N.A.	N.A.	Healthcare providers should have a working knowledge of potential areas of discussion prior to talking with patients; ask patients how much they want to know before giving information; explore cultural issues in an open-ended dialogue; explore patients' emotional cues through empathic

								statements
3	Buckman, 2001, Canada	Break bad news	Review	Literature review	To provide a practice guide for communication in palliative care	N.A.	N.A.	CLASS protocol (C-physical Context or setting; L-Listening skills; A-Acknowledge emotions and explore them; S-management Strategy; S-Summary and closure); SPIKES protocol (S-Setting; P-patient's Perception of condition and seriousness; I-Invitation from patient to give information; K-Knowledge, explaining medical facts; E-Explore Emotions and Empathise as the patient responds; S-Strategy and Summary
4	Casarett & Quill, 2007, US	Hospice referral	Journal article	Case study	To describe a structured strategy for discussing hospice	Hospital	Physicians; a patient with a limited life expectancy	A practical approach to hospice discussions has eight steps: 1. Establish the medical facts;

						<p>who still wants aggressive treatment, a patient whose goals are consistent with hospice but who has an uncertain life expectancy, and a patient for whom hospice appears to be the best option based on both prognosis</p>	<p>2. Set the stage; 3. Assess the patient's understanding of his or her prognosis; 4. Define the patient's goals for care; 5. Identify needs for care; 6. Introduce hospice; 7. Respond to emotions elicited and provide closure; 8. Recommend hospice and refer</p>
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							and patient goals	
5	Clayton et al., 2005, Australia	Discussing life expectancy with terminally ill cancer patients and their carers	Journal article	Qualitative study (focus groups and individual interviews)	To explore terminally ill patients', carers' and healthcare providers' views about discussing life expectancy	Palliative care services setting in hospitals, palliative care units and the community	Palliative care healthcare providers (7 specialist physicians and 6 senior registrars in training), 4 nurses and 5 allied health staff (an occupational therapist, physiotherapist, social worker, bereavement counsellor, and pastoral care worker);	Provide a general indication, not a time frame; provide a time frame if requested; Explain uncertainty and limitations involved; Explaining the process involved in making survival predictions

							Terminally ill cancer patients and their carers	
6	Clayton et al., 2007, Australia	Prognostic and end-of-life communication	Clinical practice guideline (on peer-reviewed journal)	Literature review (systematic review, review of consensus guidelines and expert opinion) and expert advisory panel (Delphi method)	To provide a clinical practice guideline to discuss prognostic and end-of-life issues with patients with progressive life-limiting illnesses, and their families	Any care setting with life-limiting patients	All members of the healthcare team involved in the care of patients with progressive life-limiting illnesses, and their families	Prepare for the discussion; Relate to the person; Elicit patient and caregiver preferences; Provide information, tailored to the individual needs of both patients and their families; Acknowledge emotions and concerns; Realistic hope; Encourage questions; Document
7	Clayton et al., 2017, US	Nurse-caregiver communication on the day of cancer patient death	Journal Article	Qualitative study (a descriptive secondary analysis of 44	To describe nurse-caregiver communication on the day of a cancer patient's death	Home hospice	42 caregiver-cancer patient dyads; 27 hospice	Multiple supportive communication strategies: 1. Facilitating and/or explaining final acts; 2. Honoring patient dignity; 3. Providing reassurance;

				audiotaped home-hospice, day of death, nursing visits)			nurses	4. Providing information to the caregiver, family and patient; 5. Facilitating engagement with, or referrals to, other services
8	Courteau et al., 2018, Canada	Palliative care referral	Special article (on peer-reviewed journal)	N.A.	To summarise the evidence on early palliative care referral	N.A.	N.A.	Modified SPIKESS model (S-Setting up the interview; P-assessing the patient's Perception; I-obtaining the patient's Invitation; K-giving Knowledge and information to the patient; E-addressing patient's Emotions with Empathic responses; S-Summary and Strategy; S-Self-care)
9	Coyle et al., 2015, US	Discussing death, dying, and end-of-life goals of care	Journal article	Quantitative study (pre-post study)	To adapt an end-of-life care communication skills training module for oncology nurses	Oncology setting	Oncology nurses	This module suggests five strategies: 1. Establish the relationship; 2. Develop an accurate, shared understanding of the

					and to evaluate participants' confidence in using the communication skills learned and their satisfaction with the module			<p>patient's situation, including disease features, prognosis without treatment, and psychosocial needs and concerns;</p> <p>3. Support patients and their families following the physician's discussion of death and dying and end-of-life goals;</p> <p>4. Respond empathically to patient's emotional response;</p> <p>5. Close the conversation</p>
10	Dalkin et al., 2018, UK	Facilitates death in usual place of residence	Journal article	Mixed-method study (local primary care practice death audit data, focus	To understand how, for whom and in which circumstances death in usual place of residence is facilitated	14 general practitioner practices	Primary and secondary care staff, voluntary sector organisations and care home representatives;	All the component parts of advance care planning can be considered as open communication strategies. Discussions should be open and aim to ensure that patients and their family members are involved in, understand and accept their palliative care plan

				groups and interviews)			bereaved relatives	
11	Glare et al., 2008, Australia	Predicting survival in patients with advanced disease	Review	Literature review	To describe the way to formulate a prognosis and communicate the information	N.A.	N.A.	P.R.E.P.A.R.E.D.: Prepare for the discussion; Relate to the person; Elicit patient and caregiver preferences; Provide information, tailored to the individual needs of both patients and their families; Acknowledge emotions and concerns; Realistic hope; Encourage questions; Document
12	Granek et al., 2013, Canada	Effective communication about the end of life	Journal article	Qualitative study (interview)	To explore oncologists' communication strategies and communication barriers when	Adult oncology centres	Oncologists	1. Being open and honest; 2. Having ongoing, early conversations; 3. Communicating about modifying treatment goals; 4. Balancing hope and

					discussing end-of-life issues with patients			reality
13	Hadley, 2020, UK	Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) conversations	Journal article	Qualitative study (semi-structured interviews)	To explore the experiences and communication strategies of clinical nurse specialists in palliative care when managing DNACPR conversations in the community	Community palliative care setting	Community palliative care clinical nurse specialists	<p>Begin DNACPR conversations by initially checking the patient's understanding of their condition and prognosis, inviting patients to talk about their future preferences for care and including death as part of a wider discussion.</p> <p>Participants also reported enquiring about patient preferences regarding DNACPR.</p> <p>The majority of participants said they emphasised care continuation, such as continued treatment of infections</p>
14	Hauser, 2017,	End-of-life	Review	Literature	To describe several	N.A.	N.A.	SPIKES:

	US	communication in heart failure and palliative care		review	important communication strategies that enhance patient and family support through the inevitable rises and falls of progressive heart failure			1. Setting. Getting started; 2. Perception. What does the patient know? 3. Invitation. How much does the patient want to know? 4. Knowledge. Sharing the information; 5. Emotion. Responding to feelings; 6. Subsequent/Summary. Planning and follow-up
15	Herrmann et al., 2019, Australia	To facilitate palliative care delivery	Journal article	Qualitative study (semi-structured phone interviews)	To explore, in a sample of Australian G.P.s, their perceptions of best practice palliative care and their ideal role in its delivery	Primary palliative care settings	General practitioners	Active listening, realistic communication about life expectancy and recommended care, focusing discussions on the benefits of palliation rather than giving patients false hopes for cure, and conveying that there are treatments available to keep them comfortable
16	Hickman,	End-of-life	Review	Literature	To identify barriers	N.A.	N.A.	Preparing for the

	2002, US	communicat- ion		review	to optimal communication near the end of life and strategies to overcome them			discussion by attending to the setting, permitting ample time, identifying who should be involved (Step 1), and establishing what the patient and family already know (Step 2). Clinicians should determine how a patient wants important information shared, taking into consideration that some patients prefer that their family make decisions for them (Step 3). Information should be shared in a sensitive, straightforward manner (Step 4). Patients and families need time to react to difficult news, and it is important to be prepared to respond (Step 5). New information may require
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								reevaluating treatment goals and establishing new treatment priorities, which may occur over several appointments (Step 6), before setting a plan for care (Step 7)
17	Isaacson & Minton, 2018, US	End-of-life communication	Journal article	Qualitative study (interviews)	To understand the communication practices used by rural and urban, hospice/palliative care nurses when engaging patients and families in decision-making at end of life	Five rural nurses in the home, acute care, and nursing home settings. Five urban nurses in a hospice house	10 hospice/palliative nurses	Establishing context, acknowledging through attentive listening, making it safe for them to die, planning goals of care, and being honest
18	Jacobsen et al., 2018, US	Talking about the prognosis and future	Journal article	Case study	This article describes how trained clinicians use a dual framework to help	Outpatient setting with seriously ill patients	Outpatient clinicians working with seriously ill	A dual framework that focuses on living well while acknowledging the possibility of dying

					patients navigate the developmental process of living and dying		patients are ambivalent, uncomfortable, or fearful of further discussion about the future	
19	Kehl, 2015, US	Prepare family caregivers for the patient's final days of life	Journal article	Qualitative study (Individual semi-structured interviews)	To describe how hospice clinicians prepare the family for the final days of life	The home setting from two hospice agencies	19 hospice clinicians	Preparatory messages included information on signs of impending death, symptoms, implications of the symptoms, what to expect next, and instructions on what to do. Commonly used strategies included listening, engendering trust, repetition, collaboration with other disciplines, and demonstrations. Staff tailored content and delivery of messages on

								patient, family, and hospice factors
20	Khosla et al., 2017, US	End-of-life communication	Journal article	Qualitative study (semi-structured interviews and focus group discussions)	To examine communication challenges faced by healthcare providers serving seriously ill South Asian patients and their families and present strategies recommended by providers for effective communication	Inpatient and outpatient settings	57 healthcare providers, including physicians, social workers, nurses, chaplains, and others drawn from different healthcare settings	Proactively inquiring about patients' and families' preferences and encouraging early appointment of a spokesperson
21	Koh et al., 2016, Korea	Disclosure of bad news	Journal article	Qualitative study (focus group interview)	To develop a communication model for end-of-life care decision making compatible with the clinical environment in Korea	Acute hospital settings and hospice care facilities	8 doctors and 5 nurses who provide end-of-life care for terminal cancer	Beginning with the determination of a patient's decision-making capability, followed by a patient's perception of his/her condition, a patient's wish to know, family dynamics, and a patient's and/or

							patients in acute hospital settings or hospice care facilities	family's readiness for end-of-life discussions
22	Martins et al., 2021, Portugal	End-of-life communication	Journal article	Qualitative study (ethnographic observation and interviews)	To develop an exploratory analysis of some of the interactional strategies developed by palliative care professionals in order to prepare end-of-life talks with patients and their families	Two hospital internment units providing palliative care in Mainland Portugal	Professionals in palliative care—physicians, nurses, and social workers	End-of-life talk as a wider social process: preparation strategies; coordination of actions, and more structured approaches
23	Norton & Talerico, 2000, US	End-of-life decision-making	Journal article	Qualitative study (interviews)	To examine provider behaviours that facilitated the process of decision-making	Home care setting, intensive care, oncology care	Ten participants were nurses in specialties of home	Communication strategies included: being clear, avoiding euphemisms, spelling out the goals and expectations of treatment, using words such as

					near the end of patients' lives	setting	health care (n=3), intensive care (n=4) and oncology (n=3). Five participants were physicians specialising in oncology (n=3) and family practice (n=2). Five participants were immediate family members of patients with a life-threatening	"death" and "dying", and being specific when using such words as "hope" and "better". Assessment strategies included: assessing patients' physical conditions and end-of-life wishes, patients' and family members' understandings of the disease and prognosis, and their expectations and goals
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							illness or recent decedents	
24	Ohlen et al., 2016, Sweden	End-of-life communication during ongoing palliative chemotherapy	Journal article	Qualitative study (participatory action research, focus group discussions)	To put forward a practice model for communication between patients, their family members, and professional providers during ongoing palliative chemotherapy: a model supporting the providers to enable person-centred communication	Outpatient palliative cancer care setting	Patients and healthcare providers (physician/registered nurse/ licensed practitioner nurse/social worker)	A practice-based model for person-centred communication in the context of outpatient palliative treatment is put forward: the Enabling Sense-Making (ESM) model
25	Reblin et al., 2014, US	Spiritually-sensitive communication strategies in bereavement	Journal article	Case study	To examine the communication strategies the nurse uses in order to address the widow's grief from	Home hospice care setting	Healthcare providers	Creating space to allow for the expression of emotions and spiritual beliefs and encouraging meaning-based coping, including emphasising the caregivers'

		care for caregivers			a spiritually and culturally sensitive perspective			strengths and reframing negative experiences
26	Schapira, 2015, US	End-of-life communication	Review	Literature review	To examine the ageist bias that is prevalent in clinics today and then review the basic communication principles and strategies that can help clinicians make their conversations with patients	N.A.	N.A.	Involving family caregivers allows the family and the medical team to share their understanding and worries about care and solidify a therapeutic relationship. A technique that never fails is to focus on life and living rather than death and dying. A frequently taught and useful communication strategy is to help patients articulate worst- and best-case scenarios and then recommend planning for the worst while hoping for a better outcome
27	Smith et al., 2009, US	End-of-life communication with	Journal Article	Case study	To present a case and provide suggestions on	Palliative care setting	Healthcare providers	Be open, curious, and respectful. Use of professional

		Latino patients and their families			palliative care for Latino patients and their families			interpreters in person. Clear health communication using basic terminology and avoiding all jargon. Assist in family involvement
28	van der Velden et al., 2020, The Netherlands	Prognostic communication	Review	Systematic review	To offer up-to-date, evidence-based guidance on prognostic communication in palliative oncology	N.A.	N.A.	The first strategy encompasses physicians' provision of more explicit, rather than imprecise, prognostic information. Second, physicians' tendency to stress the best-case scenario, possibly inducing patients' overestimation of life expectancy, could complement a typical and worst-case scenario. A third disclosure strategy involves physicians' reassurance about non-abandonment and support

								<p>while communicating life expectancy.</p> <p>Fourth, hope might be fostered by physicians through expert, positive and collaborative behaviour during prognostic communication</p>
29	van Vliet et al., 2015, US	End-of-life communication with older, seriously ill patients	Review	Literature review	To provide more insight into effective communication with older people with serious illness and their surrogates	N.A.	N.A.	<p>Assessing patients' information preferences and tailoring information to individual patients' needs and information processing abilities.</p> <p>Two-step approach to elicit goals of care: exploring what gives life meaning, identifying concerns.</p> <p>Recommending a treatment plan based on the patient's goals.</p> <p>Suggestions to assist surrogates in making decisions</p>

30	Wittenberg et al., 2018, US	Communicating with patients and families about difficult topics in cancer care	Review	Literature review	To examine nurse communication in cancer care and offer communication strategies for quality palliative care nursing	N.A.	N.A.	COMFORT is an acronym that stands for the seven basic principles of palliative care communication: C-Communication, O-Orientation and options, M-Mindful communication, F-Family, O-Openings, R-Relating, T-Team
31	Beddard-Huber et al., 2021, Canada	Adaptation to the Serious Illness Conversation Guide (SICG) to be more culturally safe in First Nations and Indigenous Peoples	Quality improvement project	Mixed-methods study	To adapt the SICG to be more culturally safe for First Nations and Indigenous Peoples	First Nations communities	35 older adults, elders, and community members from two First Nations communities plus approximately 80 nurses serving in First	Preparing the patient for the conversation. Asking permission. Word adjustment in accordance with health literacy. Inclusion of a question about the desire for specific cultural practices. The importance of being direct when asking questions, including family in the conversation, establishing a trusting relationship with the

							Nations communiti- es	patient, asking for permission, and scheduling time for storytelling
32	Oluya et al., 2021, US	Palliative care communicat- ion	Confer- ence Abstra- ct	Quantitat- ive study (before and after study)	To design and implement a primary palliative care communication workshop and practicum using mentored skill- based feedback; To improve resident motivation and confidence in patient/proxy/care- giver-centred advanced care planning and serious illness conversations	Hospital	Internal medicine residents	SPIKES framework; Serious Illness Conversation Guide
33	Felber et al., 2021, Switzerland	Communicat- ing about approaching	Confer- ence Abstra-	Mixed- method study (a	To develop a communication model for health	Not reported	Medical students, physicians,	The model contains three main parts: 'Before' includes recognition of the

		death	ct	systematic review and a qualitative study)	professionals to engage in conversations about approaching death with patients and families		nurses, bereaved relatives, and patient representatives	dying phase and preparation of the talk. 'During' focuses on setting the stage for communicating about dying, exploring the patient's and family's view, as well as major concerns and needs regarding the current situation and the dying process, establishing shared goals for the last days of life, defining a care plan for the dying process, and summarising and exiting the conversation. 'After' includes debriefing, self-reflection and self-care
34	Anderson et al., 2020, UK	Prognostic conversations	Journal article	Qualitative study (conversation analytic study)	To understand how clinicians and the relatives/friends of patients at the very end of life manage uncertainty and	Two inpatient wards at one UK hospice	Experienced palliative care clinicians and relatives/fr-	Clinicians provided what we term 'absolute categorical time estimates' (suggesting a prognosis of 'hours' or 'days') and explained how that

					reference time in prognostic conversations		ends of imminently dying hospice inpatients	prognosis was reached, allowing them to reduce prognostic uncertainty without committing to an overly specific timescale
35	Applebaum et al., 2018, US	Prognostic conversations	Conference Abstract	Qualitative study (semi-structured interviews)	To investigate the phenomenology of prognostic understanding by exploring the delivery of prognostic information and the mechanisms that contribute to the understanding and uptake of this information	Not reported	15 oncology, psycho-oncology, and palliative care professionals (experts) and 30 patients with advanced cancers	Patients identified treatment options and life expectancy as the most important elements of prognostic information provided and necessary to make treatment decisions and plans for the future. Interestingly, experts placed less emphasis on life expectancy in light of medical uncertainty. Experts discussed communication strategies for discussing prognosis, such as directly eliciting patient preferences for information, using data, and including family

								members in discussions
36	O'Connor et al., 2020, Australia	Goals of Care (GOC) discussions	Journal article	Qualitative study (semi-structured interviews)	To explore patients' experiences of GOC discussions in the hospital setting	Hospital	Adult patients had had a GOC discussion	Patients who experienced the GOC interaction positively emphasised patient-centred elements of the discussion, including normalising the topic, using non-verbal behaviours effectively, avoiding medical jargon, and spending time with the patient. Feeling "heard" and sensing that the doctor was listening and demonstrating understanding of their situation and preferences were very important to patients
37	Masterson et al., 2018, US	Prognostic conversations	Journal article	Qualitative study (individual semi-structured	To explore the experiences of experts in the field of palliative care in order to examine	Hospital	Expert clinical psychologists and physicians	The majority of participants spontaneously discussed the importance of assessing and respecting a patient's desire for

				interview)	the communication of prognostic information		in the fields of oncology, psycho-oncology, and palliative care	prognostic information, prior to initiating discussions related to these issues. Clinicians should identify the type of information desired, consider the optimal timing of these discussions, and with whom information should be shared with. Assessment of patient prognostic understanding. Assessment of patient prognostic understanding
38	Thomas et al., 2020, Australia	Initiating conversations about end-of-life care in general practice	Conference Abstract	Qualitative study (interviews)	To explore G.P.s' thought processes when deciding whether to initiate end-of-life conversations, and describe their approach to initiating these discussions	Not reported	Fifteen G.P.s or G.P. registrars	Preparation, finding an entry point, tailoring communication and involving the patient's family

39	Collins et al., 2018, Australia	Introducing palliative care and talking about death and dying	Confer- ence Abstra- ct	Qualitati- ve study (interviews)	To explore caregiver perspectives on communication about death, dying, and the introduction to palliative care, with a view towards a series of caregiver- informed recommendations for use in clinical practice	A tertiary metropoli- tan cancer service	English- speaking adult caregivers of people with advanced cancer (n=25)	To introduce the concept of palliative care, caregivers wanted routinely available written resources about palliative care, supplemented by conversations that are ideally staged overtime. Once death is imminent, carers want health professionals to clarify how much they want to know about the dying process
40	McCann et al., 2021, UK	Educating nursing home staff on end- of-life conversations	Confer- ence Abstra- ct	Not reported	To educate nursing home staff to hold end-of-life conversations during a pandemic using the virtual learning environment CANVAS.	Twelve facilitators from six countries completed online training	Nursing home staff	Using the Comfort Care Booklet, modules included strategies to support nursing home staff in communication, good practice and handling challenging situations
41	McCormack et	Doctors'	Journal	Qualitati-	To better	Primary	Sixteen	Planning for patient-

	al., 2021, UK	views on how to improve communication and quality of care for patients experiencing end-of-life	article	ve study (semi-structured individual interviews)	understand the views of doctors on how to improve end-of-life healthcare in light of existing challenges and processes	care (three general practices) or acute care (one National Health Service hospital trust)	doctors	centred care—conversations about end-of-life care should take place earlier to allow for care that is planned and personalised
42	Kane et al., 2020, US	Hospice care communication	Journal article	Qualitative study (a descriptive secondary analysis)	Guided by Communication Accommodation Theory, evaluating communication similarity, indicating theoretical convergence, between hospice nurses and caregivers of cancer patients, identifying nurse	Home hospice	Caregiver-patient dyads; home hospice nurse	The findings suggest the use of specific nursing communication skills such as nurse partnering and nurse emotional responses when engaging in hospice care delivery

					attributes and communication skills that were associated with greater communication similarity			
43	Kimura et al., 2020, Japan	End-of-life discussion	Journal article	Cross-sectional study	To identify barriers to end-of-life discussion with advanced cancer patients and their families as perceived by oncologists, certified/specialised nurses in cancer nursing (hereafter, collectively referred to as 'nurses') and medical social workers, as well as to clarify their	402 designated regional cancer hospitals in Japan	494 oncologists (valid response rate 30.7%), 993 nurses (46.7%) and 387 medical social workers (48.1%)	To facilitate end-of-life discussion, providing mental and emotional support for the patients and their families after end-of-life discussion' was needed most as perceived by the respondents regardless of their profession

					opinions about effective strategies to facilitate end-of-life discussion			
44	Anderson et al., 2019, UK	End-of-life communication	Review	Qualitative systematic review	To review qualitative evidence concerning characteristics of communication about prognosis and end-of-life care between healthcare professionals and relatives of patients approaching the end-of-life	N.A.	N.A.	Varied levels of family involvement in decision-making were reported. Healthcare professionals used strategies to aid understanding and collaborative decision-making, such as highlighting the patient's deterioration, referring to patient wishes and tailoring information delivery. Doctors were regarded as responsible for discussing prognosis and decision-making, and nurses for providing individualised care
45	Clayton et al., 2014, US	Home hospice	Journal article	Qualitative study (a	To identify and describe	Home hospice	Patients, caregivers	The most prevalent distress areas reflected

		communication		secondary analysis)	communication behaviours used by hospice nurses when eliciting and addressing concerns of patients with cancer and their caregivers		and home hospice nurses	psychological and physical issues. Nurses used proportionally more positive emotional statements before patient and caregiver concerns compared to the visit overall. Nurses asked proportionally more physical questions after concern statements. Nurses also used more emotional responses before and after patient and caregiver concerns relative to the entire visit
46	Pfeifer & Head, 2018, US	Conversations about dying and end-of-life care	Review	Literature review	To review what is known about the skills and strategies necessary for meaningful and effective end-of-life conversations and emphasise the	N.A.	N.A.	Being well-informed about the patient's medical history and present situation before holding any discussions related to serious illness

					valuable role of interdisciplinary approaches to these discussions			
47	VitalTalk, US	End-of-life communication training	Web page	N.A.	To train clinicians in effective communications, crowdsourced this primer to provide practical advice on how to talk about difficult topics	N.A.	N.A.	Breaking bad news using the GUIDE tool; Discussing prognosis: using the ADAPT tool; Addressing Goals of Care: using the REMAP tool; Family conference: bringing family members into the conversation; Talking about dying: 1. Choose an appropriate time & place; 2. Acknowledge the end of your routine contact; 3. Invite the patient to respond; 4. Frame your goodbye as an appreciation; 5. Allow space for the patient to reciprocate, and respond empathically; 6. Articulate

								your commitment to the patient's ongoing care; 7. Take a moment to reflect PAUSE Talking Map for an 'early' goals of care conversation
48	Ariadne Labs, US	End-of-life communication	Web page	N.A.	N.A.	N.A.	N.A.	Serious Illness Conversation Guide; Talk to patients about their goals and values: set up the conversation, assess the patient's illness understanding and information preferences, share prognosis, explore key topics, and close and document the conversation
49	Land et al., 2019, UK	Addressing possible problems with patients' expectations, plans and decisions for	Journal article	Qualitative study (conversation analysis of video-recorded	To describe how experienced hospice doctors raise potential/actual problems with patients'	Hospice care setting	Five UK hospice consultants, 37 patients and their companions	A 'Hypothetical Scenario Sequence' where doctors raise a hypothetical future scenario wherein current plans/expectations turn out to be problematic, then engage patients in

		the future (Goals of Care discussion)		consultati- ons)	expectations, plans or decisions			discussing what could be done about this
50	Friedrichsen & Strang, 2003, Sweden	Breaking bad news	Journal article	Qualitati- ve study (semi- structured interviews)	To study how doctors perceive their strategies when giving information to cancer patients about discontinuing active tumour treatment	Hospital	Thirty doctors	Explaining and convincing information; softening the impact of the information; preparing either the patient or the physician himself/herself for the information; adapting or tailoring the information to the patient
51	Dressler et al., 2020, US	Discuss patient/fami- ly preferences for aggressive treatment	Confer- ence abstract	Qualitati- ve study (semi- structured interviews)	Describe the strategies hospice clinicians use to discuss patient/family preferences for aggressive treatment or remaining full code	Hospice care setting	61% of participants were clinicians (23 nurses, 21 social workers, 7 physicians and 2 chaplains; two had	Specific strategies reported included educating about likely outcomes of aggressive treatment or CPR, employing graphic language, and frequently revisiting conversations about preferences

							multiple degrees/disciplines), 25% were executive leaders, and 14% were administrative staff	
52	Childers et al., 2017, US	Goals of care conversations	Special article (on peer-reviewed journal)	N.A.	To describe each step of the REMAP framework and provide examples	N.A.	N.A.	The REMAP framework (Reframe, Expect emotion, Map out patient values, Align with values, and Propose a plan) provides a structure for approaching goals of care conversations
53	Bernacki & Block, 2014, US	Goals of care conversations	Review	Literature review	This article (1) reviews the evidence and describes best practices in conversations about serious illness care goals	N.A.	N.A.	Sharing prognostic information, eliciting decision-making preferences, understanding fears and goals, exploring views on trade-offs and impaired function, and wishes for family

					and (2) offers practical advice for clinicians and health care systems about developing a systematic approach to quality and timing of such communication to assure that each patient has a personalised serious illness care plan			involvement
54	Strang et al., 2014, Sweden	Communication about existential issues (living and dying, relationship)	Journal article	Qualitative study (secondary analysis)	This paper describes the nurses' reflections on existential issues in their communication with patients close to death	Three in-patient hospices, six hospital oncology wards and two palliative home care	Nurses	The process domain dealt with using conversation techniques to open up conversations, being present and confirming

						teams		
55	Shaw et al., 2020, Canada	Goals of care (GOC) conversations	Journal article	Case study	To help physicians identify common barriers to effective GOC discussions that they might face and to provide them with practical tools to overcome these barriers and facilitate effective GOC conversations	Hospital	Physicians; Terminally ill patients	Serious illness conversation guide; Focus on getting to know the patient, their values, goals and quality of life. Ask patients how much they know and would like to know regarding their illness course
56	Quill et al., 2009, US	Discussing treatment preferences	Journal article	Case study	To review this approach to requests for "everything" and provide examples of how physicians can manage some aspects of the conversation	Not specified	Clinicians; patients ask for "everything "	The discussion might include questions about what balances of treatment burden and benefit the patient can tolerate and about emotional, cognitive, spiritual, and family factors that underlie the request. After this initial exploration, the clinician can propose a philosophy of treatment and make

								recommendations that capture the patient's values and preferences in light of the medical condition
57	Ngo-Metzger et al., 2008, US	Deliver the bad news, discuss the prognosis, and make appropriate referrals	Guideline (on peer-reviewed journal)	Not reported	Not reported	Primary care physicians setting	Primary care physicians	Physicians should assess the patient's emotional state, readiness to engage in the discussion, and level of understanding of the condition. The discussion should be tailored according to these assessments. Often, multiple visits are needed
58	Jain & Bernacki, 2020, US	Goals of care communication	Review	Literature review	To review on the communication strategies used to conduct successful goals of care conversations	N.A.	N.A.	Prepare for the discussion; introduce the purpose of the discussion and set an agenda; assess illness understanding, coping style, and prognosis awareness; deliver medical updates and prognosis information; expect and respond to emotion;

								explore patients' values and preferences; discuss treatment options and make a recommendation; finalize the treatment plan; and follow-up after the discussion
59	van Vliet & Epstein, 2014, UK	End-of-life communication	Review	N.A.	To propose a theory-based framework integrating SPIKES and NURSE to serve patients' double needs in progressive disease and challenging situations.	N.A.	N.A.	Setting up the encounter; assessing patients' perceptions; querying informational receipt style/obtaining invitation to share the news; delivering the news (knowledge); NURSE (name the emotion, express statements of understanding, respect, and support; and explore emotion); strategizing/summarizing next steps

3.5 Discussion

3.5.1 Main findings of the study

This scoping review systematically analyzed 59 documents to synthesize and map the recommended communication strategies for assisting healthcare professionals in conducting end-of-life discussions with terminally ill patients and their families. The identified communication strategies underscore the importance of patient-centered communication, emphasizing the need for healthcare providers to avoid stereotyping patients and imposing personal values, and instead focus on establishing shared understanding and partnerships (Barclay et al., 2007; Glare et al., 2008; Hadley, 2020; Khosla et al., 2017). However, it is crucial for healthcare professionals not to view these strategies as rigid scripts but to adapt them to the specific circumstances they encounter (Martins et al., 2021).

While understanding stakeholders' perspectives on end-of-life communication is valuable for informing effective strategies, the review revealed a bias in existing research towards healthcare professionals' viewpoints over those of patients and their families. Most empirical studies predominantly gathered professionals' opinions, with limited consideration given to patients' (Clayton et al., 2005; Dalkin et al., 2018; O'Connor et al., 2020; Ohlen et al., 2016) and families' (Anderson et al., 2020; Clayton et al., 2005; Dalkin et al., 2018; Norton & Talerico, 2000) perspectives, often with small sample sizes. This imbalance may be attributed to practical and ethical challenges in recruitment processes (Hanson et al., 2014) and patients' and families' potentially lower awareness of communication practices compared to professionals (Anderson et al., 2019).

It is essential to consider patient and family viewpoints when seeking additional

strategies for healthcare professionals, as evidenced by the lack of consensus on specific approaches in discussions about life expectancy. Rather than identifying a single best strategy, the focus should be on providing a range of options for professionals to choose from based on individual needs and circumstances. Future research could explore the relationship between patient and family characteristics and their preferences in end-of-life communication, offering evidence to support healthcare professionals in selecting appropriate communication strategies. Conducting observations and interviews may yield valuable insights, and further investigations could enhance understanding of effective communication strategies in end-of-life care.

The majority of the documents analyzed in this review were sourced from Anglo-Saxon countries, specifically the UK, US, Canada, and Australia (Louviot, 2020). Limited evidence was available from non-Anglo-Saxon countries, with only six studies from European nations and two from Asian countries. Previous studies have indicated potential differences in attitudes towards truth disclosure and patient autonomy between individuals from Anglo-Saxon and other cultural backgrounds (Clayton et al., 2007; Parker et al., 2007). Variations in end-of-life care practices and communication strategies across countries are influenced by legal, cultural, social, and political factors (Olsson et al., 2021), which may impact end-of-life communication approaches and should be considered in clinical settings (Glare et al., 2008).

For instance, in Korea, a family-centered decision-making approach influences the communication strategy for disclosing prognoses, involving a three-step process to determine the appropriate individual to deliver bad news, a practice less common in Anglo-Saxon countries (Koh et al., 2016). While recognizing differences among Anglo-Saxon countries, it is important to note that communication strategies derived primarily from research on their patient populations may not directly translate to non-Anglo-

Saxon clinical settings. Further research is warranted in non-Anglo-Saxon countries to investigate and elucidate end-of-life communication strategies relevant to healthcare professionals. Understanding the differences in clinical practices and stakeholders' perspectives in end-of-life communication is crucial for developing communication strategies tailored to local practices and meeting local communication needs.

Studies by Martina et al. (Martina, Geerse, et al., 2021; Martina et al., 2022; Martina, Lin, et al., 2021) and Mori et al. (2019; 2018) on the experiences and viewpoints of Asian healthcare professionals, patients, and families regarding advance care planning and prognostic disclosure may aid in comprehending these differences and formulating culturally adapted communication strategies. Additionally, certain ethical and practical dilemmas surrounding end-of-life communication may be similar across various cultural contexts, such as managing patient hope while preparing them for the possibility of death (Schapira, 2015), planning for an uncertain future (Martina, Geerse, et al., 2021), fluctuating decisions over time (Barclay et al., 2007), socioeconomic dynamics and family relationships (Martina, Geerse, et al., 2021; Ohlen et al., 2016), and the impact of family involvement on patient-provider communication (Clayton et al., 2007; Ohlen et al., 2016).

The current review adopted a comprehensive approach to end-of-life communication, analyzing various strategies applied in this process. While most of the reviewed documents focused on specific aspects of end-of-life communication, such as discussing prognosis or life expectancy, some addressed different communication topics and goals, yet shared similar strategies. For example, Barclay et al. (2007) and Casarett and Quill (2007) highlighted the importance of establishing medical facts and understanding the patient's perspective in conversations about advance care planning and hospice referral. These strategies could be systematically organized to enhance end-

of-life communication holistically. The review identified seven recurring themes in end-of-life communication, emphasizing that it is an ongoing and iterative process covering a range of topics (Granek et al., 2013; Hickman, 2002; Schapira, 2015; van der Velden et al., 2020). For instance, discussions about 'do not attempt cardiopulmonary resuscitation' should be integrated into broader end-of-life conversations to better address the patient's needs and improve communication efficiency (Hadley, 2020). The study's themes offer a potential framework for viewing end-of-life communication as a holistic process and promoting it effectively through these strategies. However, future research should address challenges such as uncertain prognosis, optimal timing of communication, clinical uncertainty's impact on communication, and catering to specific patient groups like older adults, individuals with low health literacy, and minority populations.

3.5.2 What this study adds

This study examined various communication strategies available to healthcare professionals for initiating and facilitating end-of-life discussions. These strategies are valuable tools that can help healthcare professionals effectively engage in conversations about end-of-life care with their patients. It is recommended that further training and educational programs be developed and implemented for healthcare professionals to enhance their skills in end-of-life communication. Evidence-based communication resources such as VitalTalk (VitalTalk, 2022) and the Serious Illness Conversation Guide (Ariadne Labs, 2021), as well as communication skills training modules like those based on the Comskil model (Coyle et al., 2015), are essential for future training initiatives. Culturally sensitive training programs should be designed, incorporating culturally relevant scenarios and enhancing healthcare professionals' cultural competence. It is crucial to incorporate the perspectives of patients and families when developing communication strategies for healthcare professionals. While many of the end-of-life communication strategies reviewed in this study were validated in Anglo-

Saxon countries, it is important to recognize the need for specific communication techniques when interacting with patients and families from diverse cultural backgrounds. Further research is warranted to explore end-of-life communication strategies in non-Anglo-Saxon countries and to address communication needs within specific communities. The themes identified in this study's communication strategies can serve as a framework for the systematic organization and application of these strategies.

3.5.3 Strengths and limitations of the study

This review demonstrates several notable strengths. Firstly, it effectively synthesizes and evaluates a wide range of evidence sources to offer a comprehensive overview of end-of-life communication strategies. The inclusion of qualitative studies involving input from patients and their families further enriches the analysis. Secondly, the paper specifically examines the available plans and approaches for effective end-of-life communication within the framework of the Comskil model's definition of communication strategy. The varying interpretations of communication strategies may result in discrepancies between the findings of this review and those of prior studies. However, certain limitations should be acknowledged. The broad nature of the topic posed challenges in devising precise and sensitive search criteria for the review. Inadequate consideration of relevant search terms could have led to the omission of pertinent literature. Additionally, the absence of a quality assessment of the studies included is a notable aspect of this scoping review, which may be perceived as a methodological constraint.

3.6 Conclusions

This scoping review outlines the various approaches that healthcare professionals can utilize to initiate and facilitate end-of-life discussions with terminally ill patients and their families. These strategies are categorized into seven themes and emphasize the

importance of adaptability in clinical practice to tailor conversations to individual cases. The review suggests the need for further research and the development of training programs for healthcare professionals based on these identified strategies. Future studies should explore the perspectives of patients and families on communication strategies, particularly in non-Anglo-Saxon countries. It is recommended that healthcare professionals adopt a comprehensive approach to end-of-life communication rather than focusing on isolated topics. The subsequent chapter introduces the conceptual framework of this PhD research project, which establishes a theoretical link between communication strategies and communication skills training.

Chapter 4: Conceptual Framework

4.1 Introduction

The conceptual framework is the overarching logical structure and interconnections that underpin an entire research project (Kivunja, 2018). A conceptual framework is constructed to illustrate the relationships between the key components of this doctoral thesis. The construction of this conceptual framework is based on two models pertaining to communication skills training for healthcare professionals, namely the Comskil model (Brown & Bylund, 2008) and the integrated training model (Parle et al., 1997), as well as our review findings described in Chapter 3. This chapter will introduce the content of both the Comskil model (Section 4.2) and the integrated training model (Section 4.3), and explain how these models contribute to and enhance the conceptual framework in this study (Section 4.4).

4.2 The Comskil model

The Memorial Sloan-Kettering Cancer Center Comskil model (Brown & Bylund, 2008) provides a conceptual framework for CST based on Goals, Plans, and Actions theories and sociolinguistic theory (Miller, 2005). The Comskil model defines five core communication components and describes how these components are integrated (Figure 4.1). Communication goals are the desired outcomes achieved through communication strategies, skills, process tasks, and cognitive appraisals. Communication strategies are advanced plans that drive behaviour toward achieving a communication goal. Communication strategy is a higher-level category than skills and process tasks. It is carried out using communication skills (i.e., discrete verbal utterances) and process tasks (i.e., nonverbal or verbal interactions that create an environment to foster communication). When communicating with patients and their families, cognitive appraisals are the internal process of healthcare providers. The

cognitive appraisal process directs the selection of communication strategies and the utilization of communication skills. The Comskil model focuses on two types of cognitive appraisal: patient cues (i.e., patient indirect requests for information or emotional support) and patient barriers (i.e., unspoken patient perceptions might obstruct effective communication). This model can be used to guide the development of training modules and materials, videos, role-play and evaluations. The training modules developed based on the Comskil model include the introduction and explanation of the five communication components around certain topics. These modules are suggested to be delivered by didactic lectures, exemplary videos, and role-play. The model is also applicable in various settings to suit different training needs (Brown & Bylund, 2008; Kissane et al., 2012).

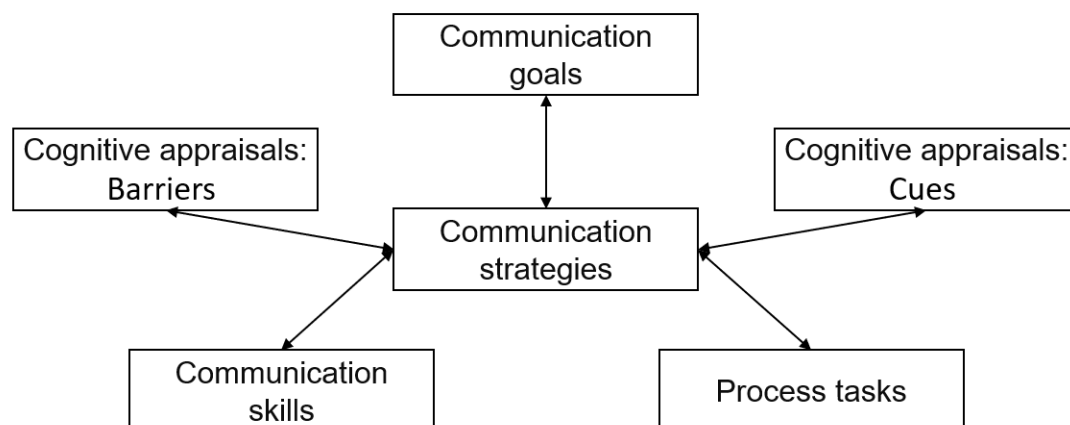


Figure 4.1 The Comskil model

4.3 The integrated training model

The integrated training model (Parle et al., 1997) integrates multi-determined factors (i.e., skills and knowledge, self-efficacy, outcome expectancies and perceived support) that affect healthcare providers' communication behaviours in cancer care settings (Figure 4.2). Skills and knowledge are necessary to identify the psychological difficulties of cancer patients. A lack of skills and knowledge may result in healthcare providers' distancing or blocking communication behaviours (Wilkinson, 1991). The

self-efficacy and outcome expectancy constructs of Bandura's social learning theory (Bandura, 1977) are found to be relevant to training and also integrated this model to explain healthcare providers' communication behaviours. Self-efficacy is an individual's assessment of his or her capacity to successfully carry out a given task (Bandura & Locke, 2003). The individual's expectations, including negative and positive expectancies for the task's outcomes, are referred to as outcome expectancies (Parle et al., 1997). Healthcare providers' perceived supports in the workplace, including practical (e.g., time) and personal (e.g., psychological) supports, are also found to be associated with the use of communication skills (Wilkinson, 1991). The integrated training model emphasizes several teaching methods, including didactic lectures with a cognitive overview (intended to promote communication problem awareness and recognition), video demonstration, small group learning, and role play. It directs training development and evaluation systematically and multidimensionally (Parle et al., 1997).

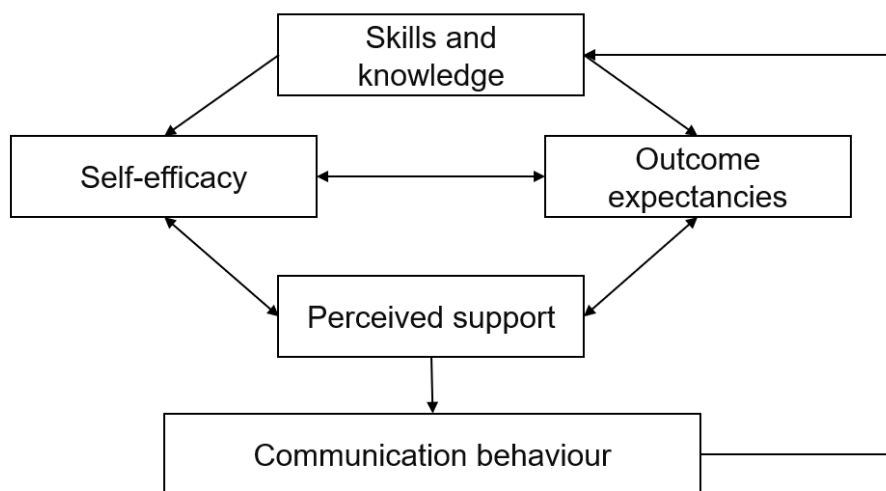


Figure 4.2 The integrated training model

4.4 Conceptual framework in the current study

The conceptual framework of the current study depicted in Figure 4.3 is established based on the aforementioned models and findings identified in the review by Chen

(Chen et al., 2023). The Comskil model (Brown & Bylund, 2008) underscores the importance of communication strategy as a foundational component, serving as both a basis for developing communication training modules and guiding healthcare providers in applying communication skills to accomplish process tasks. Grounded in the concept of communication strategy, our scoping review has identified seven key themes encompassing various end-of-life communication strategies: preparation; exploration and assessment; family involvement; provision and tailoring of information; empathic emotional responses; reframing and revisiting goals of care; and conversation closure.

The forthcoming research (Chapter 6) will further refine these strategies within the Chinese context. Understanding end-of-life communication strategies specific to the Chinese cultural context can aid healthcare providers in identifying cues and barriers, thereby improving their cognitive appraisals during end-of-life communication. These culturally tailored communication strategies within the Chinese context will also contribute to the advancement of existing knowledge and understanding of end-of-life communication strategies. Guided by the Comskil model, these culture-specific communication strategies for the Chinese context will be employed to establish communication goals, skills, process tasks, and elucidate the potential of the possible cognitive appraisal process during end-of-life communication. These components constitute the modular blueprint of a culture-specific end-of-life CST for Chinese oncology nurses. The modules should align with end-of-life communication practices within the social-cultural context of China and address the communication needs accordingly. The consideration of cultural specificity is crucial due to the profound influence of sociocultural beliefs and practices on end-of-life communication (Olsson et al., 2021). For instance, the strategy of "family involvement" is reconstructed as "negotiating with the family", including fostering family understanding and addressing their concerns regarding the disclosure of diagnosis and prognosis to patients (details

will be described in Table 7.2, Section 7.3, Chapter 7). Such strategy is consistent with the current practice of end-of-life communication in the Chinese context where the family play a significant role and patient prognosis is often concealed (Turnbull et al., 2023). Training in these communication strategies may assist nurses in enhancing their communication skills, self-efficacy, and outcome expectancies (Parle et al., 1997).

This study evaluates the communication skills of participating nurses as the primary outcome, along with their self-efficacy and communication outcome expectancies as secondary measures. Enhanced communication skills have the potential to improve self-efficacy and outcome expectancies. Both self-efficacy and outcome expectancies are significant predictors of communication behaviour (Parle et al., 1997); higher levels of self-efficacy and positive outcome expectancies may increase nurses' willingness to engage in difficult conversations with patients and families. Due to the complexity and challenges associated with evaluating actual workplace communication behaviours, this doctoral study did not measure the impact of the training program on such behaviours among participating nurses. Chapter 8 will discuss these challenges and provide recommendations for future research. As a result, perceived support, which is closely linked to the workplace, was also not included as an outcome measure in this study.

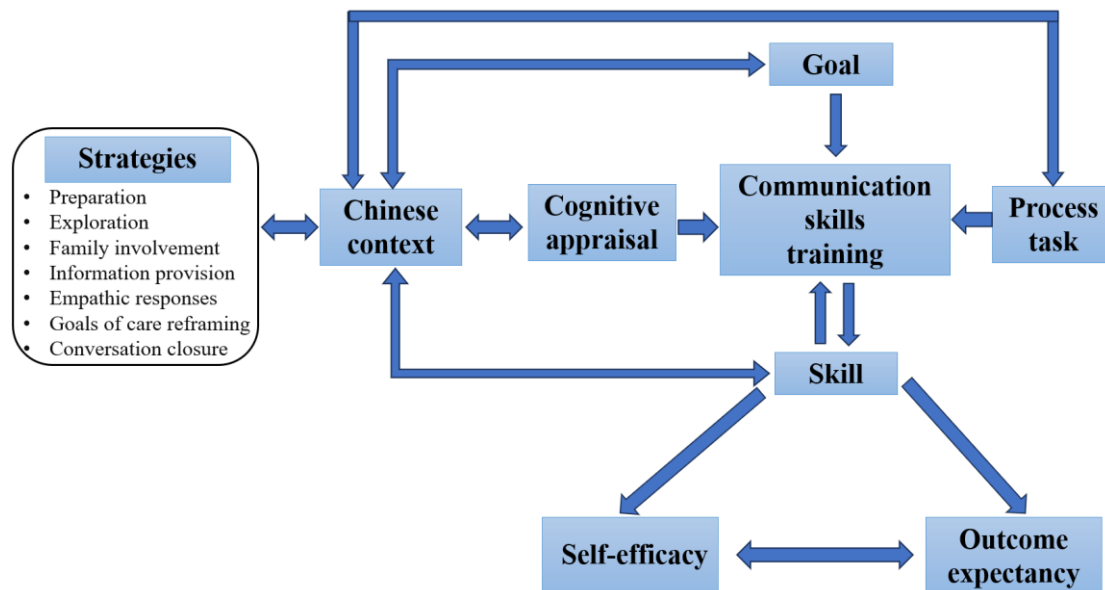


Figure 4.3 The conceptual framework in the current study

4.5 Chapter summary

In conclusion, this Chapter presents the conceptual framework of the study and its theoretical sources. It elucidates the key concepts involved in the study, which will serve as the foundation for the subsequent research design and will facilitate the subsequent data analysis and discussion of the results.

Chapter 5: Methodology

5.1 Introduction

This chapter will delineate the aims and objectives (Section 5.2), research design (Section 5.3), and ethical considerations (Section 5.4) of this doctoral study. The detailed study methods for the developmental and evaluation phases are not expounded upon in this chapter but instead presented in Chapters 6 and 8, respectively. This arrangement is primarily because the construction of the intervention protocol is predicated on the findings from the developmental phase, enhancing clarity and facilitating readers' comprehension. The ethical consideration (Section 5.4) is a part of the published study protocol (Chen et al., 2023); slight adjustments to the citation styles and reference lists were made to comply with the format and requirements of this PhD thesis. Permission to use the study protocol in this thesis has been granted by the publisher (Chen W, Chung JOK, Lam KKW, Molassiotis A. Patients', families' and healthcare providers' perspectives on end-of-life communication in Chinese hospital settings: A qualitative study protocol. PLOS ONE. 2023;18(12):e0296342.), as "this is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited".

5.2 Aims and objectives

The overarching aim of the whole PhD research was to develop and evaluate a culturally specific end-of-life CST for Chinese oncology nurses. The objectives were:

- (1) To develop an evidence-based Chinese culturally specific end-of-life CST program.
- (2) To evaluate the effectiveness of the CST program among oncology nurses regarding communication skills, self-efficacy and outcome expectancy beliefs.
- (3) To explore participants' acceptability, satisfaction, experiences and suggestions for

the training program.

5.3 Research design

To address the first study objective, a qualitative descriptive study design with semi-structured in-depth interviews and focus group discussions was adopted to (1) explore the experience of key stakeholders (patients, family caregivers and healthcare providers who are directly involved in end-of-life communication), (2) understand their perceptions, (3) gather their suggestions for improving such communication, and (4) identify their preferred end-of-life communication strategies. The qualitative description approach is focused on describing, rather than explaining, the phenomena or situation (Ayton et al., 2023). As stakeholders' perspectives regarding end-of-life communication in the Chinese context are insufficiently understood, this approach is appropriate to provide a rich, detailed understanding of their experiences and perceptions while generating practical insights to inform the development of the culturally specific end-of-life CST program. Detailed descriptions of methods used in the qualitative study can be found in Chapter 6, Section 6.2.

An RCT embedded with a process evaluation was performed to address the second and third objectives. An RCT was conducted to evaluate the effectiveness of the culturally specific end-of-life CST program on communication skills, self-efficacy and outcome expectancy beliefs among oncology nurses. RCTs are the gold standard when properly designed, implemented and reported (Schulz et al., 2010). As this study was a trial of training for nurses, rather than a complex intervention, the Medical Research Council (MRC) framework (Skivington et al., 2021) might not be appropriate, and a pilot study of feasibility testing was not performed. A process evaluation was embedded to examine the overall process of the CST, explore participants' views of the training, and provide useful information for future research. Please refer to Chapter 8, Section 8.2,

for the study methods.

5.4 Ethical consideration

Ethical approval of the research protocol was obtained from the Human Subjects Ethics Sub-Committee (HSESC) of the Hong Kong Polytechnic University and participating institutions (Appendix 1-2). The whole study process adhered to ethical research principles regarding studies and research involving human beings, as stated in the Declaration of Helsinki (World Medical Association, 2013).

5.4.1 Consent, confidentiality and data protection

Adequate information regarding the study was provided through an information sheet (Appendix 3) and verbally communicated by the researcher to enable participants to make an informed decision about their participation. Written informed consent from participants (Appendix 4) and permission for recording were obtained. In the qualitative study, the patient's interview was conducted with the informed approval of the patient's attending physician. Participant confidentiality was maintained by anonymizing interview transcripts. Participant identifying information was solely utilized for interview scheduling and consent acquisition purposes. All raw data is securely stored on a password-protected computer, and physical copies of consent forms will be stored separately in a locked cabinet for a period of five years, in accordance with the University Research Ethics Policy, accessible only to the research team. Subsequent to the retention period, all personal data will be erased.

5.4.2 Ethical considerations in the qualitative study

Prior research findings (Clayton et al., 2005; O'Connor et al., 2020; Xu et al., 2022) have indicated that interviews are generally beneficial rather than harmful, with no reported instances of participants experiencing negative long-term effects or requiring counseling as a result of being interviewed. Additionally, interviews have been recognized as potentially therapeutic for participants, as they can elicit suppressed

emotions and facilitate a deeper understanding of past events (Dempsey et al., 2016). In the qualitative study, interviews primarily focused on end-of-life communication experiences rather than discussions on the diagnosis and prognosis of life-limiting illnesses. However, these discussions could still trigger distress and discomfort by reminding participants of past or ongoing challenging experiences, potentially leading to emotional responses such as grief, anger, anxiety, and fear. It is crucial to acknowledge that end-of-life communication is a sensitive subject that can impact both participants and researchers involved in such research. Avoiding these discussions may be seen as a failure to take responsibility and respect participants' autonomy (Dickson-Swift et al., 2007). To mitigate potential harm, protect vulnerable participants, and ensure the collection of valuable data, appropriate safety measures were implemented. An risk assessment and distress protocol (Table 5.1) was developed by the research team based on existing literature on sensitive interviewing (Dempsey et al., 2016) to address participant distress. Participants were informed of their right to decline answering questions or withdraw from the study at any point.

Table 5.1 A risk assessment and distress protocol

Risks	Considerations	Measures
Risks to the participants		
● Patients/families/healthcare providers ask to pause or terminate the interview/discussion due to inappropriate time and/or location	Ill-suited time and/or location may make participants feel uncomfortable sharing their stories	1. Participants can withdraw from the research at any time without detriment 2. Participants will be provided with the opportunity to be interviewed at any time and location they prefer 3. Time and/or location will be rearranged if they ask. Safety, privacy and quiet will be ensured by the researcher to promote

<ul style="list-style-type: none"> ● Patients/families/healthcare providers experience distress during the interview/discussion 	<p>Discussions about end-of-life issues and related experiences may be sensitive for participants and cause distress and discomfort, which may need an immediate support</p>	<p>comfort</p> <ol style="list-style-type: none"> 1. Participants will be asked if they would like to pause the interview, take a break and if they want to stop the audio recording. If so, such measures will be taken; necessary support will be provided, such as water and tissue; the researcher will accompany them until they are calm 2. If participants continue to show signs of upset, family or professional support (nurses, social workers and psychological consultants of the hospital) will be sought, with the participant's consent 3. Participants decide whether to continue the interview/discussion. The interview can be rearranged for later in the day or the following day to ensure they are no longer distressed
<ul style="list-style-type: none"> ● Patients/families/healthcare providers disclose any upsetting feelings that arise from the interview/discussion 	<p>Sensitive issues may arise from participation and have lasting effects on participants, which may need an adequate follow-up support</p>	<ol style="list-style-type: none"> 1. Each participant will have the opportunity to disclose to the researcher about the interview and allow for feedback after the data collection 2. Contact details of useful numbers will be

		offered as required. Family/peer/professional support will be advised
Risks to the researcher		
● The researcher may be at risk of emotional stress	The researcher/interviewer may experience vicarious traumatisation	1. The researcher will debrief the process with senior research team members 2. The researcher will have private time to reflect after the interview/discussion 3. Professional psychological counselling should be approached if necessary

5.5 Chapter summary

This chapter sets out the purpose and design of the study. It is crucial to develop a risk assessment and distress management protocol for a topic as sensitive as end-of-life communication. This will facilitate the implementation of subsequent qualitative study (Chapter 6).

Chapter 6: End-of-life Communication from Chinese Multi-perspectives: A Qualitative Study

6.1 Introduction

To address the first objective of the whole doctoral research: To develop an evidence-based Chinese culturally specific end-of-life CST program, a qualitative study was conducted to enrich a limited understanding of stakeholders' accounts of end-of-life communication in the Chinese context. The chapter presents the qualitative study with the detailed study methods, results, discussion, implications and limitations. The qualitative study objectives specifically addressed four critical areas of end-of-life communication: experience, perception, suggestion and strategy of stakeholders. The comprehensive analysis results of the large data set are presented in two parts: (1) experience and perception and (2) suggestion and strategy. The first part, experience and perception, explores the participants' **past and present** experiences and perceptions, beliefs and attitudes towards end-of-life communication. This part aims to provide an in-depth understanding of the participants' perspectives and lived experiences related to this topic. The second part, suggestions and strategies, examines the participants' recommendations and proposed strategies for improving end-of-life communication in the **future**. This part is intended to capture the valuable insights and strategies offered by the participants to address the challenges and complexities associated with end-of-life communication. To facilitate readability, the discussions of these parts follow directly after their respective result sections. The findings of the qualitative study contribute to developing the subsequent communication skills training. The study protocol has already been published in an international peer-reviewed journal (Chen et al., 2023). Several sections of the published protocol have been used, but with slight adjustments to the citation styles and reference lists to comply with the format and requirements of this PhD thesis. Permission to use the study protocol in this thesis has

been granted by the publisher (Chen W, Chung JOK, Lam KKW, Molassiotis A. Patients', families' and healthcare providers' perspectives on end-of-life communication in Chinese hospital settings: A qualitative study protocol. PLOS ONE. 2023;18(12):e0296342.), as “this is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited”.

6.2 Methods

6.2.1 Aim and objectives

This study aims to explore stakeholders' (patients, families and healthcare providers) perspectives on end-of-life communication in Chinese hospital settings. More specific objectives are to (1) describe end-of-life communication experiences of Chinese terminally ill patients, families and healthcare providers, (2) understand their perceptions, attitudes and beliefs of end-of-life communication, (3) collect their suggestions and expectations on improving end-of-life communication, and (4) identify culturally appropriate communication strategies in the Chinese social-cultural context. The research questions are as follows: (1) what experiences do Chinese terminally ill patients, families and healthcare providers have in end-of-life communication in hospital settings? (2) what are their perceptions, attitudes and beliefs of end-of-life communication? (3) what are their suggestions and expectations for improving end-of-life communication? (4) what are the culturally appropriate communication strategies in the Chinese social-cultural context?

6.2.2 Study design

We adopted a qualitative descriptive approach with interviews and focus group discussions to explore how main stakeholders in end-of-life communication experience and perceived interactions. Since the end-of-life communication processes within the

Chinese context were understudied, this qualitative approach was suitable for answering the research questions (Creswell, 2003). In studies intended to comprehend and provide detailed personal narratives, in-depth interviews are beneficial (Braun & Clarke, 2013). The group dynamic of focus group discussions allows for participants to build on one another's responses and generate ideas that they might not have thought of in an individual interview (Braun & Clarke, 2013). It is necessary to conduct focus group discussions in this study to explore the degree of consensus on end-of-life communication. The qualitative study has been registered at ClinicalTrials.gov (NCT05734781). The Standards for Reporting Qualitative Research (SRQR) checklist (O'Brien et al., 2014) was employed to report the study.

6.2.3 Setting and participants

Purposive sampling was used to recruit patients, family caregivers and healthcare providers from two hospitals in Mainland China. Both hospitals are nationally public and academically affiliated and serve large populations, with 1,200 and 1,500 acute care beds each. Referring to national data on non-communicable diseases-attributed deaths (Peng et al., 2023), outpatient clinics and inpatient wards in the following departments were approached: cardiology, oncology, radiology, pneumology, and nephrology. Recruitment was conducted via in-person invites by the author, a PhD student without any relationship with the participants.

Eligible patients: (1) Be aged older than 18 years. (2) Have a defined incurable life-limiting illness with a likely life expectancy of fewer than 12 months (National Institute for Health and Care Excellence, 2021), according to the consultation with the patient's physician. (3) Have been informed of disease diagnosis and treatment. (4) Be able to speak Mandarin and express clearly. (5) Be able to provide informed consent. Eligible family caregivers: (1) Be aged older than 18 years. (2) One of the terminally ill patient's primary family caregivers who are familiar with the patient's situation, which is defined

in this study as lived with or visiting patients at least twice a week in the past month. (3) Have been informed of the patient's disease diagnosis and treatment. (4) Be able to speak Mandarin. (5) Be able to provide informed consent. Patients and family caregivers with severe auditory or cognitive impairment were excluded. Eligible healthcare providers: (1) Be nurses, physicians or other healthcare professionals. (2) Be experienced in providing treatment or care to patients with advanced, life-limiting illnesses (whose likely life expectancies of fewer than 12 months) and family caregivers of such patients for at least five years (Koh et al., 2016). (3) Consent to participate in the study.

In the initial stages of participant recruitment, the author sought approval from the relevant department head to access the ward. Subsequently, individuals meeting the specified criteria, including patients, family caregivers, and healthcare providers, were approached and enlisted by the author. Prior to engaging with patients, the author consulted the attending physician to confirm the patient's suitability for participation, with the option of reviewing the patient's medical records together if necessary. Furthermore, a promotional poster (Appendix 5) outlining the research project's objectives and scope was displayed on the hospital's notice board to attract potential participants who could voluntarily choose to participate and contact the researchers. Each eligible participant was personally met to establish rapport, foster trust, and address any queries or concerns.

6.2.4 Data collection

Data collection was conducted between May and October 2023. For participating patients and family caregivers, semi-structured in-depth interviews were conducted individually, to elicit personal views and freely express sensitive topics related to the end of life. Healthcare providers participated in the respective focus group discussions based on their profession, i.e., physician group, nurse group and other allied healthcare

professional group, to counteract the potential negative influence of power differentials and professional hierarchies on participation (Morgan, 1996). Some healthcare providers who had conflicting schedules with the focus group discussions were interviewed individually. The author facilitated all interviews and discussions to keep consistency. The researcher wrote a reflective journal to clarify personal positions, assumptions and beliefs before data collection and applied bracketing during the data collection process (Giorgi, 1997). Interviews and discussions were audio-taped with participants' permission. Drawing on currently available literature on the concept of end-of-life communication (Gonella et al., 2019; Olsson et al., 2021; Pfeifer & Head, 2018; Sinuff et al., 2015), four key sub-topics of end-of-life communication: (1) diagnosis and prognosis, (2) ACP, (3) GOC, and (4) death and dying, were identified. This approach refined the concept of end-of-life communication discussed in this paper and aided the development of the interview guide (Table 6.1). Questions in the interview guide were designed to elicit participants' experiences and perceptions of end-of-life communication in the hospital. Prompts were used to elicit participants' views in more details relevant to the end-of-life communication (e.g., the timing and the environment) and clarify their responses. Pilot interviews with one patient, one family caregiver and two healthcare providers (one physician and one nurse) were conducted to revise the interview guide and enhance interviewing skills.

Table 6.1 Interview guides

Patients and families	
Questions	Prompts
Experience	
Tell me about any communication experiences that you have had with healthcare providers.	<p>What topics were covered? How did you communicate...?</p> <ul style="list-style-type: none"> ● Diagnosis and prognosis (e.g., health condition; clinical course; treatment uncertainties and limitations; and life expectancy) ● Advance care planning (i.e., discussions of future care; may

	<p>include the individual's concerns, wishes, values, understandings, and preferences)</p> <ul style="list-style-type: none"> ● Goals of care (i.e., discussions of current care and decisions; may include specific medical interventions, such as whether to utilise life-sustaining treatments) ● Death and dying (e.g., end-of-life wishes; care for psychological, spiritual, and existential problems; arrangements after patients' death; and bereavement support) <p>Who was present?</p> <p>When and where did the communication occur?</p> <p>Is anything impressive or annoying during the communication process?</p> <p>Why?</p> <p>Are they good? Why?</p>
How did you feel about the communication?	
What do you think of the communication?	
Perception, attitude and belief	
If your (the patient's) condition continues getting worse, or the curative treatment effect is not satisfactory, do you think it is necessary for healthcare providers to have end-of-life communication with you?	Why or why not?
What is your understanding of end-of-life communication?	Is anything important for you to discuss with healthcare providers?
Strategy	
How would you like the healthcare provider to have end-of-life communication with you?	<p>How to communicate...?</p> <ul style="list-style-type: none"> ● Diagnosis and prognosis ● Advance care planning ● Goals of care ● Death and dying <p>What specific words or phrases do you think healthcare providers should use?</p> <p>Would you like to give me an example?</p> <p>Who do you think should initiate end-of-life communication with you?</p>

	Who should be involved? When and where are appropriate?
Suggestion	
If you are invited to give suggestions to healthcare providers who would like to have end-of-life communication with you, what would you say?	E.g., for healthcare providers who do not have much experience in end-of-life communication
Healthcare providers	
Questions	Prompts
Perception, attitude and belief	
What is your understanding of end-of-life communication?	What topics include? E.g., disclosure of diagnosis and prognosis; advance care planning; goals of care discussions; talking about death and dying, etc.
What do you think about end-of-life communication between healthcare providers and patients and their families in hospitals?	If the patient's condition continues getting worse, or the curative treatment effect is not satisfactory, do you think it is necessary for healthcare providers to have end-of-life communication with patients and their families? Why or why not?
Experience	
Tell me about any end-of-life communication experiences in your usual work.	What topics were covered? How did you communicate...? <ul style="list-style-type: none"> ● Diagnosis and prognosis ● Advance care planning ● Goals of care ● Death and dying Who was present? When and where did the communication occur?
How did you feel about the communication?	Is anything impressive or difficult during the communication process? Why?
How do you think your previous end-of-life communication?	Are they good? Why?
Strategy	
What, if any, specific strategies do you have that may be helpful for improving end-of-life communication between healthcare providers and patients and	How to communicate...? <ul style="list-style-type: none"> ● Diagnosis and prognosis ● Advance care planning ● Goals of care

their families?	<ul style="list-style-type: none"> ● Death and dying <p>What specific words or phrases do you tend to use?</p> <p>Why? Would you like to give me an example?</p> <p>Who do you think should initiate end-of-life communication?</p> <p>Who should be involved?</p> <p>When and where are appropriate?</p>
Suggestion	
What, if any, suggestions do you have for improving end-of-life communication between healthcare providers and patients and their families?	<p>Are any other end-of-life issues that should be discussed?</p> <p>Any ideas about multi-professional end-of-life communication?</p>
If you have the opportunity to participate in end-of-life communication skills training, what suggestions and expectations do you have?	<p>What do you want to learn?</p> <p>What methods do you prefer?</p>

6.2.5 Data analysis

The data analysis proceeded concurrently with the data collection until data saturation was reached, at which point no new themes could be identified in the newly collected data (Braun & Clarke, 2013). Coded identifiers were used in the recordings, transcripts, and participant demographic information. All interview recordings and discussions were transcribed verbatim in Chinese and imported to NVivo12 (QSR International). Six phases of thematic analysis were followed (Braun & Clarke, 2006). The author emerged into the transcriptions, noted initial ideas and then performed line-by-line coding inductively and systematically (Braun & Clarke, 2006). Through constant comparison, similar codes were collated and grouped into subthemes. Themes were developed based on related subthemes. Field notes (e.g., the interview environment and nonverbal interactions) taken during the data collection were reviewed to support the interpretations of the participants' responses. Significant statements related to the research questions were extracted from the transcriptions. Extracts, codes, and themes

were presented visually at a series of research team meetings with all authors, and they were discussed until a consensus was established. Two researchers translated these into English, while a third examined the translations. The team had three researchers proficient in Chinese and English and had prior experience translating qualitative study results. Discussions among the three researchers settled discrepancies in translation. The team also reflected on the bias of our own interpretation.

6.2.6 Quality and rigor

Several techniques were used to enhance the rigour and trustworthiness of the study findings regarding credibility, dependability, confirmability and transferability (Shenton, 2004). Researchers invited participants to verify the transcriptions and the preliminary descriptions to ensure their experiences were accurately reflected (credibility). Also, peer debriefing and several waves of team discussions formed the codes and themes and resolved disagreements (credibility). The author made field notes and audit the decision points during the entire process (dependability and confirmability). Thick descriptions of context, study procedures and direct quotes were provided (transferability).

6.3 Results and discussion

6.3.1 Participants' information

Nineteen patients were interviewed in 22 interviews, as 3 of them were interviewed twice due to fatigue. Eight of their family caregivers and another 14 family caregivers, totally 22 family caregivers, were also interviewed one-on-one. Patient and family caregiver interviews were all conducted face-to-face and lasted 12 to 36 minutes (mean = 25.52 minutes). One patient interview only lasted for 12 minutes due to patient fatigue and still be included for analysis, as it contributed to the code structure. Most of the interviews took place in a quiet and private interview room inside the ward (n = 30), head nurses' office (n = 6), a quiet corner of the hospital cafe (n = 5), and participants'

homes (n = 3).

Three focus group discussions were conducted with a physician group (n = 6, 3 physicians, two traditional Chinese medicine practitioners and one anaesthetist); a nurse group (n = 7); and a group of allied healthcare professionals (n = 4, 2 psychotherapists, one pharmacist and one dietician). The nurse group was arranged in a conference room in the hospital, while the other two groups used Tencent Meeting, a commonly used videoconferencing software in Mainland China, for online discussions. The duration of discussions ranged from 67 to 95 minutes (mean = 81.33 minutes). Four nurses and four physicians joined individual face-to-face interviews as they could not participate in the discussions. These eight interviews lasted 25 to 42 minutes (mean = 36.25). More information on participants' sociodemographic characteristics can be found in Table 6.2.

Table 6.2 Characteristics of participants

Characteristics (N = 66)	Patients with advanced illness (n = 19)	Family caregivers (n = 22)	Healthcare providers (n=25)
Age (years)			
● Mean	63.26	56.77	37.84
● Range	38-87	26-80	28-55
Gender			
● Male	13	8	10
● Female	6	14	15
Marital status			
● Married	14	19	/
● Divorced/ separated	2	0	/
● Single	1	2	/
● Widowed	2	1	/
Educational level			
● Primary or below	7	7	0
● Secondary	8	9	0
● Junior college	1	2	0
● Undergraduate	3	3	7
● Master	0	1	12
● Doctor	0	0	6

Religion			
● None	16	20	25
● Buddhism	1	1	0
● Christianity	2	1	0
Working status (before diagnosis)			
● Employed	9	/	/
● Retired	4	/	/
● Unemployed	6	/	/
Working status			
● Employed	/	8	/
● Retired	/	3	/
● Unemployed	/	11	/
Patient diagnosis (N = 33)	19	22	/
Cancer (Primary cancer site)	12	16	/
● Head and neck	1	2	/
● Respiratory/Thoracic	3	5	/
● Breast	2	4	/
● Gastrointestinal	2	4	/
● Genitourinary	4	1	/
Non-cancer	7	6	/
● End-stage heart failure	2	2	/
● Severe chronic obstructive pulmonary disease	3	2	/
● End-stage renal disease	2	2	/
Primary caregiver			
● Spouse	10	/	/
● Parent(s)	2	/	/
● Child(ren)	7	/	/
Relationship to patient			
● Spouse	/	14	/
● Parent(s)	/	1	/
● Child(ren)	/	7	/
Residential location			
● Metropolitan area	12	/	/
● Rural or remote area	7	/	/
Profession			
● Physician	/	/	10
● Nurse	/	/	11
● Other	/	/	4

Professional title			
● Junior	/	/	2
● Medium	/	/	16
● Senior	/	/	7
Department			
● Cardiology	/	/	2
● Oncology	/	/	6
● Radiotherapy	/	/	5
● Pneumology	/	/	6
● Nephrology	/	/	2
● Other*	/	/	4
Number of years involved in the treatment or care of advanced patients			
● Mean	/	/	12.44
● Range	/	/	5-32

*Department of Psychology, Pharmacy and Nutrition

6.3.2 Results of experiences and perceptions

Five themes were derived from 18 subthemes (see Table 6.3): (1) protective end-of-life communication (dominant family involvement, truth concealment and restricted end-of-life topics), (2) open end-of-life communication (dominant patient involvement, truth disclosure and rich end-of-life topics), (3) patient factors affecting the end-of-life communication (comfort level of talking about the end of life, burden and treatment engagement), (4) family factors affecting the end-of-life communication (comfort level of talking about the end of life, burden, expectation, value and trust in healthcare providers), and (5) healthcare provider factors affecting the end-of-life communication (comfort level of talking about the end of life, available time and priority in practice, end-of-life communication awareness, end-of-life care knowledge and communication skills).

Table 6.3 Themes, subthemes and quotes from participants

Themes	Subthemes	Quotes from participants
Protective end-of-life communication	Dominant family involvement	<p>“I adhere to protective medical measures in all my work. When starting a new case, my first question is usually, ‘Who do I talk to?’ This refers to the person who will be informed about the condition and make treatment decisions. I typically speak with the family.” (Interview 24, a 34-year-old physician with 6 years of working experience)</p> <p>“...It is up to the family to decide whether or not to communicate with the patient.” (a 35-year-old nurse with 12 years working experience) “It would be inappropriate for us to take the initiative to discuss these topics with the patient...We must let the family know first.” (a 30-year-old nurse with 8 years working experience)</p> <p>“[agreeing] Even if we think it is necessary to inform the patient, we generally consult with the family first.” (a 32-year-old nurse with 10 years working experience)</p> <p>(Focus group discussion 2)</p>
	Truth concealment	<p>“Some families would ask us to ‘keep illness confidential’ with patients. We make a note of this on the shift handover information so that all team members are aware.” (Interview 26, a 28-year-old nurse with 6 years working experience)</p> <p>“... can’t let him (the patient) know, he can’t handle it. I know him too well; he’s very timid. I don’t think we should tell him the truth until it’s absolutely necessary...I’m still telling him everything will be fine, and I want to instil hope in him. It’s preferable to keep it (the truth) from him. He avoids thinking about it, and I believe he’s scared to confront the reality...it’s better not to tell him.” (Interview 2, a 42-year-old wife of a patient with stomach cancer)</p>

	Restricted end-of-life topics	<p>“There are some notifications of deterioration of the patient’s condition; there are clear documents that need to be signed.” (Focus group discussion 1, a 38-year-old physician with 12 years of working experience)</p> <p>“When the patient reaches the final stage, our head nurse will do some comforting work... It’s basically verbal” (Interview 25, a 27-year-old nurse with 5 years of working experience)</p> <p>“We tend to focus on providing specialised knowledge, such as addressing enteral nutrition issues for advanced-stage patients and making necessary adjustments. However, we seldom initiate conversations with patients or their families regarding end-of-life issues.” (a 31-year-old dietician with 6 years of working experience)</p> <p>“...After resolving their issues or confusion, they will develop a greater trust in you. They may converse about various topics, including their understanding of the illness and future plans.” (a 34-year-old clinical pharmacist with 7 years of working experience)</p> <p>(Focus group discussion 3)</p>
Open end-of-life communication	Dominant patient involvement	<p>“From the initial diagnosis to subsequent treatment, I have handled all communications myself. I need to understand my own situation as it concerns my life. If any issues arise, I will communicate with the doctor directly.” (Interview 8, a 55-year-old patient with prostatic cancer)</p> <p>“We also talk to patients (directly)... But relatively few...Some patients make their own decisions. If a patient expresses a need, they bring it up, and we discuss it with them.” (a 38-year-old anaesthetist with 12 years working experience) “...One of my former patients had specific needs of financial arrangements, and I thought it was necessary to be honest with the patient” (a 48-year-old doctor of traditional Chinese</p>

	<p>medicine with 25 years working experience) "...if a patient can understand his/her disease, we have effective communication in the early stage, I will try to elicit the patient's thoughts..." (a 37-year-old physician with 10 years working experience) (Focus group discussion 1)</p>
Truth disclosure	<p>"The process of telling patients the truth is often tactful...Our head nurse sometimes does this work" (Interview 26, a 28-year-old nurse with 6 years of working experience)</p> <p>"She (the patient) can be told. It is important to choose the right moment" (Interview 15, a 62-year-old husband of a patient with breast cancer)</p> <p>"Some of them (the patients) may be able to be concealed, such as some older, illiterate patients, but I feel it is difficult to conceal it completely. This is an oncology hospital, and it is impossible for the patients not to know, just might not know how serious it is" (Focus group discussion 3, a 36-year-old psychotherapist with 10 years of working experience)</p>
Rich end-of-life topics	<p>"We invited doctors from the ICU for consultation and analysed the pros and cons of these treatments with them (patients and family members) ... discussed the future care" (Interview 36, a 32-year-old physician with 5 years of working experience)</p> <p>"...there was an elderly patient in poor condition in my ward, and we took the time and effort to give him a personal life review. This process touched us all, including his family ...Shortly after that, he passed away...His family was very appreciative of the work we have done." (Focus group discussion 2, a 35-year-old nurse with 12 years of working experience)</p> <p>"I once encountered a patient who came to the nurse station to talk to me when I was working at night. He knew that the effects of the treatment might not be good.</p>

Patient factors affecting the end-of-life communication		He said he was worried about his child. I just kept sitting there. Listening. I felt like I didn't do anything to help him because I didn't know how to respond then. But before he returned to his room, he thanked me for being willing to listen to what he said." (Interview 17, a 34-year-old nurse with 12 years of working experience)
	Comfort level of talking about the end of life	"I trust my daughter; she is competent and can help me decide anything" (Interview 16, a 66-year-old patient with end-stage heart failure) "We haven't talked about it yet (within the family)" (Interview 11, a 52-year-old patient with ovarian cancer) "I definitely hope the treatment is effective, but some things are inevitable, and we have to address" (Interview 49, a 76-year-old patient with severe chronic obstructive pulmonary disease)
	Burden	"The pain experienced during a cancer attack can be so excruciating that the patient may plead for death." (Interview 31, a 35-year-old physician with 10 years of working experience) "...he (the patient) told me (about his preferences) ...I told him to take it easy and not overthink it (the disease). I'm unsure what to do [emotionally]; I don't know, do I have to agree with him to give it up?" (Interview 18, a 32-year-old daughter of a patient with intestinal cancer)
	Treatment engagement	"I've had this problem (the disease) for many years, and it's gradually getting worse... I should say that I'm somewhat prepared in my heart...I think it's better if they're honest with me." (Interview 44, a 77-year-old patient with end-stage renal disease) "There's a lot he (the patient) doesn't know, and we haven't dared to tell him about it (the poor prognosis)." (Interview 23, a 45-year-old daughter of a patient with end-

Family factors affecting the end-of-life communication		stage heart failure)
	Comfort level of talking about the end of life	<p>“It’s not time yet” (Interview 10, a 54-year-old son of a patient with lung cancer)</p> <p>“My two daughters and I are well aware of the current situation, and we have been prepared for it. We have been mentally preparing for several years... We feel unfortunate and reluctant to let go... He (the patient) shared his thoughts with us while he was conscious. It’s fine for us to discuss these issues. But now he is unconscious, and we are hesitant to make any decisions.” (Interview 30, a 70-year-old wife of a patient with end-stage heart failure)</p>
	Burden	<p>“Sometimes the family members take the initiative and say, ‘We don’t want to treat him (the patient) any more’. The burden on him (the family member) is too heavy, and he can’t bear it anymore.” (Interview 31, a 35-year-old physician with 10 years working experience)</p> <p>“I feel very sad when I see him like this. Honestly, I have wanted to (give up active treatments), and I don’t want to torment him... My son is unwilling (to give up active treatments) ... I am taking care of him, and only I know how painful (the patient is).” (Interview 35, a 72-year-old wife of a patient with stomach cancer)</p>
	Expectation	<p>“Some (families) have unrealistic expectations, and part of our job is to lower their expectations.” (Interview 21, a 45-year-old nurse head with 20 years of working experience)</p> <p>“When you perceive that the family has high expectations, it will be challenging to discuss these topics.” (Interview 41, a 37-year-old physician with 10 years of working experience)</p>
	Value	<p>“Some families think that no matter what, I put you in the hospital, and you died in the hospital, not that I abandoned you... They value treatment more than anything</p>

Healthcare provider factors affecting end-of-life communication		<p>else, including the patient's thoughts...They believe it is an act of filial piety. The outsiders cannot say that they do not fulfil their duties. In such cases, we cannot say too much." (Interview 24, a 34-year-old physician with 6 years of working experience)</p> <p>"If active treatment brings a lot of pain to my father, then I think it's better not to do it. I think I would respect my father's choice." (Interview 12, a 40-year-old son of a patient with lung cancer)</p>
	Trust in healthcare providers	<p>"I have always communicated with this doctor. And if we need to discuss these issues, I prefer him to talk to me. I am more familiar with him, which makes it less scary for me." (Interview 13, a 62-year-old wife of a patient with lung cancer)</p> <p>"If the family trusts you, he/she may confide in you about her trouble." (Interview 17, a 34-year-old nurse with 12 years of working experience)</p>
	Comfort level of talking about the end of life	<p>"There appears to be greater sensitivity towards death-related topics in hospitals. Therefore, it may not be appropriate to discuss death and dying with patients and their families." (a 30-year-old nurse with 8 years of working experience) "...when talking to patients, I would have a lot of worries...such as their reactions, and I would wonder if I'd said the wrong thing." (a 32-year-old nurse with 10 years working experience)</p> <p>(Focus group discussion 2)</p> <p>"This is actually a part of my job. I think healthcare providers should consider these (end-of-life topics) first and become comfortable discussing them." (Interview 41, a 37-year-old physician with 10 years of working experience)</p>
	Available time and priority in	<p>"Time is minimal, and it is impossible to talk to each patient one by one. I mean talking in depth, which requires time and energy." (a 48-year-old doctor of</p>

practice	<p>traditional Chinese medicine with 25 years of working experience) “...To be clear, communication is humanistic in nature. Good communication is necessary, but it’s hard to measure it.” (a 38-year-old anaesthetist with 12 years working experience)</p> <p>“...We have to consider the bed turnover rate, and there are limited resources available for terminally ill patients, which simplifies the communication between these patients and us.” (a 37-year-old physician with 10 years working experience) (Focus group discussion 1)</p>
End-of-life communication awareness	<p>“Many medical professionals do not have the awareness to communicate these topics.” (Interview 36, a 32-year-old physician with 5 years of working experience)</p> <p>“No one had mentioned any of this before.” (Interview 45, a 70-year-old wife of a patient with end-stage renal disease)</p> <p>“With my experience, I will attempt to communicate with the family to understand the patient’s thoughts. However, some medical staff, particularly those who are young, may lack the awareness.” (Focus group discussion 2, a 35-year-old nurse with 12 years working experience)</p>
End-of-life care knowledge and communication skills	<p>“Sometimes I feel overwhelmed and unable to do so. The knowledge on end-of-life care is lacking, and it is difficult to grasp the psychological state of patients and their families.” (Interview 25, a 27-year-old nurse with 5 years of working experience)</p> <p>“They (providers) should listen to our concerns patiently and explain the different options to us in detail...Give us time to digest the information.” (Interview 7, a 64-year-old patient with prostatic cancer)</p>

6.3.2.1 Protective end-of-life communication

Many physicians and nurses mentioned the implementation of protective medical measures and said they would prioritise communicating end-of-life issues with families rather than patients. As for whether to communicate the accurate diagnosis and prognosis (hereinafter referred to as the "truth") with the patient, it mainly depends on the family's willingness to inform. If the family preferred not to tell the patient the truth, many physicians and nurses said they needed to respect the family's choice to avoid family dissatisfaction with medical services and potential medical disputes.

Some family caregivers expressed a strong attitude towards concealing the truth from the patient and even sought an "alliance" with healthcare providers. They believed it was inappropriate for healthcare providers to communicate directly with patients about the end of life. Their primary concern was that the patient could not accept reality and avoid making any make medical decisions. This belief was predominantly rooted in the family's emotional connection and their everyday experience with the patient. However, without knowing when and how to inform patients, families felt uncertain about such "protection" and perceived helplessness when making decisions as a surrogate. Also, one family caregiver (Interview 14, a 30-year-old daughter of a patient with breast cancer) said that she was afraid to tell her mother about end-of-life issues, and she would get very emotional if she wanted to ask her mother about the funeral arrangement, for example. Withholding the truth or avoiding discussion of the end-of-life topics from the patient may serve as a mechanism for family members to safeguard their emotional well-being by preventing vulnerability.

End-of-life communication usually occurs between physicians and families. While concealing the truth, it is almost impossible for physicians to communicate end-of-life topics, such as the diagnosis, prognonsis and goals of care, with patients. The limited

end-of-life communication is often related to medical procedures and documents, including notifications of disease progression, changes in treatment plans, ICU transfers, usages of life-sustaining treatment, etc. One family caregiver (Interview 9, a 36-year-old son of a patient with head and neck cancer) mentioned that such communication was like a “one-way” rather than a “two-way discussion” and lacked necessary explanations. Psychological and bereavement support for families often rely on verbal reassurance from the head nurse. Psychotherapists, pharmacists, and dietitians rarely engage in end-of-life communication as team members, even though some of them believe that they can provide terminally ill patients and their families with helpful information, such as medication and dietary knowledge, thereby building a trusting relationship that is considered the basis for further communication on end-of-life topics.

6.3.2.2 Open end-of-life communication

In contrast to the protective attitude of families in end-of-life communication, some patients and family caregivers stated that the patient was the primary communicator with their healthcare providers and the decision maker, and the role of families was to assist, consult and make joint decisions. Physicians and nurses reported that they would discuss various end-of-life-related topics with patients who were always involved in communicating with them, understood the disease progress, and made treatment decisions by themselves. These topics include patients’ condition and prognosis, treatment plans, personal wishes, financial issues, and funeral arrangements.

However, physicians and nurses perceived directly communicating end-of-life topics with the patient, is relatively rare in the current healthcare environment in Mainland China. A more common situation is to make patients subtly aware their disease has progressed to an advanced stage, their survival time is limited, or their “days are numbered”. Sometimes this kind of hint requires experienced providers, usually

attending physicians or nurse heads, to provide with the permission of the family; sometimes it needs to be guided by healthcare providers and invites family members who have already understand the situation and would like to inform the patient to be sensitive during daily life and seize the appropriate opportunity to give hints. For example, a 45-year-old nurse head with 20 years of working experience (Interview 21) noted, “When the patient asks about his or her condition, the family could intentionally remain silent”. Silence in such cases could make patients aware of their poor prognosis. In addition, physicians, nurses and allied healthcare providers believed that complete concealment might be challenging, as patients can understand their situation by observing their families’ behaviour and “digest” what their ward mates intended to say, or from the medical examination report forms.

When patients realise their condition is worsening, they might initiate end-of-life communication, especially topics related to future care, end-of-life wishes, financial issues, and arrangements after death. Besides, some physician and nurses believed that patient-involved end-of-life communication promotes better medical and personal outcomes. Although they might feel that sometimes there had been adequate communication with the patient about the end of life, the family still has the right to make different decisions when the patient reaches the end of life. The patient’s involvement in end-of-life communication and decision-making must still be supported by the family or agreed upon in intra-family communication.

6.3.2.3 Patient factors affecting the end-of-life communication

Participants identified several patient-related factors that could dynamically change end-of-life communication with healthcare providers from a protective state to an open state. These factors were grouped into patients’ comfort level of talking about the end of life, burdens, and treatment engagement.

Some patients expressed reluctance to think about end-of-life matters, believing that thinking about them might undermine their confidence in being cured or getting better and would also hurt the emotions and dedication of their families. They reported a heavy reliance on family caregivers for decision-making. However, as participants explained, the communication within their families did not cover or fully cover end-of-life topics. Patients' discomfort discussing end-of-life topics made them refuse or avoid end-of-life communication with healthcare providers. Instead, family caregivers intensely participated in end-of-life communication with healthcare providers, which keeps the end-of-life communication in a protective state. On the other hand, some patients said they were comfortable with healthcare providers talking to them about end-of-life matters, believing that honest communication was necessary to prepare them mentally and for personal issues. These preparations might not conflict with their desire to live, and these patients could still actively seek treatments while being prepared.

Participants mentioned that patients may become more actively involved in, or even initiate, end-of-life communication with them when patients perceive high levels of economic, symptom, or emotional burden. For example, a patient once expressed to his attending physician that he felt that his family had paid too much to treat his disease. He thought that he owed a lot to his family and sought help from the physician to give up active treatment (Focus group discussion 1, a 37-year-old physician with 10 years of working experience).

Another patient-related factor is their treatment engagement. Patient, physicians and nurses claimed that with those having prolonged hospitalization experience are more prone to engage in end-of-life communication, possibly because they are aware of or sensitive to deterioration of physical conditions, have certain psychological preparation

for their grave prognosis, and have good communication and trusting relationships with healthcare providers. In certain treatment modalities, such as renal dialysis, patients are actively engaged and committed to the treatment regimen, often preferring to discuss their condition due to being well-informed about treatment goals. However, some treatment goals appeared to be concealed from patients by their family caregivers and/or healthcare providers. “We (family members) just told him (the patient) that this is an old problem from the past, it is not serious, only infusion is needed” (Interview 5, a 72-year-old wife of a patient with gastrointestinal cancer). Low patient treatment engagement levels may allow end-of-life communication to remain protective.

6.3.2.4 Family factors affecting the end-of-life communication

Participants described five family-related factors that influenced end-of-life communication. Two of them were similar to patient factors, i.e., the comfort level of talking about the end of life and burdens. When it comes to end-of-life communication, some family caregivers immediately relate it to the patient’s deterioration and death. They believed this was a “premature” topic and might need to wait until formal notification of critical illness before considering life-sustaining treatments and funeral arrangements. In such cases, families were less likely to tell the patient the truth or involve the patient in forming open end-of-life communication. Some family caregivers were comfortable with the topic and stressed that everyone would grow old and end-of-life communication is necessary to help them prepare for the worst. Although these families were willing to tell the patients the truth, it may be too late because some patients have lost consciousness or the ability to communicate.

Participants mentioned three aspects of family burden: caregiving, emotional, and decisional. Healthcare providers explained that families rarely give up active treatment of patients due to economic burdens (which is different from the attitude of patients), but some families may take the initiative to communicate end-of-life matters because

of the heavy burden of care, such as long-term care, high effort, and only one caregiver. The relationship and intimacy between family members and patients, the degree of participation in care, and the degree of empathy for patients affect the emotional burden of family members. Additionally, family members may be burdened with decision-making by not knowing how the patient views their condition and future care. Open end-of-life communication may be developed when families perceive higher burden levels in these three areas.

The third factor is families' expectations. Some family members have high expectations for the hospital or the effects of active treatments and do not accept the fact that the patient has a poor prognosis. They may maintain their expectations by saying that "the patient's current treatment effect is uncertain" or "other patients are getting better". When the family has such expectations, end-of-life communication with healthcare providers may be maintained in a protective state in sync. The fourth family factor is values, mainly filial piety and quality of life. Some family caregivers believed that insisting on active treatment in the hospital is a kind of "filial piety"; while some were more concerned about the patient's quality of life. Different values of families may lead to varying states of end-of-life communication. In addition, healthcare providers emphasised that even within the same family, the family members' expectations and values can vary greatly, and inconsistent opinions regarding treatments and future care within the family will cause communication difficulties around end-of-life topics.

Finally, family caregivers said they prefer to talk about end-of-life topics with trusted providers who are knowledgeable and experienced, familiar with the patient's situation, have experience communicating with them, and can put themselves in their shoes. They further added that they trusted professionals who could tell patients the truth appropriately, respond to emotions and manage family conflicts. In contrast, providers

seem to have a general belief regarding the family-trusted professionals in end-of-life communication, “they (the families) have more trust in doctors and head nurses” (Focus group discussion 2, a 32-year-old nurse with 9 years of working experience).

6.3.2.5 Healthcare provider factors affecting the end-of-life communication

Similar to patient- and family-related factors, healthcare providers’ comfort level of talking about the end of life also affects end-of-life communication. Some healthcare providers were not used to and rarely had patients and families talk about end-of-life topics. They believed that these topics were sensitive and inappropriate to discuss in hospitals; topics related to death and dying were also family issues and maybe beyond providers’ responsibility. On the contrary, some providers were more comfortable with end-of-life topics and considered it part of their job.

Participants reported not having much time in clinical practice for adequate end-of-life communication with patients and family members. Some healthcare providers prefer to communicate with family caregivers to save time and respect family members’ wishes to hide the truth from patients without interfering. This may have kept end-of-life communication in a protective state. Besides, providers thought that end-of-life communication was not a priority in the current clinical practice, and the quality of end-of-life communication is difficult to measure effectively. Given this, healthcare providers do not devote much time and energy to end-of-life communication with patients and families. Participants further explained that their work focused on symptom management and that the uncertainty of prognosis made them ambivalent about the timing of end-of-life communication. Moreover, hospitals need to consider bed turnover; terminally ill patients may be transferred home or other facilities, and the necessity and continuity of end-of-life communication in hospitals are threatened.

Patients and family caregivers felt that the healthcare providers lacked the awareness

of end-of-life communication, as no one brought up these topics or talked about them too late to communicate with the patients due to cognitive impairment caused by the development of the disease. Some physicians and nurses perceived the disadvantages of concealing the truth, such as the patient's misunderstanding of the prognosis, the family's false hopes and the inability to make reasonable arrangements for unexpected situations. They tried to persuade the family members not to hide the truth from the patient, which is conducive to the formation of open end-of-life communication. These perceptions are mainly based on their work and life experience.

Nearly all participants agreed that end-of-life care knowledge and communication skills are critical for healthcare providers in end-of-life communication. Most providers thought discussing end-of-life topics requires specific knowledge and communication skills, which are rarely included in their education or training. There is little difference in the treatment and care given to terminally ill patients and other patients. They continued by highlighting a specific paucity of knowledge on the psychological, emotional and spiritual needs of terminally ill patients and their relatives. The lack of expertise in end-of-life care undermines providers' confidence in breaking protective end-of-life communication. Patients and families also noted that healthcare providers should have sufficient knowledge to explain prognosis and analyse treatment options adequately. Participants stressed the effective communication skills of healthcare providers. Some skills were mentioned, such as active listening, showing empathy and mediating family conflicts, which could encourage patients and families to express their feelings and opinions, promoting open end-of-life communication.

6.3.3 Discussion of experiences and perceptions

Overall, our findings provide an insight into the complex dynamics of client-provider end-of-life communication in Chinese hospital settings from the perspectives of patients with advanced illnesses, their family caregivers and healthcare providers.

Based on field data about participants' experiences and perceptions, we determined two end-of-life communication states: protective and open. The former is characterised by dominant family involvement, truth concealment and restricted end-of-life topics. The main characteristics of the latter are dominant patient participation, truth disclosure and rich end-of-life topics. Several factors related to the patient, family, and healthcare provider may affect the change in end-of-life communication from protective to open. A common factor shared across the three parties is the comfort level of talking about the end of life. Another factor that patients and families share is their perceived burdens, although there are subtle differences between patients and families. Other factors include patient treatment engagement, families' expectations, values and trust in healthcare providers, providers' available time and priority in practice, end-of-life communication awareness, and end-of-life care knowledge and communication skills.

The first important finding of our study is the coexistence of two end-of-life communication states, protective and open. Some aspects related to protective end-of-life communication, such as the heavy intervention of the family in decision-making and withholding the diagnosis from the patient, are discussed in some studies (Lin et al., 2019; Tang, 2019) and frequently attributed to cultural influences and compared with other cultures (e.g., collectivism versus individualism). Such compositional approaches rely on the cross-cultural comparative paradigm and provide several cultural dimensions that are clear and consistent to some extent (Hofstede, 2001). Nevertheless, it has been criticised as a static perspective to categorise culture and may result in stereotyping and overgeneralisation (Zhu, 2019). One of the reasons is that it is possible to find both ends of the cultural dimensions in one culture (Osland et al., 2000). As shown in our findings, our participants also described open end-of-life communication in addition to protective end-of-life communication. Dominant patient involvement in open end-of-life communication manifests patient autonomy, which

may challenge previous understandings of traditional cultural beliefs and their influence on end-of-life communication in the Chinese context. Stocklassa et al. found that most Chinese patients with advanced-stage cancer prefer to know about their diagnosis and prognosis and be respected as individuals (Stocklassa et al., 2022). This patient autonomy may be related to the influence of Western individualistic values and increased awareness of people's rights (Pun et al., 2018). This result suggests that healthcare professionals should avoid some preconceived assumptions based on traditional cultural beliefs and instead proactively identify the roles of patients and families in end-of-life communication and choose appropriate communication strategies.

Regardless of the protective or open state of end-of-life communication, participants highlight the significance of family involvement, support, and family consensus. On the one hand, this perception may be related to familism, which values supportive family relationships and prioritises the family over the individual (Campos et al., 2014; Choi et al., 2018). On the other hand, as there are no relevant national-level legal provisions on living wills in Mainland China (Zhang et al., 2022), although there were some attempts, and Shenzhen is the first city in Mainland China to recognise living wills legally (Yin et al., 2023), patient's preferences for end-of-life care has not been well documented; therefore the family still plays a significant role in the decision-making when the patient is incompetent in making medical decisions (Leng et al., 2022). In light of this, family participation needs to be respected; however, family attitudes and behaviours that conceal the truth prevent full patient involvement in end-of-life communication. Participants mentioned that family members may withhold the truth due to their perception of the patient's personality, their emotional connection to the patient, or as a form of self-protection. This implies that there is a need to explore why some family members withhold the truth and adopt targeted communication strategies

in practice. Meanwhile, it is essential to note that not all family members wish to conceal the truth and may struggle with when and how to disclose it, leading to helplessness in decision-making. Therefore, healthcare providers may need to understand the family's willingness to tell the patient the truth. More importantly, they are expected to take a greater leadership role in truth-telling. Due to the inconsistency of end-of-life care preferences between patients and family caregivers (Chuang et al., 2020), it is necessary to go beyond relying solely on family members to understand patient preferences (Pun et al., 2020). Healthcare professionals should provide education and guidance to family members regarding truth-telling and truly incorporate the patient's voice and choices into the decision-making process, ultimately promoting better outcomes.

Our study discovered that truth disclosure was seldom conducted directly but rather through indirect means such as suggestive informing, including intentional silence, as reported by participants. This may align with the high-context communication style in the Chinese context (Kim et al., 1998). Similarly, indirect communication approaches are also recommended to initiate end-of-life communication with older Chinese American patients, such as using another person's end-of-life care experience (Chi et al., 2018). However, there is still a lack of detailed indirect communication strategies for implicitly disclosing the truth to the patient in the context of serious illness. The non-verbal cues may be culturally appropriate and helpful for healthcare providers and families wanting to tell the patient the truth. More case studies with clear background information and application scenarios of culturally appropriate communication strategies may provide valuable knowledge and practical directions.

Medico-legal and policy-related issues are essential to create environments and establish confidence for healthcare providers to communicate end-of-life topics

(Turnbull et al., 2023). However, implementing protective medical measures in Mainland China may affect the willingness and confidence of medical staff to communicate with patients regarding end-of-life topics, indulge and fuel the dominant family participation in end-of-life communication, providing a basis for protective end-of-life communication. Protective medical measures refer to the medical measures taken to prevent vulnerable patients, including terminally ill patients, who are not suitable for their informed consent, from having negative and pessimistic emotions after learning the true disease information and affecting the treatment effect, so that their family members exercise informed consent on their behalf (Wang et al., 2013). They are considered to have a profound ethical foundation, have been enacted in the “Regulations on the Administration of Medical Institutions” in 1994, and are widely practised in healthcare settings in Mainland China (Hahne et al., 2020). However, there are some inherent contradictions in the protective medical measures. For example, they are intended to safeguard patients’ life and health interests, while families are often informed of the condition and treatment plan. In addition, protective medical measures are based on the assumption that patients are unwilling to accept adverse news about their condition and know the actual condition is not conducive to the patient’s health (Li & Li, 2021), which is not supported by the current research evidence (Stocklassa et al., 2022; Tang et al., 2006; Tang, 2019). More importantly, the current provisions related to protective medicine are only scattered in medical-related laws and regulations, and the relevant provisions are vague, with no specific explanation of their specific implementation scope and procedures. This allows flexibility for healthcare professionals to implement these measures in practice, while also explaining the coexistence of protective and open end-of-life communication at an institutional level. With the development of China’s social economy and the awakening of modern people’s awareness of autonomy, whether protective medical measures based on traditional culture and cognition is suitable for the current medical cultural environment

and whether it is conducive to promoting end-of-life communication, deserves in-depth consideration and appropriate adjustment.

Healthcare professionals, families, and patients were considered a triad of experts (Dalkin et al., 2018), and our study results show that the factors related to each triad member may affect end-of-life communication. People's comfort level of talking about the end of life was quite individual and related to their attitudes towards death, similar to the previous findings (Bergenholtz et al., 2020; O'Connor et al., 2020). The common comfort around end-of-life topics among the three parties is essential for open end-of-life communication. Educational interventions improve physicians' comfort with end-of-life communication (Miller et al., 2018; Schmit et al., 2016). However, the effect of these interventions on comfort has not been demonstrated among other groups despite positive impacts on death attitudes (Chu & Jang, 2021; Zhang et al., 2024). Tailored educational programs for all three parties may be necessary as this could promote end-of-life communication based on promoting comfort levels in all three parties.

Terminally ill patients and family caregivers may experience multifaceted burdens (Emanuel et al., 2000; Wen et al., 2019). Participants highlighted three burdens on patients (i.e., economic burden, symptom burden and emotional burden) and three burdens on family caregivers related to caregiving, decision-making and emotion. Perceived higher stress levels in these areas appear to be associated with a tendency toward open end-of-life communication. Patient's symptom burden was found to be related to their information needs (Verhoef et al., 2022), and the family caregiver's decisional burden calls on an early decision-making process incorporating the patient's values (Yamamoto et al., 2017), which partly explains their tendency towards open end-of-life communication. According to Johnson et al. (Johnson et al., 2007), patients with advanced illness share common concerns about being a burden on their families. They

may adopt several strategies to minimise the burden, including planning for future care. This is similar to our study, in which the patients' emotional burden motivated them to engage in or initiate end-of-life communication, thus leading to open end-of-life communication. Whether these burdens are expressed directly by patients or families or learned by healthcare providers through assessment tools, the above burdens may be essential signals that patients and families desire open communication in the context of serious illness.

Participants described time constraints as a barrier towards open end-of-life communication, which was also found in previous research (Bennett & O'Conner-Von, 2020). The survey results showed that relevant training is beneficial in decreasing providers' commonly perceived barriers, including time constraints (Chan et al., 2020). Although end-of-life communication has been considered a vital component of the care provided at the end of life (Olsson et al., 2021) and hospitals remain the primary setting for end-of-life care (Virdun et al., 2015; Weng et al., 2022), it is not currently a priority for hospital staff in Mainland China. Providers' end-of-life communication awareness is mainly derived from their own experiences. A systematic end-of-life communication and quality evaluation system should be established to encourage providers' end-of-life communication practices. Moreover, relevant education and training must be strengthened to improve providers' end-of-life communication awareness, knowledge and skills, especially emotional and psychological support and managing family disagreements. This also helps providers establish a trusting relationship with families and lays the foundation for open communication.

6.3.4 Results of suggestions and strategies

Participants' recommendations for improving end-of-life communication in hospitals were categorized into four themes: (1) Clarify the responsibilities of hospital-based healthcare providers; (2) Evaluate the quality of end-of-life communication; (3)

Provide end-of-life communication training; and (4) Communication strategies: IGNITE. It is an acronym that stands for the following end-of-life communication strategies: a) **Identify** the primary communicator(s) and prepare the family if necessary; b) Initiate end-of-life communication in a **Gradual** and **Natural** manner; c) **Navigate** realistic expectations; d) **Inner** healing with emotional support and meaning reconstruction; and e) **Timing** and **Environment**. Table 6.4 shows these themes and subthemes with participants' quotes. A visual representation of themes and subthemes is presented in Figure 6.1.

Table 6.4 Themes, subthemes and representative quotes from participants

Themes	Subthemes	Representative quotes from participants
Clarify the responsibilities of hospital-based healthcare providers in end-of-life communication	Responsible healthcare providers	<p>"First of all, there has to be a basis that the doctor in charge, for example, has communicated some information. In my opinion, much communication about the condition should be with the doctor before we care." (Interview 17, a 34-year-old nurse with 12 years of working experience)</p> <p>"...The nurse's role is very important; they can provide us with the patient and the family's situation, emotions, etc., which can help us better communicate with the patient and the family...Specialist development may enable this part of the communication to be done better, because the care resources are relatively concentrated, so what kind of resources we can provide to the terminal patients, what kind of services we can provide, then we can better communicate; otherwise it becomes a paper exercise, what we can do for the terminal patients at present is relatively limited." (Interview 31, a 35-year-old physician with 10 years of working experience)</p> <p>"I think that end-of-life communication can't rely entirely on hospitals. It'd be better to involve the community and the whole society more. If a patient has had advance care planning explained and discussed with them before being admitted to the hospital, they'll have a clearer concept of what to expect. These communications should be documented for the medical staff's reference and discussion." (a 36-year-old psychotherapist with 10 years of working experience from focus group 3)</p>
	Multidisciplinary collaboration	<p>"There's no set procedure for what we must do and how to cooperate (end-of-life communication). Often, it's down to the nurse's sense of responsibility. For</p>

Evaluate the quality of end-of-life communication	approaches	instance, if a patient has something on their mind, we'll discuss it with their doctors. It's not mandatory, though; many nurses don't consider it. For instance, could we have some clear guideline or something like that to help us figure out how to do it?" (a 32-year-old nurse with 10 years of working experience from focus group 2)
	Team reflection and consensus	"As doctors, we should be aware of the impact of continuing treatment on patients and their families. Is it really necessary? It's not just us doctors who communicate with the patients and their families. The whole healthcare team should be aware of the condition and work together to form a united idea. This will help us to communicate more effectively." (a 38-year-old physician with 12 years of working experience from focus group 1)
	The necessity of quality evaluation	"Communication is part of the medical humanities, but it doesn't get the respect it deserves in practice. In many ways, the focus on technology over humanities is a persistent problem in our healthcare environment. This problem may be even more pronounced in the care of end-stage patients. We need to set quality evaluation indicators to make medical staff aware of how well we communicate, what areas we are affecting, and how to strengthen it in the future." (a 48-year-old doctor of traditional Chinese medicine with 25 years of working experience from focus group 1)
	A comprehensive process	"We usually assess how satisfied patients and their families are with the communication they receive. This assessment may be general, focusing on the feelings of the patient and the family. We can think more about how effective end-of-life communication has been, whether the patient's thoughts have been taken into account, whether there has been a reduction in the use of intensive care, and so

Provide end-of-life communication training	Preferred training methods	<p>on.” (Interview 17, a 34-year-old nurse with 12 years of working experience)</p> <p>"It's better to have an ongoing focus (on the communication needs of patients and families) where some of our ideas and feedback can be discussed promptly."</p> <p>(Interview 13, a 62-year-old wife of a patient with lung cancer)</p> <p>“I think case-based training could be more interesting. It could be more engaging to split up into different groups, like doctors and nurses in a team, and see how to solve the patient's problem from different perspectives.” (Interview 25, a 27-year-old nurse with 5 years of working experience)</p> <p>"There is still relatively little training in this area, and if I had the opportunity to attend such a training, I would hope that this training would be very practical, incorporating a large number of real clinical cases, on the basis of which knowledge and methods of communication are explained to medical staff."</p> <p>(Interview 36, a 32-year-old physician with 5 years of working experience)</p>
	Preferred training contents	<p>“Training is best done in a way that can be continued. Training isn't just about training a group of healthcare providers. It's better to form an empirical summary that is constantly updated and can be shared (a 38-year-old anaesthetist with 12 years of working experience) ... The content should be "down to earth" and appropriate to our cultural environment (a 48-year-old doctor of traditional Chinese medicine with 25 years working experience)” (Focus Group 1)</p> <p>“... (The contents should include) Emotional identification and responses (a 35-year-old nurse with 12 years working experience) ... I think the difficulty is that some special groups, such as ‘white-haired person seeing off black-haired person’ and ‘a member of the sandwich generation’ (a 32-year-old nurse with 9 years working experience) ... This is still training in medical humanities. It's also</p>

Communication strategies: IGNITE	<p>Identify the primary communicator(s) and prepare the family if necessary</p> <p>Initiate end-of-life communication in a Gradual</p>	<p>possible that some nurses are reluctant to participate because of their own traumatic experiences, avoiding end-of-life communication. That's a group of nurses that we need to pay more attention to as well (a 35-year-old nurse with 12 years of working experience). [Agreeing] Maybe we can add this part in, which is how to self-care and deal with your emotions (a 30-year-old nurse with 8 years working experience)” (Focus group 2)</p> <p>"If the patient is clear on their own thoughts and there's plenty of direct communication with them. ... It's important to assess the family structure, start with the main decision-maker and then discuss these issues with the patient together." (a 35-year-old nurse with 12 years of working experience from focus group 2)</p> <p>"We should be careful about the family's request to keep the patient's condition confidential. This could hide some dangerous follow-up issues. Many young nurses easily agree with the family, which can be very dangerous...This is a good chance to communicate with the family." (Interview 21, a 45-year-old nurse head with 20 years of working experience)</p> <p>“My sister and I have different ideas, but she's been looking after my dad, so it's hard for me to discuss these topics. Hopefully, the medical staff can act as a neutral party and help us communicate with each other.” (Interview 9, a 36-year-old son of a patient with head and neck cancer)</p> <p>“This (end-of-life) communication process should always be gradual, going to the patient and family at the very beginning and creating a connection with them.” (a 32-year-old nurse with 10 years of working experience from focus group 2)</p> <p>“I think they can start by asking if we're ready (to talk about this); we need time to</p>
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and Natural manner	digest the information.” (Interview 18, a 32-year-old daughter of a patient with intestinal cancer) “I think the process (of end-of-life communication) must be natural, not too deliberate, and it's natural to talk about it in everyday interactions so I don't get too nervous.” (Interview 11, a 52-year-old patient with ovarian cancer)
Navigate realistic expectations	"Assess the patient's changing condition and explain what may happen, including what we are trying to do. Medicine is not a panacea, and patients and families must be reminded of this. Tell them what else we can do to preserve their hope." (a 37-year-old physician with 10 years of working experience from focus group 1) “I don't want to know that there is nothing they can do, even a little bit, to make him (the patient) feel more comfortable.” (Interview 30, a 70-year-old wife of a patient with end-stage heart failure)
Inner healing with emotional support and meaning reconstruction	“Patients like me may be more or less uneasy or even restless inside, in short, an unsettled feeling, and I would like to have someone to talk to, or sometimes, even if I don't say anything at all, I will feel more at ease when I see her (the nurse). (Interview 49, a 76-year-old patient with severe chronic obstructive pulmonary disease) “The patient dies with no regrets, and the family is also able to reduce their regrets and accept the loss. This is what it means to care for the terminally ill and their families in the so-called ‘peace for both the living and the dead’.” (Interview 41, a 37-year-old physician with 10 years of working experience)
Timing and Environment	“It can be easier for patients and their families if you talk about this when there is a change in the condition. Many people don't like communicating this in advance and might think it's a sign of something bad happening.” (a 32-year-old nurse with

9 years of working experience from focus group 2)

“I think it should have been made clear to me at the time of diagnosis.” (Interview 8, a 55-year-old patient with prostatic cancer)

“It's best to have a quiet space where the patient and family can open up and talk freely.” (Interview 25, a 27-year-old nurse with 5 years of working experience)

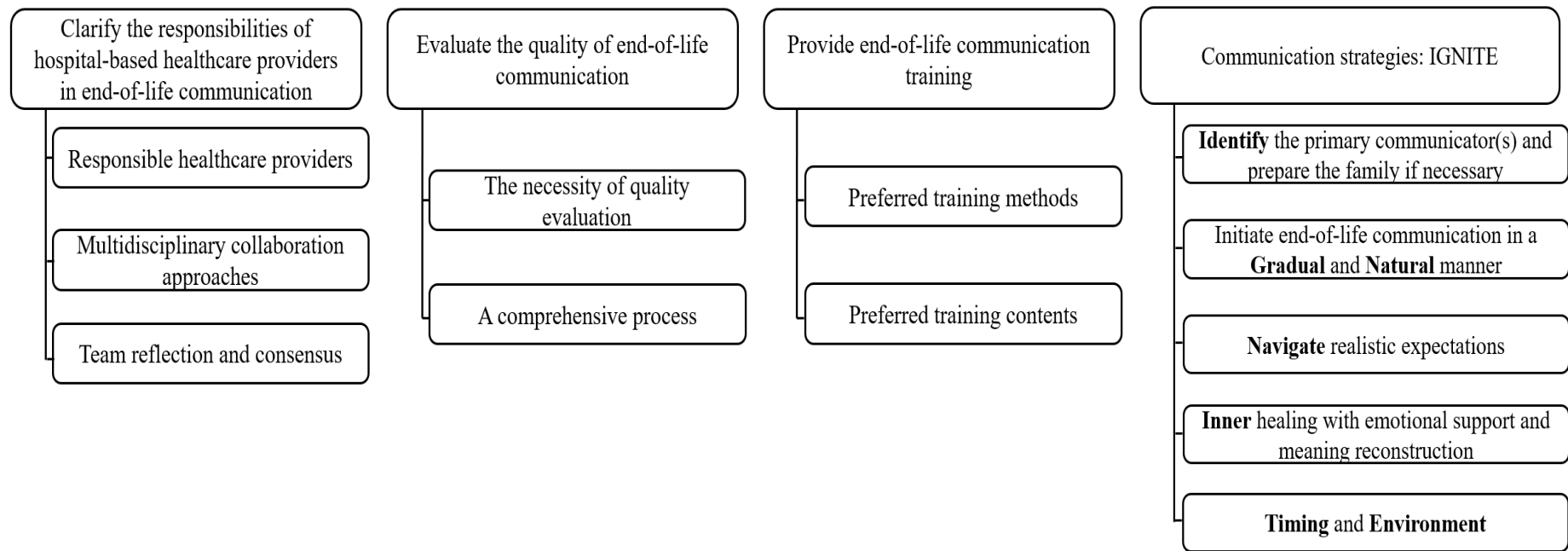


Figure 6.1 Visual representation of themes and subthemes

6.3.4.1 Clarify the responsibilities of hospital-based healthcare providers

Participants suggested that the patient's attending physician assume the primary responsibility for end-of-life communication and communication among team members in the hospital, ensuring comprehensive discussions on the patient's condition, prognosis, treatment plan, etc., while considering their preferences. Nurses are expected to be more active in understanding family dynamics, sensitively observing and responding to emotions, addressing patients' cues, reconstructing meaning, and providing support during grieving processes. It was suggested that multidisciplinary professionals, such as professionals from the intensive care unit and psychology departments, should be involved to enhance decisional and psychological support. Some providers recommended that specialist palliative care be further developed and specialized providers be involved in end-of-life communication to alleviate pressure on non-specialist providers and departments. Additionally, allied providers argued that hospitals may not be the most suitable setting for discussing personal values and end-of-life wishes. Hospitals primarily focus on acute treatment and care, with end-of-life care and communication often not prioritized as a primary responsibility. They advocated for initiating discussions about advance care planning and arrangements after patients' death in the community or at home before hospital admission, allowing relevant preferences to be documented for reference by providers in hospitals. Following patient discharge, the community can provide ongoing bereavement support.

Although multiple disciplines should be included in end-of-life communication, participants highlighted the lack of clarity in the collaboration framework. There is a notable absence of consensus among multidisciplinary approaches to communicating with patients and families at the end stage, as well as significant variability in end-of-life communication practices. Some participants suggested developing guidebooks or communication templates for terminally ill patients within hospitals to address these issues. These guidelines would clarify multidisciplinary responsibilities and provide specific actions for consistent approaches and principles in end-of-life communication

for hospital-based providers.

Participants suggested the healthcare team reflect on the patient's condition and prognosis, consciousness and decision-making capacity, the significance of active treatment, treatment options, and the patient's and family's distress and concerns through team meetings. The healthcare team should establish a consensus on care provision, and end-of-life communication goals should be formulated and evaluated.

6.3.4.2 Evaluate the quality of end-of-life communication

Participants emphasized that end-of-life communication is essential to care for individuals with severe or terminal illnesses. However, end-of-life communication has not received adequate attention in clinical practice due to the inherent challenges in evaluating humanistic care in practical settings and the current emphasis on technical and therapeutic outcomes. Implementing a suitable evaluation system may draw the attention of healthcare providers to end-of-life communication.

While some assessments of service quality include patient and family satisfaction with interpersonal communication with healthcare providers, these evaluations only touch upon general aspects of communication. A comprehensive evaluation of end-of-life communication should encompass more specific details such as whether the medical team has thoroughly discussed treatment options and their potential benefits and drawbacks, whether the communication needs of patients and families are explored and met, to what extent the patient and family understand the prognosis, to what extent the patient's preferences are considered in making medical decisions and the effects on end-of-life care. Some healthcare professionals also cautioned against relying solely on quantifiable measures to assess end-of-life communication quality as it may oversimplify its inherent human nature; thus, careful consideration is needed when developing an evaluation system for this purpose. Nevertheless, certain fundamental evaluation indicators are worth considering as they can serve as reference standards for healthcare providers to enhance their practices. Assessing the quality of end-of-life

communication may assist healthcare workers in self-reflection and improvement regarding their approach to such crucial conversations. Patients and family caregivers expected that the assessment of end-of-life communication quality should not be a mere formality but a comprehensive process incorporating communication feedback and follow-up mechanisms to address their actual needs.

6.3.4.3 Provide end-of-life communication training

Most healthcare providers expressed that there is currently a dearth of tertiary and continuing education courses and training resources on end-of-life communication. Furthermore, they have limited opportunities to receive comprehensive training in end-of-life communication skills. However, the urgency of their actual needs becomes apparent when caring for terminally ill patients and their families. Participants are expected to acquire practical knowledge and skills in end-of-life communication through engaging case studies and accumulate experience in actual or simulated situations via simulation exercises and role-playing activities. It was also recommended to incorporate multidisciplinary discussions centred around the same case as a training method. The pharmacist and psychotherapists emphasized the significance of interdisciplinary mutual learning and exchanges.

The training content should primarily focus on emotional recognition and care for patients in the terminal stage, precautions related to end-of-life communication within traditional cultural contexts and religious beliefs, and addressing specific groups such as young patients and their parents. Participants also suggested the need for regular updates to training content. On the one hand, cases should be continuously expanded and improved based on practical needs and in-depth research. At the same time, practical strategies for end-of-life communication should be promptly shared with related healthcare providers. On the other hand, the latest resources for patient care services at end-stage and policy changes should be communicated through irregular training sessions or group meetings, enabling providers to relay up-to-date information to patients and their families.

Several nurses mentioned that some providers may refrain from engaging in end-of-life communication practices and related training due to their own traumatic experiences, thus emphasizing the importance of respecting the willingness of providers to participate in such communication and training. The inclusion of real-life cases in the training may potentially have a negative emotional impact on these healthcare professionals. Therefore, it was recommended that self-care approaches be incorporated into the training program to enhance providers' awareness and ability for self-care. Moreover, it is advised to continue monitoring the emotions and responses of providers following end-of-life communication practice and training while providing necessary support such as debriefing sessions with the nursing supervisor, peer communication opportunities, and psychological counselling.

6.3.4.4 Communication strategies: **IGNITE**

*6.3.4.4.1 **Identify** the primary communicator(s) and prepare the family if necessary*

Almost all participants recommended obtaining comprehensive information about patients and their families before initiating end-of-life communication, including the patient's medical history, treatment experiences, disease progression and prognosis, the implications of aggressive interventions, and the extent of patient suffering. It was also suggested that healthcare providers gather details regarding family dynamics, primary caregivers involved in decision-making processes, and their associated burdens. Doctors, nurses, and other allied healthcare providers emphasized the importance of observing and identifying family communication patterns during daily interactions with patients and their relatives and recognizing that both parties often play a significant role in end-of-life communication and decision-making processes. Most participants believed that when family members assumed the role of primary communicators, providers needed to demonstrate respect towards family involvement. The respectation includes seeking family permission before engaging in end-of-life communication with patients and actively exploring the family's preferences concerning disclosure of diagnosis and prognosis to patients.

In cases where family members were the primary communicators but hesitated to disclose the truth to the patient, participants mentioned several communication strategies that could be explored with the family to inform the patient about the truth while emphasizing the importance of respecting the family's preferences. These included: (1) examining the underlying reasons for the family's reluctance to disclose the truth. Doctors and nurses noted that some family members may be unprepared for or know how to handle such a sensitive conversation. It is crucial to understand these reasons clearly to select an appropriate communication strategy for subsequent discussions. When family members approached medical staff with a request to keep the patient's condition confidential, participants viewed it as an opportunity to delve into their motivations for concealment. The phrases suggested by nurses: "Why would you consider hiding the condition from the patient?" and "Did you choose to hide it because you were worried about something?" (2) Discussing with the family about potentially concealing information from the patient while highlighting the challenges associated with doing so. The phrase suggested by physicians: "It's hard to keep a patient completely in the dark, and diverse resources may inform the patient." (3) Guide family members to empathize with the patient's perspective (e.g. experiencing feelings of invisibility as a patient). The phrase suggested by physicians, nurses and allied healthcare providers: "Imagine if it was you lying in a hospital bed receiving these treatments, but you didn't know what was happening." (4) Engaging in conversations with family members regarding potential consequences or outcomes of withholding information from patients, emphasizing negative impacts through examples or narratives (e.g., causing regret; increasing patient fear). The phrase suggested by physicians: "People are usually more scared of what they don't know and tend to think things are way worse than they are." (5) indicating and emphasizing the responsibilities of surrogate decision-makers, highlighting any discrepancies between familial preferences and those of patients themselves, as well as stressing the importance of understanding patients' wishes. The phrase suggested by physicians and nurses: "You

have to understand that afterwards you need to make medical decisions on behalf of the patient, and you can think carefully about whether you understand the patient's preferences while being able to take on this responsibility.”

There may exist variations in preferences for end-of-life communication among family members, and some healthcare providers advocated "striking a balance" through convening family meetings to foster consensus within the family unit. Certain patients and families preferred providers to assume the role of an impartial intermediary in resolving disparities in end-of-life communication, as they perceive the neutral stance and position of healthcare providers to be beneficial.

*6.3.4.4.2 Initiate end-of-life communication in a **Gradual and Natural** manner*

All participants unanimously recommended a gradual and natural process of end-of-life communication. Physicians, nurses, and allied healthcare providers advocated for increased companionship and attentive care to establish a connection with patients before discussing end-of-life topics. Assessing the patient and family's understanding and plans regarding the medical condition is essential. Some participants suggested that exploring patients' and family members' perspectives on death-related taboos and their experiences with end-of-life communication within the family could help gauge their acceptance of such topics. The phrases suggested by patients, family caregivers, and nurses are as follows: “Many of us Chinese may be sensitive to the topic of death. Is it a taboo topic for you? Do you usually discuss it among your family?” In cases where patients and families are not yet prepared to discuss end-of-life matters, all participants agreed that respecting their willingness to engage in such conversation is crucial, allowing them time for reflection and acceptance of the patient's unfavourable prognosis. Nurses and allied healthcare providers proposed that providing a declaration of willingness to assist, along with accessible educational material related to end-of-life care, could create more opportunities for initiating end-of-life communication.

During regular interactions, some physicians and nurses have observed that certain patients may subtly indicate their desire to discuss end-of-life matters with them, particularly if there is an established trust and familiarity between the patient and provider. Patients often employ suggestive or tentative expressions such as expressing concerns about sleep problems and the fear of not waking up, asking questions like "You've cared for so many people; is there any hope left?" or inquiring about their remaining time. Rather than engaging in formal and intentional conversations about end-of-life issues, some patients tended to approach these discussions casually as a means of reducing stress, anxiety, and fear. These patients expected their cues to be recognized by healthcare providers, who can then naturally initiate conversations regarding end-of-life topics. Physicians and nurses emphasized the importance of active listening during these encounters. They viewed these cues from patients as rare opportunities for meaningful dialogue that can organically progress towards end-of-life communication.

Participants proposed several communication strategies to address patients' verbal cues:

- (1) Acknowledge the patient's willingness to express themselves and appreciate their trust. The phrase suggested by patients and nurses: "I appreciate you telling me this. It must be a lot of trust on your part."
- (2) Exploring underlying concerns. Some phrases suggested by patients, family caregivers and healthcare providers: "Can you tell me what you think?" "Is there anything you're worried about?"
- (3) Normalizing discussions about death and dying. Some phrases suggested by patients, family caregivers and healthcare providers: "We all have to face birth, ageing, sickness, and death (the four inevitables in human life)." "Everyone, even if they don't get sick, will come to the end of their life."
- (4) Eliciting the patient's thoughts, preferences and wishes hypothetically. Some phrases suggested by patients, family caregivers, and healthcare providers include: "How do you see the future if, sadly indeed, there comes a time when the treatment does not work so well?" "Do you think it would be better to tell you or hide it from you if something happens in the future?"

*6.3.4.4.3 **Navigate** realistic expectations*

Doctors, nurses, and allied providers advocated acknowledging and appropriately addressing unrealistic expectations of patients and their families. This involves providing detailed explanations about the disease progression and potential outcomes, discussing the efforts made by the medical team, and discussing the limitations of current medical technology. Additionally, it is crucial to “give preventive shots” to patients and their families and guide them to make “double-handed preparations”. Some phrases suggested by physicians and nurses: “We’ll get to the bottom of what’s going on. It’s not looking good at the moment, so we may all need to be prepared.” “(Explaining the treatment process) We all hope for a good outcome, but we also need to be prepared if these treatments don’t work well or if there are significant side effects.” Some healthcare providers also recommended exploring patients’ and families’ preferences for quality and length of life to align the goals of care. Some phrases suggested by physicians and nurses: “Is it more important to you to live happily for one day or to suffer for ten years?” “We’ll try to make sure you’re happy with your quality of life while also increasing your chances of living longer.” Patients and family caregivers expected doctors to provide them with clear and easily understandable explanations of the diagnosis, prognosis and treatment options, facilitating joint decision-making through thorough discussions. Some doctors preferred utilizing the term “supportive care” to delineate palliative care, as they believed this terminology is more readily embraced by patients and their families, concurrently fostering their hopes. One nurse employed the metaphor of “putting the brakes on” to explain palliative care, describing the treatments and supportive resources available to end-stage patients to manage their symptoms and promote comfort.

*6.3.4.4.4 **Inner** healing with emotional support and meaning reconstruction*

Providers of cancer care recommended utilizing the knowledge of psychological stages in cancer patients to discern their emotional state and implement tailored interventions accordingly. Some providers argued that specialized psychological counselling or treatment may not always be necessary, but rather, a means for patients to express their

internal emotions is crucial. Patients expressed the desire to be heard and emotionally acknowledged as a way to alleviate inner anxiety, fear, and restlessness. Moreover, some providers advocated for the proactive creation of opportunities for terminally ill patients and their families to openly express emotions through activities like memorial days and life reviews with family involvement. Respecting and verbally praising the diverse ways patients and family members convey their feelings requires careful observation since these expressions are often indirect or non-verbal. Furthermore, participants suggested making appropriate environmental modifications in terminal patient wards, such as incorporating green plants, displaying family photos, and accommodating patient preferences to enhance feelings of security and comfort.

Another crucial aspect of end-of-life communication strategies is to help patients and family members reconstruct a sense of meaning. Some doctors and nurses suggested guiding patients to focus on their current lives and discuss end-of-life wishes and preferences by emphasizing alleviating the burden and offering reassurance to the family. They suggested the phrase: “If you haven't discussed this with your family before, it's likely that they don't know exactly what you have in mind and how to help you. A voluntary discussion by you might help put your family at ease.” The patient's sense of meaning can also be fostered by acknowledging their value and contribution in reviewing their lifetime and significant moments. The sense of meaning for family members is derived from their active involvement in end-of-life care for their loved ones and from respecting patients' values and helping them fulfil their end-of-life preferences and wishes. Encouraging family involvement in end-of-life care and respecting patients' end-of-life preferences and wishes may contribute to effective end-of-life communication.

Some nurses proposed documenting significant moments involving family participation in end-of-life care (photographs, videos, and other mementoes) to strengthen emotional bonds between patients and their loved ones and assist family members in mitigating

feelings of loss or regret. Additionally, these records are suggested to be utilized during grief counselling following bereavement.

6.3.4.4.5 *Timing and Environment*

Participants held divergent views on the timing of end-of-life communication. Some participants suggested that the optimal time for discussing these topics should be when there is a significant change in the disease, such as signs of a worsening condition. Some participants preferred to have end-of-life communication when active treatments failed to yield the desired effects. Another group of participants proposed that patients and their families should be adequately prepared for various potential scenarios, including unfavourable prognosis and available treatments along with their respective advantages and disadvantages, at the time of diagnosis.

Most participants underscore the significance of ensuring quiet and privacy during end-of-life communication. It was recommended that these discussions be conducted in a designated room rather than in a shared patient ward or hallway. It may be worth considering the provision of a separate and tranquil conversation room that can accommodate large family members. Patients and family caregivers preferred ample time and a comfortable conversation environment, facilitating their willingness to open up.

6.3.5 Discussion of suggestions and strategies

In summary, our study outlines the recommendations and culturally appropriate strategies for end-of-life communication in hospitals provided by significant stakeholders. These recommendations and strategies are categorized into four themes, focusing on the roles of healthcare professionals in hospitals, quality assessment, training in end-of-life communication (which are relatively macro-level aspects), as well as micro end-of-life communication strategies (based on the acronym IGNITE for easy recall using keyword initials).

Participants acknowledged that effective end-of-life communication necessitates the

involvement of professionals from various disciplines, a finding consistent with prior research (Nedjat-Haiem et al., 2017; Pfeifer & Head, 2018), which may be attributed to the intricate and multifaceted needs of patients in the terminal stage and their families (Cheng & Chen, 2023). The findings from a previous scoping review (Olsson et al., 2021) examining practice guidelines on end-of-life communication in nine countries revealed variations in national preferences regarding the responsibilities and modes of collaboration among healthcare professionals, except for a shared inclination towards assigning primary responsibility to physicians. This communication responsibility remains inadequately defined within the mainland Chinese healthcare system, making our findings particularly valuable.

Similar to previous studies (Anderson et al., 2019; Nedjat-Haiem et al., 2017; Olsson et al., 2021; Strachan et al., 2018), physician-led, nurse-supported end-of-life communication is preferred. Some healthcare systems incorporate social workers and chaplains into the end-of-life communication team to share responsibilities for advance care planning, psychological support, and spiritual care, as observed in the United States (Nedjat-Haiem et al., 2017; Pfeifer & Head, 2018). In contrast, these roles are not typically included in the regular providers of Chinese healthcare systems, which accounts for the absence, ambiguity, or overlap of end-of-life communication-related duties. Only 17.5% of hospitals routinely engage in medical social work that usually does not encompass end-of-life communication (Chen et al., 2019). Surveys consistently indicate that China is among the least religious countries globally, with less than 15% of its population practising religion (Zhang & Lu, 2020).

Participants recommended transferring communication responsibilities for advance care planning and bereavement support to community settings. It can be a valuable, sustainable, and cost-effective strategy to establish effective partnerships between hospitals and communities for bereavement services (Boven et al., 2022). A compassionate community approach is needed to ensure ongoing bereavement support

(Aoun et al., 2018). The participants believed hospital healthcare providers should have minimum communication responsibility regarding advance care planning. However, a UK survey revealed that only 4.8% of patients had advance care planning available to the medical team upon admission (Knight et al., 2020), and advance care planning document completion rates in China were also low (Liao et al., 2019). These findings suggest a potential need for effective intervention strategies or information sharing between the community and the hospital. Implementing patient education materials, interdisciplinary team training, policies supporting advance care planning clinical workflows, and integrating advance care planning into electronic health records (Arnett et al., 2017; Hemsley et al., 2019; Owen et al., 2022) through systematic clinical routines across settings may prove beneficial in bridging this communication gap.

The second recommendation from participants was to develop a comprehensive evaluation of end-of-life communication quality to enhance end-of-life communication practices. While there are existing tools for assessing communication quality concerning end-of-life communication (End-of-Life Care Research Program at UW School of Medicine, 2023; Van Scoy et al., 2022), their Chinese versions have not yet been developed and validated. Some healthcare systems have implemented systematic evaluations of end-of-life communication quality, such as a pilot evaluation system that assesses structure, process, experience, and outcome in the United States, United Kingdom, and Canada (Sanders et al., 2019). The Audit of Communication, Care Planning, and Documentation (ACCEPT) in Canada has demonstrated feasibility and partial effectiveness (Heyland et al., 2017). It was suggested that the measurement of end-of-life communication quality requires indicators that reflect discussions on patients' personal life goals (as opposed to solely focusing on medical care goals) and that evaluate patients' or surrogate decision makers' understanding of diagnosis and prognosis (Myers, 2017). Our participants also have suggestions on these evaluation indicators, which can be further considered when developing the evaluation tools or system.

Concerns were raised by participants regarding the evaluation methodology's potential formality; these concerns echo those previously expressed, which suggested that the use of standardised measures of end-of-life communication quality may result in healthcare professionals focusing their attention on the completion of documentation rather than exploring patient and family preferences within the end-of-life communication process (Tolle & Teno, 2018). Novel technology-enabled measurements such as natural language processing, machine learning, open note platforms, and patient portals appear promising for future development to make the evaluation multi-channel, flexible and reliable (Esch et al., 2016; Sanders et al., 2019).

Participants reported a lack of sufficient training in end-of-life communication to meet the demands of their clinical practice. This finding aligns with previous studies conducted with Chinese physicians and nurses (Dong et al., 2016; Hahne et al., 2022; Zheng et al., 2015). There are only a few palliative care training for specialist nurses (X. Chen, Y. Zhang, et al., 2022; Q. Cheng et al., 2021; Hao et al., 2021; Lu et al., 2024) and communication skills training for breaking bad news for oncologists (Wuensch et al., 2013) in mainland China, and there is a lack of communication training for non-specialist healthcare providers working with terminally ill patients and families in hospitals. Researchers in the United States and Canada translated the national consensus on end-of-life care into communication curriculums (Ferrell et al., 2019; Rawlings et al., 2019). End-of-life communication strategies such as COMFORT (Wittenberg et al., 2016), SPIKES (Kaplan, 2010), and REMAP (Childers et al., 2017) have also been used to develop training programs. However, these communication strategies are controversial in their application directly in other cultural contexts (Pun et al., 2020; Wuensch et al., 2013) due to their Western origins. It is crucial to value the development of communication strategies that are culturally appropriate within the Chinese socio-cultural context, as participants said that the training should be "down-to-earth". The set of end-of-life communication strategies, IGNITE, recommended by

participants, can be incorporated into future training while considering other preferences expressed by participants regarding the training contents and methods.

Our previous scoping review (Chen et al., 2023) mapped the international literature on available end-of-life communication strategies for terminally ill patients and their families. It revealed that the research evidence is uneven between Anglo-Saxon and non-Anglo-Saxon countries, with existing end-communication strategies predominantly coming from the former, including the UK, USA, Canada and Australia. This current qualitative study is believed to be the first to directly explore perspectives on end-of-life communication strategies from Chinese stakeholders. Our participants emphasized the importance of end-of-life communication preparations with patients and families, stressing the need to share this information among the healthcare team and establish clear and consistent end-of-life communication goals. Compared to our previous knowledge based on the review (Chen et al., 2023), participants identified additional communication strategies for preparing family engagement, including recognizing family communication patterns, understanding family dynamics, and exploring and responding to family preferences for disclosing diagnosis and prognosis to patients. The intensive involvement of family members in end-of-life communication in the Chinese context (Pun et al., 2020) may contribute to this communication strategy. The extent of family involvement in end-of-life communication varies across different socio-cultural contexts, which affects end-of-life communication between healthcare providers and patients. For instance, the legal and medical systems in the United States encourage patient engagement in their end-of-life decision-making; family members acting as patient-designated surrogate decision-makers usually make decisions for patients when the patient is incapable of making decisions (Trees et al., 2017). End-of-life communication primarily occurs between patients and healthcare providers, and family involvement requires consideration and respect for the patient's preferences regarding family presence (Harris et al., 2021). These practices stem from the individualistic values and emphasis on autonomy prevalent in Western culture.

Influenced by Chinese culture and philosophy of life and death (Turnbull et al., 2023), the involvement of Chinese family members in end-of-life communication goes beyond surrogate decision-making. It represents a more intensive way of family participation. For instance, due to the cultural taboo surrounding discussions about death, it is customary for doctors to seek consultation from families before engaging with patients. A doctor's disclosure of the diagnosis and prognosis to a patient is largely contingent upon the patient's family's attitude towards disclosure (Xu & Yuan, 2024). The practice of healthcare providers communicating with family members while withholding information from patients is prevalent in Asian countries, including China, as well as in certain Western societies where families are closely connected (Sarafis et al., 2013). This phenomenon has also been referred to as "collusion" (Stiefel et al., 2017). While some strategies to reduce collusion have been discussed in countries where the ethical principle of patient autonomy is deeply believed, such as the United States of America (Low et al., 2009) and Australia (Clayton, Hancock, Butow, Tattersall, & Currow, 2007), there has been a paucity of discussion on how to deal with this phenomenon in other socio-cultural environments. Our participants identified several communication strategies to encourage healthcare professionals to proactively avoid potential collusion.

Participants acknowledged that both patients and families are likely to be the primary end-of-life communicators and that identifying primary communicators is an essential step for effective end-of-life communication. This implies that cultural beliefs that only consider family involvement may not necessarily apply to every individual's situation. Patients in East Asia are increasingly demonstrating a preference for communication involvement and autonomy (Pun et al., 2018), which places higher demands on the end-of-life communication skills of healthcare providers (Gan et al., 2018), such as balancing a high level of family involvement with the patient such preferences. The enhanced understanding of family dynamics, such as open, closed, or random family systems (Clifton & Ross, 2018), and family end-of-life communication (Xu et al., 2022) can be beneficial for healthcare professionals in identifying primary communicators.

All participants recommended a gradual and natural approach to end-of-life communication. Similar findings were observed in a previous study of older Chinese Americans (Chi et al., 2018), who preferred a gentle approach to examining older adults' readiness for end-of-life communication. Medical procedure-focused end-of-life communication may be perceived as single-minded, surprising, and discomforting to patients, potentially exacerbating their sense of abandonment (Harris et al., 2021). The regression analysis revealed a positive correlation between engaging in small talk and exhibiting higher levels of empathy (Gillotti et al., 2002). Participants highlighted end-of-life communication strategies for detecting and responding to patient cues and seizing these opportunities may allow end-of-life communication to progress naturally. The preference of patients and families for trust and rapport in their interactions with healthcare providers (Bergenholtz et al., 2020; Peerboom et al., 2023) may account for this communication strategy. The process of effective end-of-life communication should not be limited to initiated it naturally, but rather should encompass the involvement of families in order to facilitate shared decision-making. It is also crucial to formally document patient preferences and goals of care (Clayton, Hancock, Butow, Tattersall, & Currow, 2007). Among healthcare professionals, nurses demonstrate the potential to assume a more pivotal role in gradual and natural end-of-life communication (Strachan et al., 2018). Wittenberg et al. (2024) proposed two communication pathways which could enhance nurses' ability to fulfil this responsibility.

Another end-of-life communication strategy mentioned by participants was guiding patients and their families towards realistic expectations through explanations, reminders, and appropriate language. Patients and families expected to proceed this process with clear and understandable information, which may allow them to integrate the information cognitively and emotionally (Jackson & Emanuel, 2024). The skilful application of metaphors may facilitate the comprehension of patients and their families

(Hui et al., 2018).

Participants highlighted the inner healing function of end-of-life communication through emotional support and meaning reframing, demonstrating that end-of-life communication is an ever-deepening interactive process not limited to healthcare-related information and decision-making. Moreover, this perspective seems to go deeper than the existing understanding of the purpose and contents of end-of-life communication (Olsson et al., 2021). In addition to active listening and empathetic responses, emotional support encompasses facilitating emotional communication and connection within the family unit. Terminally ill patients in China consider harmonious family relationships and support as aspects of a good death (Fu & Glasdam, 2022). A previous feasibility study found that patient-caregiver dyad life review enhances mutual understanding and appreciation between patients and their families while alleviating caregiver stress (Y. Chen et al., 2022). Participants also identified reconstructing a sense of meaning as an end-of-life communication strategy. Reflecting on the past may activate patients' existential or spiritual strengths, which can be used to cope with current challenges and to help form plans for the near future (Haufe et al., 2020). Focusing on the present moment and proactively talking to family members about end-of-life wishes are meaningful to some patients if these approaches provide reassurance to their loved ones. These may be related to a sense of burden on others that is prevalent in terminally ill patients (Chochinov et al., 2007).

Creating a sense of meaning for family members can facilitate end-of-life communication, including encouraging family involvement in end-of-life care and respecting patients' preferences and wishes. When families are involved in the care of their patients, this can facilitate discussions between families and healthcare professionals about end-of-life issues, such as different aspects of palliative care (Saarinen et al., 2023). However, it is essential to note that knowledge about family involvement in end-of-life care in hospitals is minimal, particularly in some Asian

countries where it is common for families to accompany patients in hospitals, and there is a lack of research on how to involve families in end-of-life care in hospitals and how to support them in this role (Lee, 2001; Park et al., 2022; Saarinen et al., 2023). Respecting the patient's preferences and wishes may allow the patient to feel supported by the family, thereby facilitating the patient's discussion of death and dying (Fu & Glasdam, 2022); conversely, the family may derive a sense of meaning from this perception and behaviour and may be able to improve the family's bereavement experience (Stroebe et al., 2014).

The appropriate timing of end-of-life communication in hospitals is difficult to determine, possibly because the transition trajectory from curative to end-of-life care is not always predictable (Nevin et al., 2020). Another reason may be that end-of-life communication is an iterative process involving many rounds of communication, adding to the uncertainty of end-of-life communication. The timing mentioned by participants was similar to previous recommendations (Clayton, Hancock, Butow, Tattersall, & Currow, 2007), although the timing mentioned in the latter was not specific to the acute care setting. Earlier studies suggested that the timing of end-of-life communication should be based on patients' information preferences and needs (Anderson et al., 2019; Masterson et al., 2018; Parker et al., 2007). Healthcare professionals may need to be equipped with the potential timing of end-of-life communication to search for possible timing in practice. Recording and evaluation of the timing and content of such communication, for example, a years, months, and days framework (Tranberg et al., 2022), may contribute to proceeding with the end-of-life communication rather than waiting until it becomes too late, such as when the patient becomes unable to communicate effectively.

Ensuring the appropriate environment is an integral part of the communication strategy. O'Connor et al. highlighted the absence of quiet and private hospital spaces (O'Connor et al., 2020). The spatial layout in acute care settings poses challenges to effective

communication, particularly when discussing sensitive topics like end-of-life communication. Some environmental design interventions that can be implemented include establishing clear boundaries and signage visually and physically, optimizing the arrangement of ward spaces to minimize disruptions, and creating designated communication areas (Sagha Zadeh et al., 2018). Moreover, consideration should be given to the interior decoration of these designated spaces and ensuring sufficient capacity.

6.4 Implications for clinical practice, education, policy, and research

In clinical practice, healthcare providers need to identify the role of patients and families in end-of-life communication in a more proactive way rather than relying solely on possible biases brought about by cultural influences. Patient and family factors affecting end-of-life communication can strengthen the cognitive appraisal of healthcare providers on end-of-life communication. For example, assessing the burden of patients and family caregivers can provide a reference for clarifying the tendency of patients and family caregivers to communicate end-of-life topics. Healthcare providers may consider adopting the IGNITE end-of-life communication strategy recommended by stakeholders. These communication strategies are optional and should be adjusted according to the situation.

It is urgent to strengthen end-of-life communication education and training for healthcare providers to improve their end-of-life communication awareness, knowledge and skills. Such education and training must consider stakeholders' end-of-life communication preferences, such as indirect communication approaches and ways of expressing emotions. Case-based training can be practical, and particular attention should be paid to applying the IGNITE end-of-life communication strategy. More culturally sensitive cases deserve further development to enrich such education and training.

Policymakers may need to reconsider the applicability of protective medical measures in mainland China in this new era and make the necessary adjustments and clarifications to create a policy environment conducive to end-of-life communication. Hospitals may not be able to take full responsibility for end-of-life communication, and there may be value in establishing partnerships with the community. Developing and piloting cross-setting intervention programmes for end-of-life communication holds excellent promise. Moreover, integrated end-of-life communication intervention programs that fully account for patient-family-provider tripartite factors may be worth developing and evaluating as they may contribute to open end-of-life communication. Developing and embedding systems for assessing the quality of end-of-life communication that applies to the local healthcare system can clarify the effectiveness of these interventions.

6.5 Strength and limitation

Our study has several strengths. Firstly, the data came from a large sample of critical stakeholders in end-of-life communication (19 patients, 22 family caregivers and 25 healthcare providers), and data saturation was achieved for each group. Secondly, whilst reporting data from distinct participant groups, such as patients, is plausible, presenting the viewpoints of all three parties concurrently allowed us to make comparisons of experiences and perceptions from multiple perspectives. This might result in a balanced and thoughtful data analysis and a more profound comprehension of and response to the research questions. Thirdly, we adopted several techniques to enhance the trustworthiness of the study findings.

There are also some limitations to this study. Firstly, patients and family caregivers who were unable to express themselves clearly were excluded from the interviews, for example, those who had severe auditory or cognitive impairment. They may have different perspectives and special needs regarding end-of-life communication. Secondly, all the healthcare providers included had at least five years of experience working with patients with advanced illnesses. This study may not represent experiences and

perceptions from providers with less work experience and needs further exploration. Thirdly, the participants were from two hospitals in one city, although the two hospitals receive patients from all over the country. Given the imbalance in end-of-life care resources and development in different cities in China (Lu et al., 2024), the transferability of our findings may be limited. These findings' direct applicability and transferability to other countries and regions, including those with similar cultural backgrounds, may be limited due to the potential influence of local political, legal, and healthcare systems on end-of-life communication. Nevertheless, these findings have implications for promoting effective end-of-life communication in societies with similar cultural backgrounds.

6.6 Conclusion

This qualitative study has attempted to describe end-of-life communication in the Chinese context from practitioners' and service users' experiences and perceptions, and it has also collected their recommendations on improving such communication. Participants have diverse end-of-life communication experiences in hospitals, ranging from protective to open. Multiple individual factors affect end-of-life communication tendencies, and future assessments and interventions regarding these factors may improve end-of-life communication in hospitals. Healthcare providers should avoid stereotypes stemming from ingrained cultural values and take a more active approach to identifying the roles of patients and families. The IGNITE communication strategies can be used in relevant training and selected to enhance the end-of-life communication practice. Furthermore, it is necessary to re-examine and clarify the applicability of protective medical measures and improve the environment of end-of-life communication at the legal and institutional levels. The following chapter outlines the application of these qualitative findings in the training of oncology nurses.

Chapter 7: Development of A Culturally Specific End-of-life CST For Chinese Oncology Nurses

7.1 Introduction

The chapter presents the development of a Chinese culturally specific end-of-life CST program, including the CST development process (Section 7.2), training modules (Section 7.3), and the training protocol (Section 7.4). It describes how the qualitative study findings from the preceding phase (Chapter 6) are integrated into the CST. It addresses the doctoral research **objective #1: To develop an evidence-based Chinese culturally specific end-of-life CST program**. As this training programme was first evaluated among oncology nurses (for reasons explained in Chapter 2, Section 2.3.3 End-of-life CST for nurses), adaptations were made to nurses when applying the qualitative study results. Section 7.5 summarises this chapter.

7.2 The development process

The Chinese culturally specific end-of-life CST was developed based on (1) our previous work of the scoping review of the end-of-life communication strategies (Chen et al., 2023) and the qualitative study findings of end-of-life communication experiences, perceptions, suggestions and strategies from Chinese perspectives; (2) available resources related to end-of-life communication, including a guideline (Clayton, Hancock, Butow, Tattersall, & Currow, 2007), literature (Brown & Bylund, 2008), and textbooks (Boyd & Dare, 2014; Kissane (ed.), 2017; Maureen Nokuthula, 2018; Ragan, 2015); and (3) discussions with an expert advisory group. The experts' characteristics are shown in Table 7.1. All of the experts were experienced in teaching general communication skills.

Table 7.1 Characteristics of experts

	Age (years)	Gender	Educational level	Profession	Professional title	Work experiences (years)
1	42	Male	Doctor	Oncologist	Senior	12
2	47	Female	Master	Oncology nurse	Senior	25
3	45	Female	Master	Oncology nurse	Senior	20
4	36	Female	Master	Palliative care specialist nurse	Medium	10
5	33	Female	Master	Palliative care specialist nurse	Medium	11
6	36	Female	Doctor	Psychotherapist	Medium	8

Following the conceptual framework in this study (Chapter 4, Section 4.4), the author initially developed preliminary training modules and the training protocol based on the materials mentioned above and research findings. Specifically, the seven end-of-life communication strategies that emerged from the scoping review (Chapter 3, Section 3.4) provided a framework for developing training modules. Building on this framework, the authors integrated qualitative research findings that revealed both protective and open end-of-life communication states in the Chinese context, as well as communication strategies recommended by stakeholders (i.e., the IGNITE, Chapter 6, Section 6.3.4.4), resulting in an initial set of six training modules: responding to patients' concerns about diagnosis and prognosis; exploring family preferences for informing patients of their condition and prognosis; organizing family meetings; empathically responding to patients' and family members' emotions; promoting the reconstruction of meaning; and supporting bereaved family members. Subsequently, this draft was sent to members of the expert advisory group for review. The expert consultation group has a two-week period to thoroughly review the training modules and the protocol and provide comprehensive evaluations and recommendations. Two weeks later, the expert advisory group held its first meeting to discuss the content of the six modules, suggesting that communication between nurses and family members be combined into one module to provide nurses with a holistic approach to communicating with patients' families rather than fragmenting progressive communication practices; additionally, the group suggested combining emotional expression and meaning construction into one module because they are interconnected and mutually reinforcing in practice. The author condensed the six modules into four based on the expert's recommendations. The expert advisory group held its second meeting to simulate training on the communication strategies, skills, and process tasks involved in these revised modules and to pilot test the training protocol. It made appropriate modifications, ultimately finalizing the training modules (Table 7.2) and the protocol (Table 7.3). All expert consultation meetings took place in the hospital's conference room.

7.3 The training modules

The training includes four modules: (1) Respond to patient cues, (2) Negotiate with the family, (3) Nurture hope, and (4) Bereavement support. The Comksil model (Brown & Bylund, 2008) was followed to guide the development of five core communication components: goals, strategies, skills, process tasks, and cognitive appraisals.

The first module, responding to patient cues, aims at equipping nurses with the skills necessary for respectfully and empathetically addressing patient cues within their daily interactions (communication goal). The development of this module stems from our qualitative research indicating that it is incumbent upon nurses to actively observe, acknowledge emotions, and address implicit patient cues effectively (Chapter 6, Section 6.3.4.1 *Clarify the responsibilities of hospital-based healthcare providers*). Within China's high-context culture, patients subtly desire to discuss end-of-life matters with trusted and familiar nursing staff (Chapter 6, Section 6.3.2.2 *Open end-of-life communication*; Section 6.3.4.4.2 *Initiate end-of-life communication in a Gradual and Natural manner*). Consequently, nurses must identify and respond to these communication needs. Nine communication strategies have been designed to achieve the communication goal, from identifying patient hints to ending the conversation. Communication skills and process tasks can help nurses implement communication strategies. For example, nurses can use communication skills such as open-ended questions, active listening, checking understanding, clarification, and restating, and process tasks such as ensuring patient privacy, avoiding interruption, and correcting misunderstandings to implement the communication strategy of exploring the patient's potential concerns. In addition, the participants in the qualitative research mentioned the patient's implicit verbal language, such as "You've cared for so many people; is there any hope left?" which serves as essential knowledge points to enhance nurses' cognitive appraisals.

The second module is “Negotiate with the family”. The communication goal of this module is to discuss the patient's diagnosis and prognosis with the family, including promoting understanding and addressing concerns. This module concerned protective end-of-life communication in the Chinese context (Chapter 6, Section 6.3.2.1 *Protective end-of-life communication*). Patients, family caregivers and healthcare providers suggested that the negotiation process can be facilitated by identifying the primary communicator and preparing the family (Chapter 6, Section 6.3.4.4.1 *Identify the primary communicator(s) and prepare the family if necessary*). Eight communication strategies are available for nurses to choose to achieve the communication goal, including adapting the negotiation agenda to meet the family's needs, exploring the family's concerns about disclosure, acknowledging cultural taboos about discussing death, etc. The five sub-strategies included in Strategy 4 to address family concerns are based on stakeholders' recommendations from qualitative research (Chapter 6, Section 6.3.4.4.1 *Identify the primary communicator(s) and prepare the family if necessary*). As with Module 1, the available communication skills and process tasks related to achieving the corresponding communication strategies are listed in Module 2. Timing and environment (Chapter 6, Section 6.3.4.4.5 *Timing and Environment*) and the family's burden (Chapter 6, Section 6.3.2.4 *Family factors affecting the end-of-life communication*) that may affect end-of-life communication, among other essential knowledge points, can promote the nurses' cognitive appraisal process.

Module 3's communication goal is “to nurture hope in realistic expectations in a way that encourages emotional expression and reconstructs a sense of meaning”. This module was established because patients and family members often have unrealistic expectations, such as a desire for a cure, which requires healthcare professionals, including nurses, to balance unrealistic expectations with available practical support. This module integrates stakeholders' strategies for navigating realistic expectations (Chapter 6, Section 6.3.4.4.3 *Navigate realistic expectations*) and inner healing (Chapter 6, Section 6.3.4.4.4 *Inner healing with emotional support and meaning*

reconstruction) to achieve this goal. It is worth noting that these strategies suggested by stakeholders are not fully incorporated because activities such as explaining detailed disease progression and potential outcomes to patients may not be within a nurse's role, so the seven strategies included in module 3 have been appropriately adjusted to match the communication role of nurses in their work, including educating and guiding patients and families to implement the Four Principles of Life (expressing gratitude, forgiveness, love and saying goodbye) (Chao, 2015; Hsu, 2019). The skills, process tasks, and cognitive appraisals corresponding to these strategies are also included in the module.

Module 4 focuses on providing support to bereaved families. The module was developed based on nurses' role and training needs in end-of-life communication as identified in the literature review and the qualitative study (Chapter 6, Section 6.3.4.1 *Clarify the responsibilities of hospital-based healthcare providers*). It also incorporated guidance from academic resources on providing support during the grieving process (Kissane (ed.), 2017; Ragan, 2015). Strategy 6, "Review the family efforts and help focus on the positive impact, " continues the family involvement strategy introduced in Module 3. Eight strategies were incorporated to achieve the communication goal. Communication skills, process tasks, and cognitive appraisals support nurses in implementing these strategies.

Table 7.2 Modules of Chinese culturally specific end-of-life CST for nurses

<p>● Module 1: RESPOND TO PATIENT CUES</p> <p>Communication goal: To respond to patient cues related to end-of-life topics in daily interactions in a way that demonstrates respect, empathy, perception and exploration.</p>			
Communication strategies	Communication skills	Process tasks	Cognitive appraisals
1. Recognize the cues based on the understanding of the patient's information and situation	/	<ul style="list-style-type: none"> ● Careful observation ● Use eye contact ● Use appropriate body language, such as an open posture ● Understand the patient's cues ● Make time, or at least tell the patient what time is available 	<ul style="list-style-type: none"> ● Be prepared (through checking medical records, team reflection and communication, etc.) when caring for a patient with a poor prognosis ● Patient cues related to end-of-life topics include suggestive or tentative expressions such as expressing concerns about sleep problems and the fear of not waking up, asking questions like "You've cared for so many people; is there any hope left?" or inquiring about their remaining time ● Patient cues convey trust in nurses
2. Acknowledge the patient's willingness to express and appreciate the trust	<ul style="list-style-type: none"> ● Express feelings ● Express gratitude ● Express a willingness to help 	<ul style="list-style-type: none"> ● Seek permission before proceeding if the family is present ● Understand non-verbal language (e.g., facial expressions the family doesn't want to talk) 	
3. Explore underlying concerns	<ul style="list-style-type: none"> ● Ask open questions ● Active listening ● Check understanding ● Clarify 	<ul style="list-style-type: none"> ● Use appropriate body language, such as sitting close to the patient (at eye level) 	

	<ul style="list-style-type: none"> ● Restate 	<ul style="list-style-type: none"> ● Ensure the patient's privacy ● Avoid interruptions ● Make notes if necessary ● Correct any misunderstandings 	<ul style="list-style-type: none"> ● Patient perceived burden (e.g., economic, symptom, or emotional) may trigger these cues ● Patient misconceptions about diagnosis, prognosis, and treatment can cause unnecessary concerns ● Patient often have more than one concern, or more than just the verbal one ● Barriers from the family and misconceptions about advance care planning may impede the communication process ● Facilitate the communication process gradually and naturally
4. Normalize discussions about death and dying	<ul style="list-style-type: none"> ● Validate ● Normalize ● Express a willingness to help 	<ul style="list-style-type: none"> ● Avoid making the patient think that discussing death and dying is a taboo ● Use examples or stories to explain the benefits of discussions of death and dying 	
5. Elicit the patient's thoughts, preferences and wishes hypothetically	<ul style="list-style-type: none"> ● Hypothetical questions ● Encourage expression of thoughts and feelings ● Clarify ● Restate ● Make a "take stock" statement 	<ul style="list-style-type: none"> ● Allow time to process ● Make notes if necessary 	
6. Respond to emotional reactions with empathy	<ul style="list-style-type: none"> ● Empathize ● Validate ● Acknowledge ● Normalize ● Simplify ● Praise the patient's efforts 	<ul style="list-style-type: none"> ● Maintain eye contact ● Allow time to integrate ● Offer tissues 	

	<ul style="list-style-type: none"> ● Express a willingness to help ● Encourage the expression of feelings 		
7. Check previous discussions between the patient and family about these topics	<ul style="list-style-type: none"> ● Review previous discussions, if any ● Active listening ● Clarify ● Restate ● Summarize 	<ul style="list-style-type: none"> ● Allow time to recall ● Make notes if necessary ● Understand the family end-of-life communication 	
8. Introduce advance care planning	<ul style="list-style-type: none"> ● Information giving ● Offer the choice ● Check understanding ● Invite questions 	<ul style="list-style-type: none"> ● Use simple language and avoid technical terms ● Use available documents, educational materials, or explanatory videos to explain advance care planning ● Address all questions ● Allow the patient not to discuss, and provide opportunities for addressing these topics at a later time ● Prepare the patient for the next communication about advance care planning if the patient is interested 	

		<ul style="list-style-type: none"> ● Invite family members/ significant others/ physician/ other healthcare providers with informed consent of the patient 	
9. Make a closure	<ul style="list-style-type: none"> ● Check understanding ● Invite questions ● Endorse question asking ● Reinforce joint decision-making ● Summarize ● Review next steps 	/	
<ul style="list-style-type: none"> ● Module 2: NEGOTIATE WITH THE FAMILY <p>Communication goal: To negotiate with the family about the disclosure of diagnosis and prognosis to patients, including fostering understanding and addressing concerns.</p>			
Communication strategies	Communication skills	Process tasks	Cognitive appraisals
1. Tailor the negotiation to the family's needs	<ul style="list-style-type: none"> ● Declare your agenda items ● Invite family agenda items ● Negotiate agenda 	<ul style="list-style-type: none"> ● Ensure a quiet and privacy environment ● Greet appropriately ● Make introductions ● Sit at eye level ● Check the family's understanding of the patient's prognosis and their family plans 	<ul style="list-style-type: none"> ● Timing/ Opportunity: When family members approached medical staff with a request to keep the patient's condition confidential ● The family may withhold the truth due to their perception of the patient's personality, their emotional connection to

		<ul style="list-style-type: none"> ● Explore the family preferences concerning the disclosure of diagnosis and prognosis to patients ● Avoid the bias that all families prefer to non-disclosure 	<p>the patient, or as a form of self-protection</p> <ul style="list-style-type: none"> ● Misunderstandings about the impact of the disclosure; a lack of knowledge of the disclosure process; persistent concerns or disagreements may impede the communication process ● Family's burdens (e.g., caregiving, emotional, and decisional) may trigger their desire for open end-of-life communication ● The family may have preferences about the disclosure process (e.g., preferred providers and approaches, whether they want to participate in the disclosure)
2. Explore the family's concerns about the disclosure	<ul style="list-style-type: none"> ● Ask open questions ● Encourage the expression of feelings ● Active listening ● Invite questions ● Endorse question asking ● Clarify ● Restate 	<ul style="list-style-type: none"> ● Allow time to process ● Avoid interruptions ● Make notes if necessary 	
3. Check previous family communication around end-of-life topics; acknowledge the cultural taboo if appropriate	<ul style="list-style-type: none"> ● Review previous discussions, if any ● Active listening ● Acknowledge ● Normalize 	<ul style="list-style-type: none"> ● Allow time to recall ● Make notes if necessary ● Understand the family end-of-life communication 	
4. Respond to the family's concerns <ul style="list-style-type: none"> ● Explore the underlying reasons for the family's reluctance to disclose the 	<ul style="list-style-type: none"> ● Ask open questions ● Empathize ● Validate ● Acknowledge ● Normalize 	<ul style="list-style-type: none"> ● Understand the underlying reasons for the family's reluctance to disclose the truth ● Use examples or stories to 	

<p>truth</p> <ul style="list-style-type: none"> ● Discuss with the family about potentially concealing information from the patient while highlighting the challenges associated with doing so ● Guide the family to empathize with the patient's perspective ● Discuss with the family the potential consequences or outcomes of withholding information from patients while emphasizing the negative impacts ● Indicate the responsibilities of surrogate decision-makers, highlight discrepancies between familial preferences and those of patients themselves, and the importance of understanding patients' wishes 	<ul style="list-style-type: none"> ● Information giving ● Analyze ● Invite questions ● Endorse question asking ● Summarize 	<p>explain the risks of concealment</p> <ul style="list-style-type: none"> ● Use survey data to explain differences in end-of-life preferences between patients and their families ● Correct misunderstandings ● Address all questions 	
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5. Propose a plan if there are persistent concerns or disagreements among family members	<ul style="list-style-type: none">● Information giving● Invite questions● Negotiate agenda	<ul style="list-style-type: none">● Acquire further input from specialists● Prepare for the next steps (e.g., ask who should be involved in the family meeting and invite them)	
6. Propose a plan for the disclosure	<ul style="list-style-type: none">● Information giving● Invite questions● Negotiate agenda	<ul style="list-style-type: none">● Use examples or stories to describe the disclosure process● Prepare for next steps● Allow time for consideration and leave open for further communication	
7. Tailor the disclosure to the family’s needs	<ul style="list-style-type: none">● Check understanding● Invite questions	<ul style="list-style-type: none">● Address all questions● Repeat	
8. Make a closure	<ul style="list-style-type: none">● Check understanding● Invite questions● Endorse question asking● Reinforce joint decision-making● Summarize● Review next steps	/	

Module 3: **NURTURE HOPE**

Communication goal: To nurture hope in realistic expectations in a way that encourages emotional expression and reconstructs a sense of meaning.

Communication strategies	Communication skills	Process tasks	Cognitive appraisals
1. Review physician's discussion	<ul style="list-style-type: none"> ● Check understanding ● Explain in plain language ● Acknowledge the (unrealistic) expectations ● Reinforce the efforts of both sides 	<ul style="list-style-type: none"> ● Greet patient appropriately ● Make introduction ● Sit at eye level ● Ensure a quiet and privacy environment 	<ul style="list-style-type: none"> ● Discussions with doctors (diagnosis, prognosis and goals of care discussions) may lead to new concerns and needs for patients and families; the progress that has been made and the positive aspects of communication can be easily overlooked ● Cues: the need of a sense of ongoing support; the family's wish of participating in the patient's end-of-life care; patients may lose interest in everyday life ● Encourage rather than discourage or suppress emotional expression; these expressions can be indirect or non-verbal ● Respect and be sensitive to the patient's/ family's ways
2. Explore the patient/family's thoughts and needs	<ul style="list-style-type: none"> ● Ask open questions ● Active listening ● Encourage the expression of feelings ● Invite questions 	<ul style="list-style-type: none"> ● Seek realistic expectations ● Follow up on the physician's discussion (what has already been discussed and reactions) ● Invite a third party if necessary (e.g., psychologist and social worker) 	
3. Respond to emotional reactions with empathy	<ul style="list-style-type: none"> ● Empathize ● Validate ● Acknowledge ● Normalize ● Simplify ● Praise the efforts ● Express a willingness to help ● Encourage the expression of feelings 	<ul style="list-style-type: none"> ● Maintain eye contact ● Show compassion by using a warm, caring, and respectful manner ● Allow time to integrate ● Offer tissues 	
4. Analyze the progress and	<ul style="list-style-type: none"> ● Analyze 	<ul style="list-style-type: none"> ● Maintain eye contact 	

emphasize the positive aspects of the previous discussion	<ul style="list-style-type: none"> ● Summarize ● Praise the efforts ● Encourage optimism 	<ul style="list-style-type: none"> ● Allow time to integrate 	<p>of coping</p> <ul style="list-style-type: none"> ● The patient and family may have varying degrees of hope and that they may simultaneously accept the terminal nature of the disease and hope for a cure.
5. Emphasize what can be done and reassure available ongoing support, if it is possible; otherwise, make reliable alternative arrangements	<ul style="list-style-type: none"> ● Use metaphor to explain palliative care ● Reinforce joint decision-making ● Make partnership statements 	<ul style="list-style-type: none"> ● Avoid over-assurance ● Avoid making the patient feel abandoned ● Facilitate realistic goals and reframe the patient's and family's expectations 	
6. Discuss and facilitate day-to-day coping	<ul style="list-style-type: none"> ● Information giving ● Identify areas where control can be fostered (e.g., advance care planning, tidying up unfinished business, focusing on important relationships, involving the family in end-of-life care for patients, etc.) 	<ul style="list-style-type: none"> ● Use examples, stories or educational materials to provide information ● Use simple language and avoid technical terms ● Understand the patient's and the family's coping style ● Make appropriate environmental modifications to accommodate the patient's preference 	
7. Follow-ups (e.g., provide opportunities for emotional exchanges between the patient and the family/ significant others; introduce Four Principles of Life)	<ul style="list-style-type: none"> ● Encourage the expression of feelings ● Praise the diverse ways of the expression of emotion 	<ul style="list-style-type: none"> ● Careful observation ● Arrange activities like memorial days and life reviews with family involvement 	

		<ul style="list-style-type: none"> ● Document significant moments (e.g., photographs, videos, and other mementoes) 	
Module 4: BEREAVEMENT SUPPORT Communication goal: To support bereaved families, including presence and sharing useful information about grief coping.			
Communication strategies	Communication skills	Process tasks	Cognitive appraisals
1. Tailor the support to the family's needs	<ul style="list-style-type: none"> ● Express a willingness to help ● Ask permission for the accompanying 	<ul style="list-style-type: none"> ● Greet the family appropriately ● Make introduction ● Ensure a quiet and privacy environment 	<ul style="list-style-type: none"> ● Everyone reacts differently to grief, which contributes to the difference in communication strategies selection ● Cues of the need for bereavement support: the family may feel guilt and blame ● Encourage rather than discourage or suppress emotional expression; these expressions can be indirect or non-verbal
2. Express grief appropriately	<ul style="list-style-type: none"> ● Express feelings 	<ul style="list-style-type: none"> ● Maintain eye contact ● Show compassion by using a warm, caring, and respectful manner ● Respect and cooperate with the family's beliefs (e.g., pray or chant) 	
3. Elicit descriptions of personal experience of loss	<ul style="list-style-type: none"> ● Encourage the expression of feelings ● Active listening 	<ul style="list-style-type: none"> ● Careful observation ● Listen carefully for any metaphors used by the family and explore the meaning 	
4. Respond to emotional	<ul style="list-style-type: none"> ● Empathize 	<ul style="list-style-type: none"> ● Maintain eye contact 	

reactions with empathy	<ul style="list-style-type: none"> ● Validate ● Acknowledge ● Normalize ● Encourage the expression of feelings 	<ul style="list-style-type: none"> ● Show compassion by using a warm, caring, and respectful manner ● Allow time to integrate ● Offer tissues 	
5. Assist the family in relaxing	<ul style="list-style-type: none"> ● Demonstrate 	<ul style="list-style-type: none"> ● Avoid interruptions ● Allow time to process 	
6. Review the family efforts and help focus on the positive impact	<ul style="list-style-type: none"> ● Review ● Praise the efforts 	<ul style="list-style-type: none"> ● Review the documentation of significant moments if appropriate 	
7. Normalize through education by explaining the normal range of grief experiences	<ul style="list-style-type: none"> ● Normalize (emphasize that others experience similar symptoms) ● Information giving ● Acknowledge that although it doesn't feel normal, grief is normal ● Invite questions 	<ul style="list-style-type: none"> ● Use simple language and avoid technical terms ● Invite an appropriate third-party ● Address all questions 	
8. Provide useful information for ongoing support and make a closure	<ul style="list-style-type: none"> ● Information giving ● Check understanding ● Summarize 	<ul style="list-style-type: none"> ● Provide information in a medium that can be reviewed repeatedly if possible ● Facilitate access to professional and community resources if necessary 	

7.4 The training protocol

The overall training protocol is presented in Table 7.3. This is an eight-week, eight-session training. The total number of hours of training was 12 hours. The training consists of four modules. Each module was completed in 2 sessions: (1) a lecture (30 minutes, except the first lecture was 45 minutes as it contained an overview of the training), a video demonstration (60 minutes) and self-study materials (30 minutes), and (2) a role-play simulation (60 minutes).

The lectures and video demonstrations were intensive training for each group of 30 – 40 nurses. To accommodate participants' busy schedules in clinical practice and enhance engagement, two time slots were offered during the week for them to choose from. The lectures encompass knowledge pertinent to the module's content. Standardised patient (SP) cases were also developed for role plays and outcome evaluation. The research team produced four video clips based on each module's communication components (a sample video introduction is shown in Appendix 6) and employed them for case studies and demonstrations. The four video clips utilised a case study of a male gastric cancer patient's disease trajectory, encompassing the nurse's adept response to the patient's cues, the consultation with the family about the disclosure of the diagnosis and prognosis to the patient, the nurse's supportive communication following discussions about discontinuing chemotherapy by the doctor, and finally, highlighting how the nurse supports the patient's suffering wife after the patient death. Before viewing the video, the trainers reviewed the case background and facilitated group discussions and reflections on general clinical practices relevant to the case. They examined the communication components within the module. Following the participants' video viewing, two trainers provided demonstrations and coordinated group practice sessions within self-organized teams. Additionally, participants were furnished with self-study materials pertaining to module content. Lectures and video demonstrations were scheduled in the same session during the first week of each

module.

The following week, participants were randomly assigned to groups of 3 – 4 nurses for role-playing arrangements, with necessary adjustments for schedule conflicts. Each group engaged in role-play activities with specific cases and subsequently performed role-exchange exercises, after which they received immediate feedback from the same group of observers and the trainers. The training was jointly conducted by the author (a PhD candidate with six years of part-time experience in education and training) and an oncology nurse with 20 years of experience in cancer care and nursing education. Both trainers had received training in communication skills. They did not have any relationship with the nurse participants before the study. The facilitators remain the same across all sessions.

Table 7.3 Chinese culturally specific end-of-life CST protocol

Week/session	Training contents	Training methods	Time allocation
1	<ul style="list-style-type: none"> ● Training overview ● Content and purpose of end-of-life communication ● Overview of clinical cases related to end-of-life communication ● Responsible healthcare providers in end-of-life communication and nurses' roles ● Timing and environment of end-of-life communication ● Implementation status and challenges of end-of-life communication in Chinese hospitals ● Module 1: RESPOND TO PATIENT CUES <ul style="list-style-type: none"> ● Case background ● Group discussion and reflection on death taboos and common clinical practices ● Overview of communication strategies and skills ● Watch a video vignette of a nurse-patient interaction on the patient query "How long have I got?"; and review the communication strategies and skills ● Demonstration and free group practice ● References and suggested reading <ul style="list-style-type: none"> ● Generic communication skills - empathic communication skill ● Reading materials about advance care planning ● A clinical story of nurse-patient rapport 	Lecture Case study Group discussion and reflection Video demonstration Demonstration Role-play Self-study	45 mins 60 mins 30 mins

	<ul style="list-style-type: none"> ● Anticipatory grief ● Noncomplicated bereavement ● Psycho-education and emotional support needs ● Self-care in end-of-life communication 		
	<ul style="list-style-type: none"> ● Module 4: BEREAVEMENT SUPPORT 	Case study	60 mins
	<ul style="list-style-type: none"> <ul style="list-style-type: none"> ● Case background ● Group discussion and reflection on loss and grief history and common clinical practices ● Overview of communication strategies and skills ● Watch a video vignette of a nurse's support for a bereaved family member; and review the communication strategies and skills ● Demonstration and free group practice 	Group discussion and reflection Video demonstration Demonstration Role-play	
	<ul style="list-style-type: none"> ● References and suggested reading 	Self-study	30 mins
	<ul style="list-style-type: none"> <ul style="list-style-type: none"> ● Reading and audio-visual materials about self-care ● Non-verbal communication ● Anticipatory grief and bereavement assessment and care plan ● A clinical story of ongoing support during bereavement 		
8	<ul style="list-style-type: none"> ● Module 4: Bereavement support (Simulation) 	Role-play	60 mins
	<ul style="list-style-type: none"> <ul style="list-style-type: none"> ● 3 trainees per group (a family caregiver, a nurse and an observer) ● Role-play; switch roles ● Feedback 		

7.5 Chapter summary

Overall, this chapter describes the development process and the content of the Chinese culturally specific end-of-life CST. The training appropriately considers Chinese cultural specificities and is linked to our previous research findings. The chapter also provides a detailed training protocol. The next chapter will evaluate the effectiveness of this training programme among Chinese oncology nurses.

Chapter 8: Effects of A Culturally Specific End-of-life CST For Chinese Oncology Nurses: A RCT

8.1 Introduction

The chapter presents a detailed evaluation of the RCT of the culturally specific end-of-life CST for Chinese oncology nurses. The study methods described in Section 8.2 include study design, settings, participants, procedure, intervention (more details in Chapter 7), data collection, contamination handling, and data analysis. The study results, including participants' characteristics and baseline comparison, effects on primary (skills) and secondary (self-efficacy and outcome expectancies) outcomes, post-hoc analysis results of contamination, and process evaluation, are presented in Section 8.3. They address the doctoral research **objective #2: To evaluate the effectiveness of the CST program among oncology nurses regarding communication skills, self-efficacy and outcome expectancy beliefs**, and **objective #3: To explore participants' acceptability, satisfaction, experiences and suggestions for the training program**. Section 8.4 presents a discussion of the study results. The strengths and limitations of the study and the implications for practice, education, policy and research are discussed in Sections 8.5 and 8.6, respectively. Section 8.7 concludes the chapter.

8.2 Methods

8.2.1 Study design

This is a RCT with a process evaluation. The trial has been registered at ClinicalTrials.gov (NCT05888480). This study follows the Consolidated Standards of Reporting Trials (CONSORT) statement (Schulz et al., 2010) and the Reporting Checklist for Training Interventions (Brighton et al., 2017).

8.2.2 Setting and participants

Eligible nurses were recruited from two tertiary hospitals in Hangzhou, China. Registered nurses who work with advanced cancer patients in hospital settings and

consent to participate in the study were included. Nurses working temporarily in the two hospitals as scholars or trainees from other hospitals and specialised nurses in palliative care were excluded.

Sample size calculation was performed by G*power 3.1.9.2 (Faul et al., 2007). A similar study (Harnischfeger et al., 2020) reported a moderate effect (Cohen's d value = 0.5) (Cohen, 1992) on communication skills and self-efficacy. Given medium effect size $d = 0.5$, in a two-tailed test with a power of 0.8 at a significance level of $p < 0.05$, the total sample size was 128, 64 per group. Considering an estimated dropout rate of 15%, recruiting 148 nurses, 74 per group, was necessary.

The two hospitals were large public hospitals (one cancer hospital and one general hospital), and they could provide sufficient registered nurse participants (around 500 and 80 oncology nurses in each hospital). The training schedule was negotiated with the Directors of the Nursing department of the participating hospitals to encourage participation. Besides, a training completion certificate (see Appendix 7) and two credits were offered. Recruitment posters (see Appendix 5) featuring comprehensive training information were displayed on the hospital notice board and distributed to relevant departments. The training was carried out in teaching rooms at the hospital.

8.2.3 Procedure

Recruitment was conducted from October to December 2023. The author approached the participants and screened them for eligibility at the study sites. One team member who did not interact with study subjects before subject recruitment began constructed a sequence of the group identities based on computer-generated random codes using 1:1 allocation and placed them in serially numbered opaque sealed envelopes. The author randomly assigned the participants to either the intervention group (IG) or the waitlist control group (CG) at the study location by opening a serially numbered opaque sealed envelope. The IG received the 8-week end-of-life CST between time point 0 (T0, baseline) and time point 1 (T1, immediately after the training) from January to February

2024. After the end of data collection (time point 2, T2, one month after IG completed the training), the CG received the same training between April and May 2024. The waiting period was 12 weeks.

One research assistant who collected data on the trial outcomes and three external observers in the simulation evaluation were unaware of the participant's group allocation, i.e., they were blinded to it (Page & Persch, 2013). Figure 8.1 shows the training procedure.

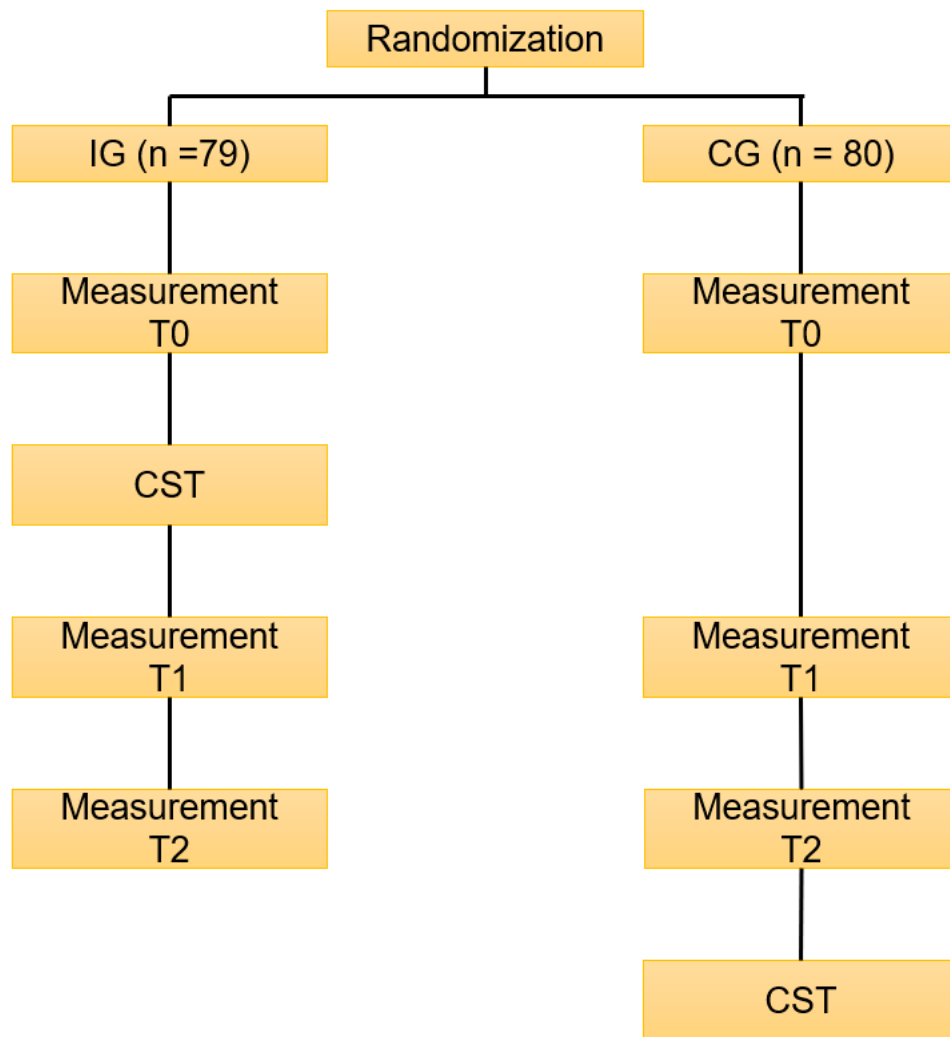


Figure 8.1 The study procedure

8.2.4 Intervention

Four modules were developed based on available literature, findings from our scoping review and qualitative study, and expert meetings. These modules were delivered in eight weeks. Lectures, video demonstrations and role-play simulations were adopted in the CST. Details of the intervention has been described in chapter 7.

8.2.5 Data collection

Data collection was conducted for both groups before (T0), immediately after (T1) and one month after the IG received the intervention (T2). Assessment at the three time points includes a simulation assessment with SPs and self-report questionnaires. Cases and actor scripts related to the training modules were used in the simulation assessment. Two experienced actors were trained to play the roles (the patient and the family) in these cases. The nurse participants were randomly given a case file and communicated with the SPs. Three oncology nurses were invited and trained as observers at each simulation assessment to assess the nurse participants' communication performance using a study-specific assessment checklist (Appendix 8). They were registered nurses from other hospitals (not from the two study sites) and had no relationship with the nurse participants prior to the study. Each simulation evaluation was completed in about 40 minutes.

Table 8.1 shows an overview of measurements. These questionnaires can be found in Appendix 8 – 11. Demographic characteristics of participants were also collected before the training using self-developed questionnaires (Appendix 12).

Table 8.1 Summary of measurements

Outcomes		Instruments	Measurement time point			Source of data	Items and scales
Primary outcomes	Secondary outcomes		Baseline/Pre-training (T0)	Post-training (T1)	One-month post-training (T2)		
Skills		● Nurses' Clinic Communication Competency Scale	√	√	√	Nurse self-report	52 items (Likert scale 1-5) ● Basic verbal communication competency (11 items) ● Basic non-verbal communication competency (7 items) ● Emotional perception competency (9 items) ● Emotional support competency (6 items) ● Communication competency in the difficult clinical situation (19 items)
		● Observer checklist	√	√	√	External assessment by observers	216 items ● Module 1 ● Module 2 ● Module 3 ● Module 4
	Self-efficacy	● Hospice Care Self-efficacy	√	√	√	Nurse self-report	12 items (Likert scale 1-5) ● Mental and spiritual care of

		Scale on Nurses					<ul style="list-style-type: none"> ● dying patients (7 items) ● Family care (5 items)
Outcome expectancy beliefs	●	Communication Outcomes Questionnaire (COQ)	√	√	√	Nurse self-report	23 items (Likert scale 1-9) <ul style="list-style-type: none"> ● Positive outcome ● Negative outcome

8.2.5.1 Primary outcomes

Both external and self-assessed instruments were adopted for primary outcomes – skills. Nurses' Clinic Communication Skill Scale (Appendix 9) is a 58-item self-reported scale which measures six dimensions: team communication skills, basic verbal communication skills, basic non-verbal communication skills, emotional perception skills, emotional support skills, and communication skills in difficult clinical situations. Six items on team communication were excluded because they were irrelevant to this training; therefore, 52 items were used. A 5-point Likert scale is used from (1) very poor to (5) very good. The scale has been validated in Chinese nurses and reported good reliability (Cronbach's alpha = 0.978) (Zeng, 2010).

The study-specific observer checklist (Appendix 8) was developed based on the training modules and applied as an external assessment tool in simulation assessments. The checklist assesses nurses' performance in four aspects of simulated communication assessment: achievement of communication goals, application of communication strategies, skills, and process tasks. The trained observers appropriately marked any recognised or observed list item. Each identified item is assigned a score of 1 point, which is then added to calculate the individual module scores and the overall total score. Higher scores indicate better communication performance. The mean scores of the three observers were utilised for statistical analysis.

8.2.5.2 Secondary outcomes

Self-efficacy was assessed using the Hospice Care Self-efficacy Scale on Nurses (Chen, 2012; Wu, 2004) (Appendix 10). It measures the confidence level in dying patients' physical, mental and spiritual care and family care. The physical part of the scale was excluded because its content is irrelevant to communication, so 12 items were used. The rating adopts a 5-point Likert scale from (1) very diffident to (5) very confident. The instrument has proved valid and reliable in Chinese oncology nurses (Cronbach's alpha = 0.969) (Huang, 2021).

Outcome expectancy beliefs were measured using the Communication Outcomes Questionnaire (COQ) (Appendix 11), a 23-item self-report questionnaire (Parle et al., 1997). A 9-point Likert scale from 1 = very likely and 9 = very unlikely allows nurses to assess the likelihood that a number of potential outcomes may occur when interacting with cancer patients. The reverse scoring is required for six items. A higher overall score indicates a greater expectancy for positive communication (Baile et al., 1997). The scale's reliability (Cronbach's alpha = 0.97) was reported in a previous study (Liu et al., 2007).

8.2.5.3 Process evaluation

A process evaluation was embedded to examine the overall process of the CST, explore participants' views of the training, and provide helpful information for future research. Participant retention, program attendance and adherence were reported to assess the program's acceptability. Participants who had attended at least six sessions of 8 sessions (i.e., the attendance rate was equal to or greater than 75%) were recorded as adhering to the training. After completing week eight of training, all participants in the IG were cordially invited to assess their satisfaction with five critical aspects of the training program, namely training structure (e.g., duration), content, methods, work relevance, and overall satisfaction. This evaluation used the self-reported questionnaire with visual analogue scales ranging from 0 to 10 (see Appendix 13). The higher the scores indicate the greater the level of satisfaction. Focus group discussions were conducted to explore participants' experience of the training program and suggestions for future training. Members of the focus groups were selected from the IG using the convenient sampling method. Three to six focus groups, 4 to 8 participants each, were considered to be carried out by the researcher using a semi-structured interview guide (Appendix 14) within one month after receiving the training. The data collection was conducted in Mandarin with audio-taped and ended until the data saturation.

Following the Reporting Checklist for Training Interventions (Brighton et al., 2017), adverse events (for example, dropouts due to emotional or sensitive content in the

training) and training costs were also reported.

8.2.6 Contamination

Contamination refers to individuals in the control arm being exposed to the intervention or treatment intended for the trial arm, which causes bias and reduces power (Magill et al., 2019). Trials of educational interventions are particularly susceptible to contamination as the essential components might be portable and challenging to contain (Keogh-Brown et al., 2007). Contamination may occur if some training content is passed on to and learned by the control group, either by disseminating the training materials or through communication between nurses in different groups. The most popular method of handling contamination in design was cluster randomization. However, cluster randomization to prevent contamination and the magnitude of the treatment effect estimate did not appear to be related (Magill et al., 2019). Moreover, cluster randomization can also introduce unpredictable sources of bias, which needs to be carefully weighed in terms of the benefits and potential drawbacks (Hemming & Taljaard, 2023).

Individual randomisation is appropriate over cluster randomisation for the current study as all control participants will equally receive the training after data collection, and communication skills take time to acquire and change (time-dependent contamination) (Keogh-Brown et al., 2007). Moreover, a cluster randomised trial generally needs a larger sample size and greater financial resources (Hemming et al., 2021), which is challenging in a PhD project. Some measures were taken to avoid contamination. Firstly, nurses were requested not to discuss the training with colleagues and keep the training materials only by themselves until the end of the study (Keogh-Brown et al., 2007). Secondly, specific free-text boxes in the questionnaire were added to assess contamination at T1 (immediately after the training of IG) and T2 (one month after the training of IG). Control group participants who reported they had read another participant's training material or had discussed the training contents with other participants were recorded as contaminated. Thirdly, these contaminated data were post

hoc analysed separately (L. Chen et al., 2021; Lidington et al., 2020).

8.2.7 Data analysis

8.2.7.1 Data entry and cleaning

All the questionnaires were coded and entered into the IBM SPSS Statistics for Windows, Version 25.0 software (IBM Corp., Armonk, NY, USA) by the author and double-checked by a research assistant. A third team member checked the whole dataset to ensure the accuracy of the inputs, and no discrepancies were found between the dataset and the original questionnaires. The Z-score method, a statistical technique that quantifies the number of standard deviations a given data point is from the mean, was utilized to detect potential outliers (Shiffler, 1988). The Z-score is a robust indicator for outliers, with a threshold of 3 or higher, signifying that the data point lies beyond the range of approximately 99.7% of the dataset. Consequently, the likelihood of encountering a Z-score exceeding three or dropping below -3 is exceedingly rare, approximately 0.3% (Mowbray et al., 2018). A new variable is formulated using the "Z-score = (variable – mean) / standard deviation" formula. In cases where potential outliers were detected, we conducted a meticulous manual cross-checking of the input data against the raw data sources, correcting any errors identified during data entry. These comprehensive steps identified and corrected less than 1% of the data as outliers, thereby enhancing the dataset's reliability and integrity.

8.2.7.2 Missing data management

Upon receipt of the questionnaires from participants, meticulous scrutiny was conducted by the data collector research assistant to avert any omissions in the data. The "Missing Value Analysis" feature in SPSS was utilized to ascertain and quantify missing data. The Little's Missing Completely at Random (MCAR) test (Little, 1988), a multivariate chi-square test, was then applied to determine if the missing data correlated with any observable or unobservable variables. Should the missing data meet the assumptions of the Generalized Estimating Equations (GEE) model—implying that the missingness is either random or unrelated to the independent variables, as indicated by a non-significant MCAR test result—the missing data would be imputed within the

GEE model itself, eschewing alternative imputation methods like group means or last observation carried forward. Conversely, if the MCAR test yields a significant result, the missing data would first be imputed using multiple imputation techniques before GEE analysis (Little & Rubin, 2020). In this particular study, the data was categorized into three types: demographic data, outcomes data (skill, self-efficacy, and outcome expectancy belief), and participants' self-reported satisfaction levels. Notably, there were no missing entries in the demographic data. All variables underwent Little's MCAR test and returned non-significant results: self-reported skills ($\chi^2 = 18.78$, $df = 25$, $p = .808$); observer-assessed skills ($\chi^2 = 11.37$, $df = 12$, $p = .498$); self-efficacy ($\chi^2 = .35$, $df = 2$, $p = .840$); outcome expectancy belief ($\chi^2 = 3.89$, $df = 3$, $p = .274$); and satisfaction ($\chi^2 = 14.18$, $df = 12$, $p = .290$). These outcomes suggest that the dataset's missing data mechanism was entirely random. Consequently, the missing data were estimated using the GEE model without additional imputation methods in preparation for the Intention to Treat (ITT) analysis (Little & Rubin, 2020). The study employed the ITT analysis to evaluate the effects of the program. The ITT principle ensures that all participants, once enrolled and randomly assigned to treatment groups, are included in the data analysis, regardless of dropouts. This approach helps maintain unbiased comparisons among groups and mitigates the influence of crossover and dropout effects that could undermine the study's randomized treatment assignments (Gupta, 2011).

8.2.7.3 Data analysis for quantitative data

Descriptive statistics were used to analyze the baseline characteristics of the study participants and the outcomes of interest. For continuous data, such as the outcomes of interest, mean (M) and standard deviation (SD) were reported. For nominal data, such as participants' gender and education level, frequency and percentage were presented. The homogeneity of the two study groups was examined by comparing the participants' characteristics and baseline scores using appropriate statistical tests. For continuous variables, independent sample *t*-tests or Mann-Whitney *U* tests were used, and for categorical variables, Chi-square tests or Fisher's exact tests were conducted. This homogeneity assessment also helped identify any potential covariates - continuous

control variables that could affect the study outcomes, even though they were not manipulated. The aim was to make statistical adjustments to account for the effects of the identified covariates. If significant differences were found between the two groups at baseline, the identification of covariates would be based on the strength of the association between the demographic and the outcome variables (Portney & Watkins, 2014). The threshold for statistical significance was set at $p < .05$ for all tests conducted, adopting a two-tailed approach. Kolmogorov-Smirnov (KS) test was used to check the normality of distribution.

GEE was performed to examine the study outcomes between the IG and CG across the three time points (T0, T1, and T2). GEE relaxes the assumptions of normality, which was beneficial because some of the outcome data were not normally distributed (Wu et al., 2001). GEE is also robust to missing values (Molenberghs et al., 2014). When participants drop out of a study, leading to missing data, GEE can still provide consistent estimates as long as the missing data are MCAR. In this study, the missing values were MCAR, as mentioned above (Section 8.2.7.2 Missing data management). Traditional repeated measures analysis, such as repeated measures ANOVA, would have excluded the dropout participants entirely, leading to a loss of statistical power. GEE, on the other hand, can utilize all available data to model the missing values, resulting in more efficient effect estimation (Wu et al., 2001). Moreover, the time interval between the three measurement points (baseline, post-intervention, and one-month follow-up) was unequal. Traditional repeated measures ANOVA assumes sphericity, which means having constant variance across time points and constant correlation between any two time points. This assumption was likely violated in this study due to the unequal time intervals, which could have led to inflated Type I error rates. GEE, however, does not require the sphericity assumption, making it a more appropriate choice for the study design (Ma et al., 2012). In summary, GEE was selected as the statistical method because it can accommodate non-normal data, missing data due to dropouts, and unequal time intervals between measurement points, providing

more robust and efficient estimates of the intervention effects compared to traditional repeated measures approaches.

In the GEE analysis, the dependent variables were the mean total and subscale scores of the communication skill, self-efficacy and outcome expectancy belief. The independent variables were group, time, and group-by-time interaction effect. Group effect means the difference between groups averaged across time; the time effect implies the change from one time to another averaged across groups; the group-by-time interaction effect is the extent to which the difference between groups differs at different times (Leppink et al., 2017). The results from the GEE model were reported, including the standard errors (SE), mean differences (MD), Wald χ^2 , p -values, and 95% confidence intervals (CI) for the mean differences between the groups. In addition, post-hoc pairwise comparisons were conducted to determine which specific pairs of time points (e.g., T0 vs T1, T0 vs T2, T1 vs T2) showed statistically significant differences in the outcome measures. These pairwise comparisons provided more granular insights into the patterns of change throughout the study. Post-hoc pairwise comparisons were also conducted to analyze the impact of the contamination (i.e., IG vs contaminated CG, IG vs non-contaminated CG, and contaminated CG vs non-contaminated CG). This approach provides valuable insights into the relative efficacy of the intervention and the potential impact of contamination within the CGs.

Cohen's d is a standardized measure of effect size calculated from the difference between two mean values divided by their pooled standard deviation (McGough & Faraone, 2009). This standardized effect size metric provides a way to quantify the magnitude of the difference between groups, regardless of the specific scale of the measured outcome. In terms of interpreting Cohen's d values, the following general guidelines are commonly used: small (0.2), medium (0.5), or large (0.8) effect sizes. A small effect size indicates a relatively subtle difference, a medium effect size suggests a moderate or noticeable difference, and a large effect size represents a substantial,

meaningful difference between the compared groups (Cohen, 2013). By calculating and reporting the Cohen's *d* effect size, researchers can provide additional context beyond just statistical significance (*p*-values). This allows for a more nuanced interpretation of the substantive importance of the observed findings, which is crucial for evaluating the real-world implications of the study results (Sullivan & Feinn, 2012).

8.2.7.4 Data analysis for qualitative data

Recordings of the focus group discussions were first digitally transcribed verbatim in Chinese. The transcriptions were entered into NVivo software version 12 (QSR International). Content analysis with an inductive approach was used for data analysis (Vears & Gillam, 2022), as the focus group discussions were part of the process evaluation to explore the participants' experiences and collect their suggestions. The author read and coded the transcripts line by line. Initial codes were created and revised as necessary based on new data. Codes describing similarities, differences, and various aspects of the text content were identified and grouped into categories, then consolidated into themes. Extracts, codes, categories, and themes were discussed during research team meetings with supervisors, and a consensus was established (Elo & Kyngäs, 2008). The research team, consisting of three members (including the author) proficient in Chinese and English, translated the analysis results into English for broader dissemination. The author and one team member handled the initial translations, while a third researcher examined the translated versions. The three researchers had prior experience in translating qualitative research findings. The team members engaged in discussions during the translation process to address and resolve discrepancies. This collaborative approach ensured the accuracy and consistency of the translations.

The trustworthiness of the data analysis was presented in terms of four aspects: credibility, dependability, confirmability, and transferability (Guba, 1981). Credibility was addressed through member checking, where the analyzed data were returned to the participants to enhance the reflections of their experiences. Dependability was assured

by documenting the data analysis process in detail, allowing peer researchers to repeat the study. Confirmability was attained by the previously described member checking and intensive discussions to ensure the findings were based on the participants' responses, not the researcher's biases. Transferability was addressed by providing detailed descriptions of the participants, methods, and settings, as well as representative condensed quotes, allowing researchers in relevant areas to assess the applicability of the findings.

8.3 Results

8.3.1 Characteristics and homogeneity at baseline of the participants

A total of 170 nurses were approached, out of whom 159 met the selection criteria and consented to participate in the study. The participants ($n = 159$) were randomly assigned to either the IG ($n = 79$) or the CG ($n = 80$). Ten nurses were lost at T1 and T2, resulting in a loss rate of 8.18%. The CONSORT flow chart is shown in Figure 8.2. Table 8.2 summarises the demographic characteristics of the participants.

The mean age of the participants was 31.36 years, with a majority being female nurses (94.30%). Over half of the participants held medium professional titles (64.80%), while most had bachelor's degrees (87.40%). On average, the participants had nearly nine years of work experience and 8.33 years of caring for terminally ill patients. Only three participants were religious (1.90%). Approximately half (43.40%) of the participants were from the radiation oncology department. The two groups had no statistically significant differences in baseline demographic characteristics (all $p > .05$). There were no significant differences between baseline outcomes of interest between the two groups (all $p > .05$), indicating their comparability (Table 8.3). Moreover, employing covariates to examine the intervention effect in the GEE model is deemed unnecessary.

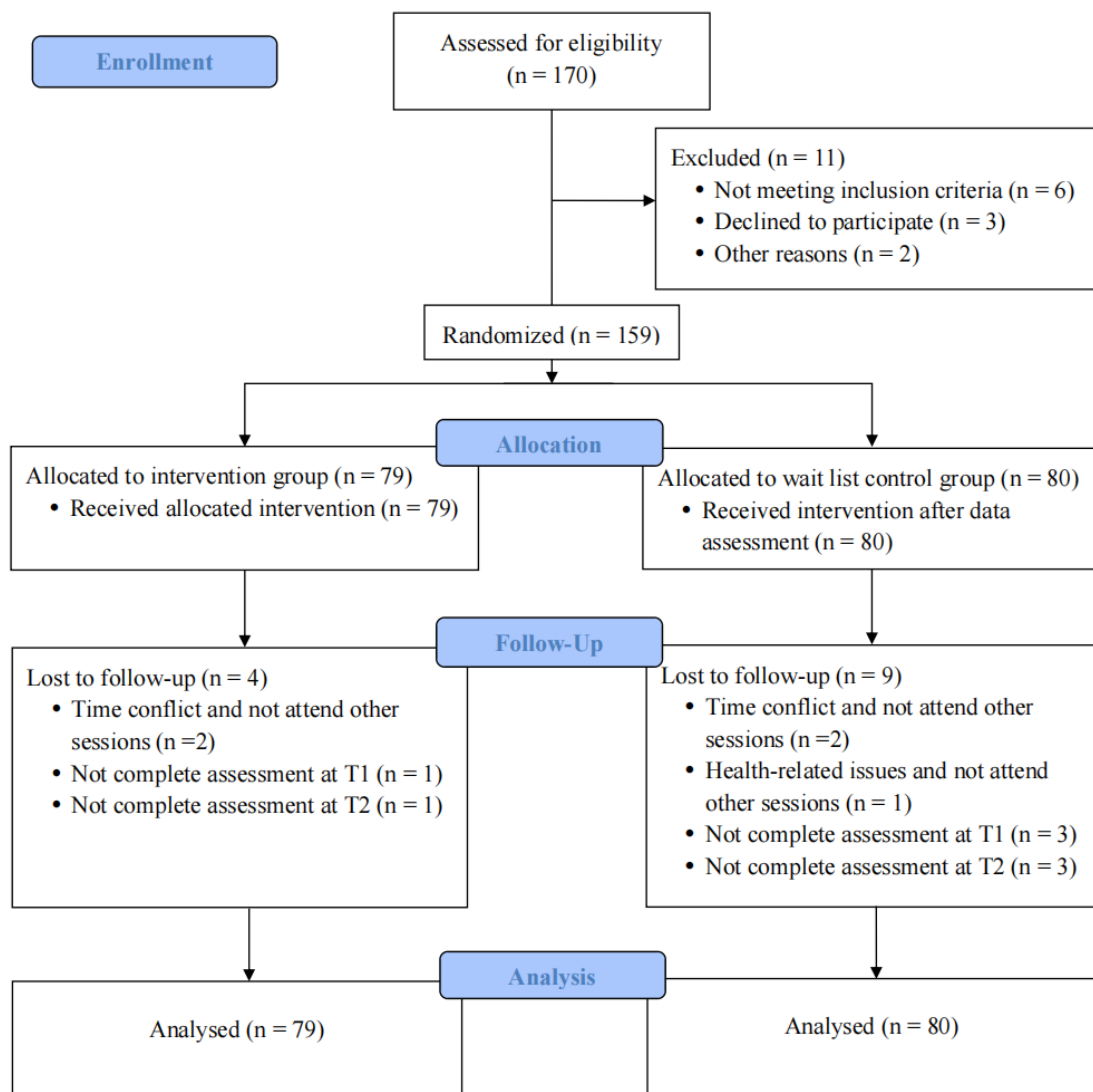


Figure 8.2 Study flow chart

Table 8.2 Participants' characteristics

	All (N = 159)			IG (n = 79)			CG (n = 80)			χ^2/t	<i>p</i>
	Frequency	M	SD	Frequency	M	SD	Frequency	M	SD		
Age (years)	/	31.36	6.19	/	31.41	6.39	/	31.33	6.02	0.08	.935
Gender										0.11	.746
● Male	9 (5.70%)	/	/	4 (5.06%)	/	/	5 (6.25%)	/	/		
● Female	150 (94.30%)	/	/	75 (94.94%)	/	/	75 (93.75%)	/	/		
Professional title										0.22	.894
● Junior	51 (32.10%)	/	/	26 (32.91%)	/	/	25 (31.25%)				
● Medium	103 (64.80%)	/	/	51 (64.56%)	/	/	52 (65.00%)				
● Senior	5 (3.10%)	/	/	2 (2.53%)	/	/	3 (3.75%)				
Education level										4.35	.226
● Junior college	1 (0.60%)	/	/	1 (1.27%)	/	/	0	/	/		
● Undergraduate	139 (87.40%)	/	/	66 (83.54%)	/	/	73 (91.25%)	/	/		
● Master	18 (11.30%)	/	/	12 (15.19%)	/	/	6 (7.50%)	/	/		
● Doctor	1 (0.60%)	/	/	0	/	/	1 (1.25%)	/	/		
Working years	/	8.99	6.16	/	8.89	6.31	/	9.09	6.05	-0.21	.838
Number of years involved in the care of advanced patients	/	8.33	5.51	/	7.94	5.37	/	8.71	5.65	-0.89	.376

Religion										0.99	.608
● None	156	/	/	78 (98.73%)	/	/	78 (97.50%)	/	/		
	(98.10%)										
● Buddhism	2 (1.30%)	/	/	1 (1.27%)	/	/	1 (1.25%)	/	/		
● Christianity	1 (0.60%)	/	/	0	/	/	1 (1.25%)	/	/		
Department										5.86	.119
● Surgical oncology	38	/	/	23 (29.11%)	/	/	15 (18.75%)	/	/		
	(23.90%)										
● Radiation oncology	69	/	/	37 (46.84%)	/	/	32 (40.00%)	/	/		
	(43.40%)										
● Medical oncology	23	/	/	8 (10.13%)	/	/	15 (18.75%)	/	/		
	(14.50%)										
● Other	29	/	/	11 (13.92%)	/	/	18 (22.50%)	/	/		
	(18.20%)										

Table 8.3 Comparison of outcomes between the two groups at baseline

Variable	Possible range	All (N=159)		IG (n = 79)		CG (n = 80)		<i>t/z</i>	<i>p</i>
		M	SD	M	SD	M	SD		
Self-report communication skill									
● Overall skills	1-5	3.85	0.54	3.84	0.54	3.86	0.54	-0.31	.758
● Basic verbal communication skills	1-5	3.93	0.66	3.94	0.61	3.92	0.71	-0.10	.920
● Basic non-verbal communication skills	1-5	3.97	0.55	3.98	0.56	3.96	0.55	-0.08	.938
● Emotional perception skills	1-5	3.93	0.58	3.91	0.58	3.95	0.58	-0.47	.636
● Emotional support skills	1-5	3.72	0.70	3.73	0.70	3.71	0.71	-0.26	.793
● Communication skills in difficult clinical situations	1-5	3.77	0.53	3.75	0.56	3.79	0.49	-0.36	.722
Observer-assessed communication skill									
● Total score	0-216	36.41	6.24	36.74	6.42	36.08	6.09	0.66	.510
● Module 1	0-59	9.56	2.70	9.51	2.83	9.60	2.57	-0.12	.904
● Module 2	0-55	11.52	2.72	11.81	3.03	11.22	2.36	-1.38	.167
● Module 3	0-54	8.51	4.59	8.59	4.72	8.43	4.48	-0.32	.751
● Module 4	0-48	6.82	2.17	6.82	2.23	6.83	2.12	-0.16	.872
Self-efficacy									
● Overall self-efficacy	1-5	3.70	0.28	3.72	0.55	3.69	0.50	-0.76	.450
● Mental and spiritual care of dying patients	1-5	3.72	0.55	3.74	0.58	3.71	0.53	-0.55	.584

● Family care	1-5	3.68	0.54	3.69	0.57	3.66	0.51	-0.88	.379
Outcome expectancy belief									
● Total score	23-207	122.45	23.31	121.94	25.58	122.95	20.99	-0.52	.602
● Positive outcome	6-54	33.53	8.59	32.57	7.99	34.49	9.09	-1.70	.089
● Negative outcome	17-153	88.91	20.08	89.37	21.25	88.46	18.98	-0.12	.908

8.3.2 Effects on primary outcomes (skills)

The evaluation results of participants' communication skills included self-reporting using the Nurses' Clinic Communication Skill Scale and external assessment through an observer checklist.

8.3.2.1 Effects on self-reported skills

In the GEE analysis of nurses' self-reported communication skills (Table 8.4 and Figure 8.3 – 8.8), the interaction effect between groups and time points (T0, T1 and T2) on the overall and dimensional scores were statistically significant (all $p \leq .001$). The time effects on the overall and dimensional scores were also statistically significant (all $p < .001$). The group effects on the overall communication skills (Wald $\chi^2 = 13.22, p < .001$), basic verbal communication skills (Wald $\chi^2 = 5.33, p = .021$), basic non-verbal communication skills (Wald $\chi^2 = 22.06, p < .001$), emotional perception skills (Wald $\chi^2 = 12.32, p < .001$) and communication skills in difficult clinical situations (Wald $\chi^2 = 13.99, p < .001$) were statistically significant. The effects on improving the overall communication skills, basic non-verbal communication skills, emotional perception skills and communication skills in difficult clinical situations at T1 were high (Cohen's $d = 0.81 \sim 0.89$). For basic non-verbal communication skills, emotional perception skills and communication skills in difficult clinical situations, the effect sizes increased to 0.95, 0.90 and 0.90, respectively, at T2. Small to medium effects were detected in improving the overall skill (T2), basic verbal communication skills and emotional support skills at both time points (Cohen's $d = 0.42 \sim 0.79$). The post-hoc pairwise comparisons of time points in IG and CG are shown in Tables 8.5 and 8.6. In the IG (Table 8.5), the overall and dimensional scores at T1 and T2 were significantly higher than those at T0 (all $p < .001$). Moreover, basic non-verbal communication skills at T2 significantly improved than at T1 (MD = -0.08, 95% CI -0.14, -0.02, $p = .007$). In the CG (Table 8.6), most dimensions of communication skills did not show significant changes, except the overall communication skill at T2 (MD = 0.04, 95% CI 0.01, 0.08, $p = .024$), basic verbal communication skills at T1 (MD = 0.03, 95% CI 0.00, 0.06, $p = .048$), communication skill in difficult clinical situations at T2 (MD = 0.06, 95% CI

0.01, 0.11, $p = .010$) were significantly decreased when compared to the baseline (T0). The results of the GEE analysis and the post-hoc pairwise comparisons indicated that the IG exhibited significant improvements in self-reported communication skills compared with the CG. Following the intervention, the IG showed substantial increases in the overall and dimensional communication skills at T1, with further enhancements maintained at the one-month follow-up (T2). In contrast, the CG displayed minimal changes over the same period.

Table 8.4 Self-report communication skills at three time points between IG and CG

Nurses' Clinic Communication Skill Scale	Time points	IG (n =79)		CG (n =80)		GEE analysis	Statistics value		Effect size Cohen's <i>d</i>
		M	SE	M	SE		Wald χ^2	<i>p</i>	
● Overall skills	T0	3.84	0.06	3.86	0.06	Group effect	13.22	<.001	
	T1	4.19	0.03	3.84	0.06	Time effect	62.96	<.001	0.81
	T2	4.21	0.03	3.82	0.05	Group x Time effect	82.40	<.001	0.79
● Basic verbal communication skills	T0	3.94	0.07	3.92	0.08	Group effect	5.33	.021	
	T1	4.18	0.05	3.89	0.08	Time effect	19.40	<.001	0.49
	T2	4.18	0.04	3.88	0.07	Group x Time effect	32.34	<.001	0.47
● Basic non-verbal communication skills	T0	3.98	0.06	3.96	0.06	Group effect	22.06	<.001	
	T1	4.40	0.05	3.96	0.06	Time effect	52.59	<.001	0.89
	T2	4.48	0.04	3.95	0.06	Group x Time effect	56.50	<.001	0.95
● Emotional perception skills	T0	3.91	0.06	3.95	0.06	Group effect	12.32	<.001	
	T1	4.31	0.05	3.91	0.06	Time effect	35.41	<.001	0.81
	T2	4.33	0.06	3.89	0.06	Group x Time effect	57.67	<.001	0.90
● Emotional support skills	T0	3.73	0.08	3.71	0.08	Group effect	3.36	.067	
	T1	3.99	0.05	3.74	0.08	Time effect	23.14	<.001	0.42
	T2	3.99	0.05	3.75	0.07	Group x Time effect	14.42	.001	0.58
● Communication skills in	T0	3.75	0.06	3.79	0.05	Group effect	13.99	<.001	
	T1	4.13	0.05	3.76	0.05	Time effect	33.07	<.001	0.83

difficult clinical situations	T2	4.14	0.04	3.73	0.05	Group x Time effect	52.93	<.001	0.90
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Table 8.5 Pairwise comparison of self-report communication skills between time points in IG (n = 79)

Nurses' Clinic Communication Skill Scale	Pairwise comparison	Mean Difference	Standard Error	95% Confidence Interval		<i>p</i>
● Overall skills	T0 – T1	-0.35	0.04	-0.43	-0.27	<.001
	T0 – T2	-0.37	0.04	-0.45	-0.28	<.001
	T1 – T2	-0.02	0.01	-0.04	0.01	.150
● Basic verbal communication skills	T0 – T1	-0.24	0.05	-0.33	-0.15	<.001
	T0 – T2	-0.25	0.05	-0.35	-0.14	<.001
	T1 – T2	0.00	0.02	-0.05	0.04	.820
● Basic non-verbal communication skills	T0 – T1	-0.42	0.06	-0.54	-0.30	<.001
	T0 – T2	-0.50	0.06	-0.63	-0.37	<.001
	T1 – T2	-0.08	0.03	-0.14	-0.02	.007
● Emotional perception skills	T0 – T1	-0.40	0.06	-0.51	-0.29	<.001
	T0 – T2	-0.42	0.06	-0.54	-0.30	<.001
	T1 – T2	-0.02	0.03	-0.07	0.04	.545
● Emotional support skills	T0 – T1	-0.26	0.06	-0.37	-0.15	<.001
	T0 – T2	-0.26	0.06	-0.39	-0.14	<.001
	T1 – T2	0.00	0.03	-0.06	0.05	.881
● Communication skills in difficult clinical situations	T0 – T1	-0.39	0.06	-0.50	-0.28	<.001
	T0 – T2	-0.39	0.06	-0.51	-0.28	<.001
	T1 – T2	0.00	0.02	-0.04	0.03	.797

Table 8.6 Pairwise comparison of self-report communication skills between time points in CG (n = 80)

Nurses' Clinic Communication Skill Scale	Pairwise comparison	Mean Difference	Standard Error	95% Confidence Interval		<i>p</i>
● Overall skills	T0 – T1	0.02	0.01	0.00	0.05	.050
	T0 – T2	0.04	0.02	0.01	0.08	.024
	T1 – T2	0.02	0.02	-0.02	0.05	.342
● Basic verbal communication skills	T0 – T1	0.03	0.02	0.00	0.06	.048
	T0 – T2	0.04	0.04	-0.03	0.11	.219
	T1 – T2	0.01	0.03	-0.05	0.08	.705
● Basic non- verbal communication skills	T0 – T1	0.00	0.00	0.00	0.00	1.000
	T0 – T2	0.01	0.03	-0.04	0.07	.609
	T1 – T2	0.01	0.03	-0.04	0.07	.609
● Emotional perception skills	T0 – T1	0.04	0.03	-0.01	0.10	.131
	T0 – T2	0.06	0.03	-0.01	0.13	.078
	T1 – T2	0.02	0.04	-0.07	0.11	.695
● Emotional support skills	T0 – T1	-0.03	0.02	-0.07	0.01	.191
	T0 – T2	-0.04	0.03	-0.09	0.02	.219
	T1 – T2	-0.01	0.04	-0.08	0.06	.858
● Communication skills in difficult clinical situations	T0 – T1	0.03	0.02	-0.01	0.08	.173
	T0 – T2	0.06	0.02	0.01	0.11	.010
	T1 – T2	0.03	0.03	-0.04	0.10	.417

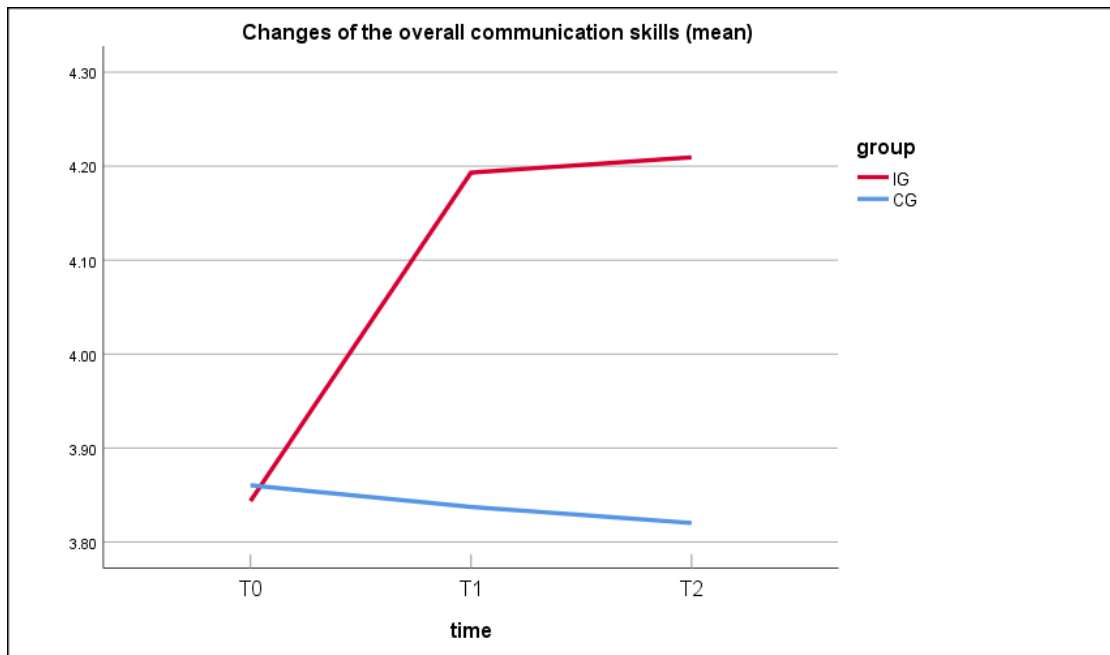


Figure 8.3 Comparison of the overall communication skill between groups over the three time points

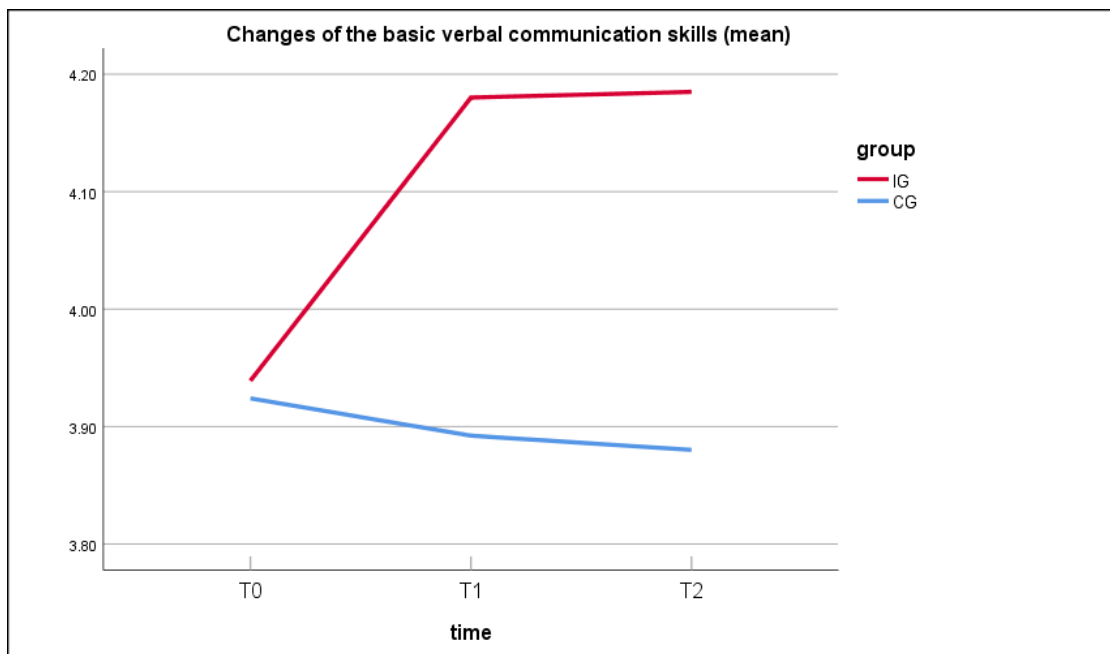


Figure 8.4 Comparison of the basic verbal communication skills between groups over the three time points

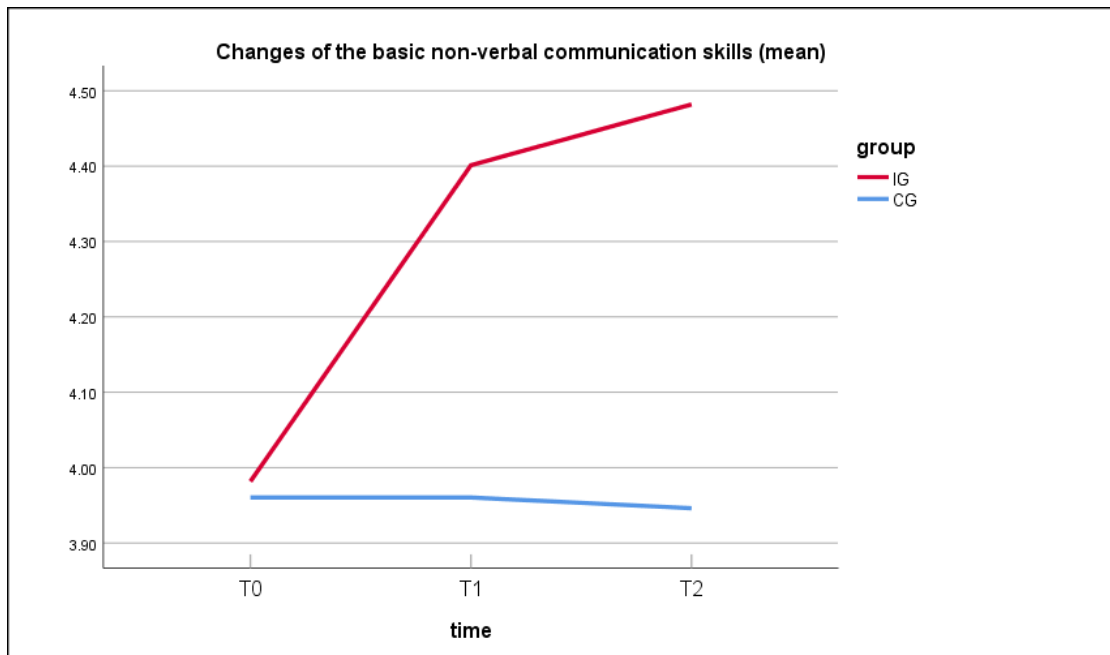


Figure 8.5 Comparison of the basic non-verbal communication skills between groups over the three time points



Figure 8.6 Comparison of the emotional perception skills between groups over the three time points



Figure 8.7 Comparison of the emotional support skills between groups over the three time points

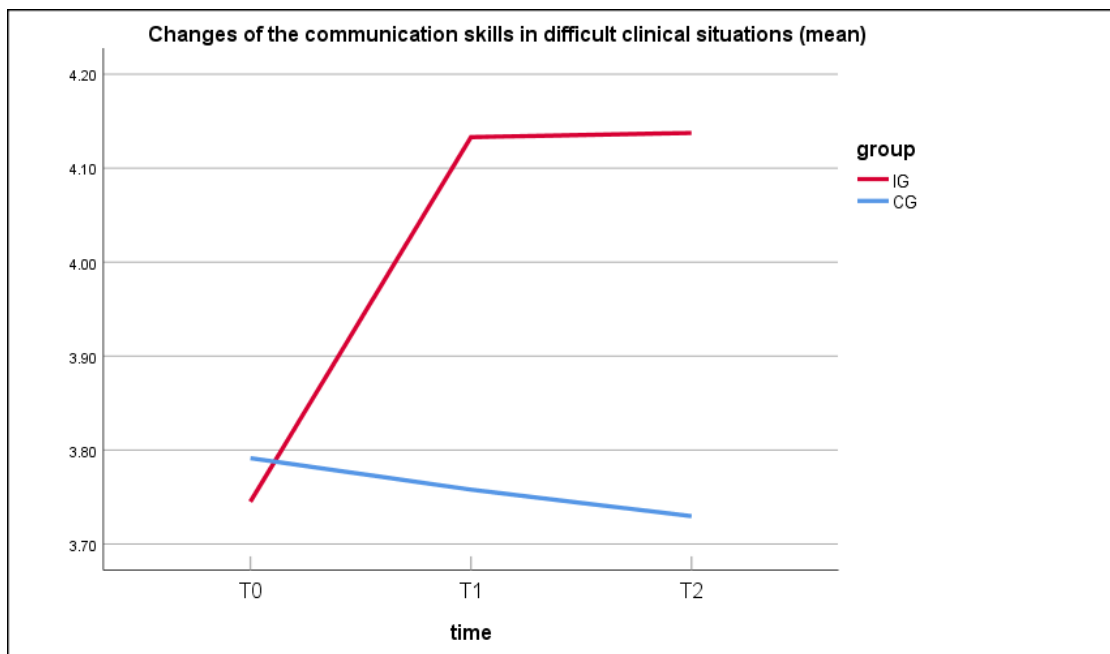


Figure 8.8 Comparison of the communication skills in difficult clinical situations between groups over the three time points

8.3.2.2 Effects on observer-assessed skills

The observer assessment of communication skills was conducted using a study-specific checklist to evaluate the IG and the CG at three time points: baseline (T0), post-intervention (T1), and at a one-month follow-up (T2). In the GEE analysis of observer-assessed communication skills (Table 8.7 and Figure 8.9 – 8.13), there were significant group effects, time effects, and group-by-time interaction effects on the total score of the observer checklist and scores of all the sub-modules (all $p < .001$). The effect size on improving the total score was large at T1 (Cohen's $d = 1.95$) and T2 (Cohen's $d = 1.81$). Small to medium effects were detected in modules 1 to 4 (Cohen's $d = 0.32\sim 0.55$). The post-hoc pairwise comparisons of time points in IG and CG are shown in Tables 8.8 and 8.9. In the IG (Table 8.8), the total and modular scores at T1 and T2 were significantly higher than those at T0 (all $p < .001$). No significant changes between T1 and T2 indicated that the skills acquired were retained over time. In the CG (Table 8.9), there were no significant improvements from T0 to T1 and only a few significant changes from T0 to T2 and between T1 and T2 in some modules, suggesting little to no improvement in communication skills over time.

The results of the GEE analysis and the post-hoc pairwise comparisons revealed that the IG exhibited significant improvements in observer-assessed communication skills compared with the CG. Following the intervention, the IG showed substantial increases in the overall and modular communication skills at T1, with these improvements primarily maintained at the one-month follow-up (T2). In contrast, the CG showed minimal changes over the same period, with some fluctuations but no consistent pattern of improvement.

Table 8.7 Observer-assessed communication skills at three time points between IG and CG

Observer checklist	Time points	IG (n =79)		CG (n =80)		GEE analysis	Statistics value		Effect size
		M	SE	M	SE		Wald χ^2	<i>p</i>	
● Total score	T0	36.74	0.72	36.08	0.68	Group effect	89.19	<.001	
	T1	50.10	0.96	35.54	0.69	Time effect	198.10	<.001	1.95
	T2	49.87	0.90	36.59	0.74	Group x Time effect	202.74	<.001	1.81
● Module 1	T0	9.51	0.32	9.60	0.29	Group effect	23.32	<.001	
	T1	12.65	0.36	9.56	0.27	Time effect	53.12	<.001	0.42
	T2	12.56	0.36	10.03	0.29	Group x Time effect	49.98	<.001	0.33
● Module 2	T0	11.81	0.34	11.22	0.26	Group effect	32.53	<.001	
	T1	14.34	0.43	10.70	0.33	Time effect	32.37	<.001	0.44
	T2	14.34	0.37	10.92	0.35	Group x Time effect	61.76	<.001	0.45
● Module 3	T0	8.59	0.53	8.43	0.50	Group effect	28.60	<.001	
	T1	13.22	0.39	8.40	0.48	Time effect	73.17	<.001	0.55
	T2	13.03	0.37	8.39	0.49	Group x Time effect	75.27	<.001	0.52
● Module 4	T0	6.82	0.25	6.83	0.24	Group effect	24.66	<.001	
	T1	9.89	0.44	6.88	0.23	Time effect	46.10	<.001	0.39
	T2	9.94	0.44	7.25	0.25	Group x Time effect	38.22	<.001	0.32

Table 8.8 Pairwise comparison of observer-assessed communication skills between time points in IG (n = 79)

Observer checklist	Pairwise comparison	Mean Difference	Standard Error	95% Confidence Interval		<i>p</i>
● Total score	T0 – T1	-13.36	0.96	-15.24	-11.48	<.001
	T0 – T2	-13.13	0.91	-14.91	-11.35	<.001
	T1 – T2	0.23	0.36	-0.48	0.94	.529
● Module 1	T0 – T1	-3.14	0.45	-4.03	-2.25	<.001
	T0 – T2	-3.05	0.44	-3.92	-2.18	<.001
	T1 – T2	0.09	0.18	-0.26	0.45	.607
● Module 2	T0 – T1	-2.52	0.37	-3.24	-1.81	<.001
	T0 – T2	-2.53	0.35	-3.22	-1.84	<.001
	T1 – T2	0.00	0.27	-0.53	0.52	.987
● Module 3	T0 – T1	-4.63	0.53	-5.68	-3.59	<.001
	T0 – T2	-4.44	0.53	-5.47	-3.40	<.001
	T1 – T2	0.19	0.14	-0.08	0.47	.164
● Module 4	T0 – T1	-3.06	0.50	-4.04	-2.09	<.001
	T0 – T2	-3.12	0.50	-4.09	-2.15	<.001
	T1 – T2	-0.05	0.11	-0.26	0.15	.604

Table 8.9 Pairwise comparison of observer-assessed communication skills between time points in CG (n = 80)

Observer checklist	Pairwise comparison	Mean Difference	Standard Error	95% Confidence Interval		<i>p</i>
● Total score	T0 – T1	0.55	0.18	0.19	0.90	.003
	T0 – T2	-0.50	0.35	-1.18	0.18	.146
	T1 – T2	-1.05	0.29	-1.61	-0.49	<.001
● Module 1	T0 – T1	0.04	0.06	-0.08	0.16	.499
	T0 – T2	-0.43	0.18	-0.79	-0.07	.019
	T1 – T2	-0.47	0.15	-0.77	-0.17	.002
● Module 2	T0 – T1	0.53	0.17	0.00	0.20	.852
	T0 – T2	0.30	0.19	0.11	-0.07	.675
	T1 – T2	-0.22	0.08	-0.37	-0.07	.004
● Module 3	T0 – T1	0.03	0.07	-0.11	0.17	.641
	T0 – T2	0.04	0.17	-0.29	0.38	.807
	T1 – T2	0.01	0.14	-0.27	0.28	.952
● Module 4	T0 – T1	-0.05	0.03	-0.12	0.01	.117
	T0 – T2	-0.42	0.16	-0.74	-0.10	.010
	T1 – T2	-0.37	0.15	-0.66	-0.08	.013

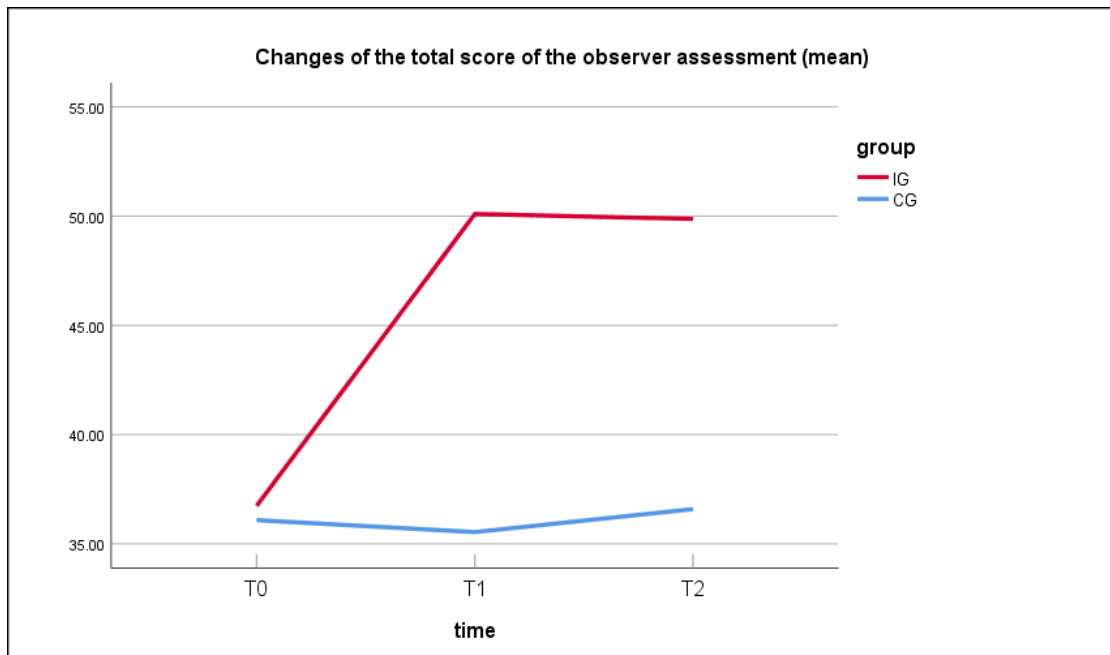


Figure 8.9 Comparison of the total score of the observer assessment between groups over the three time points

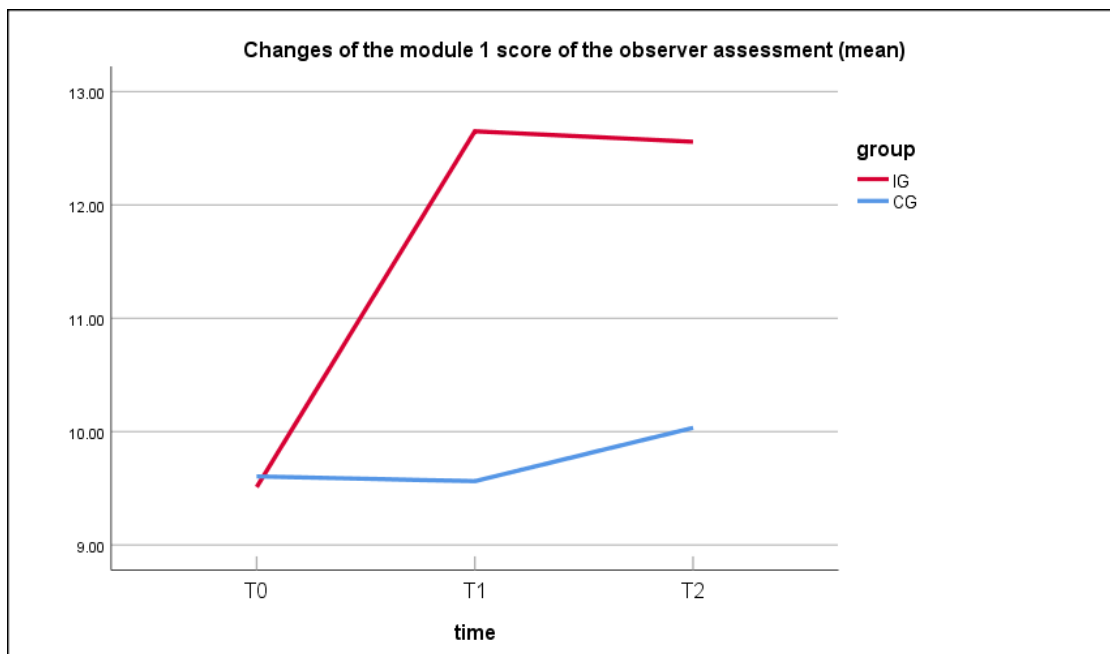


Figure 8.10 Comparison of the module 1 score of the observer assessment between groups over the three time points

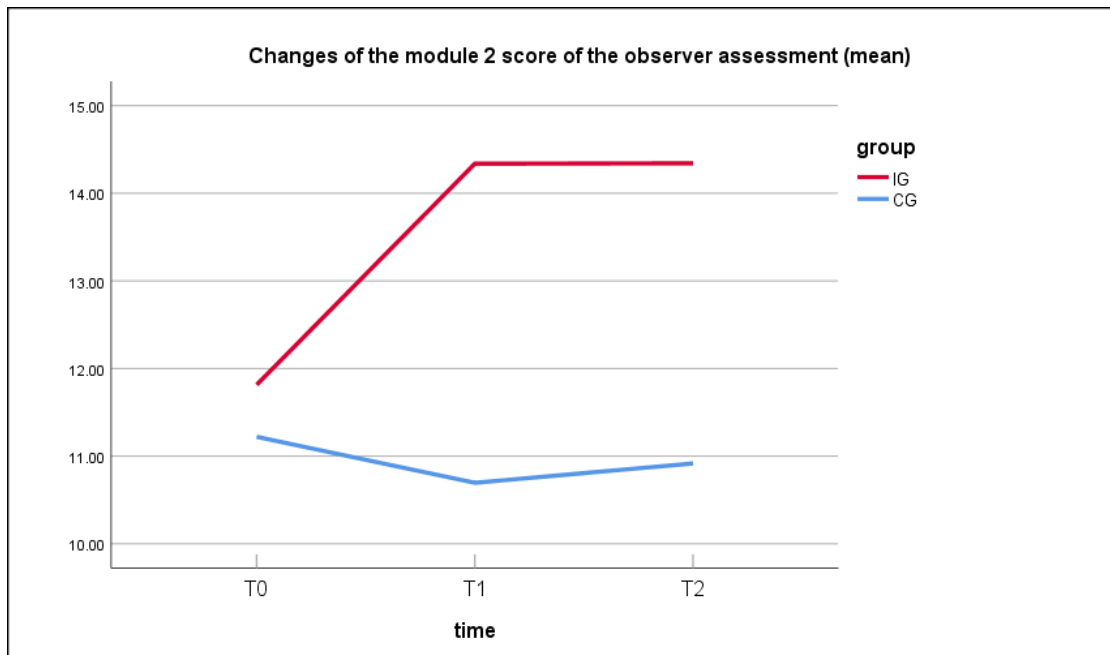


Figure 8.11 Comparison of the module 2 score of the observer assessment between groups over the three time points

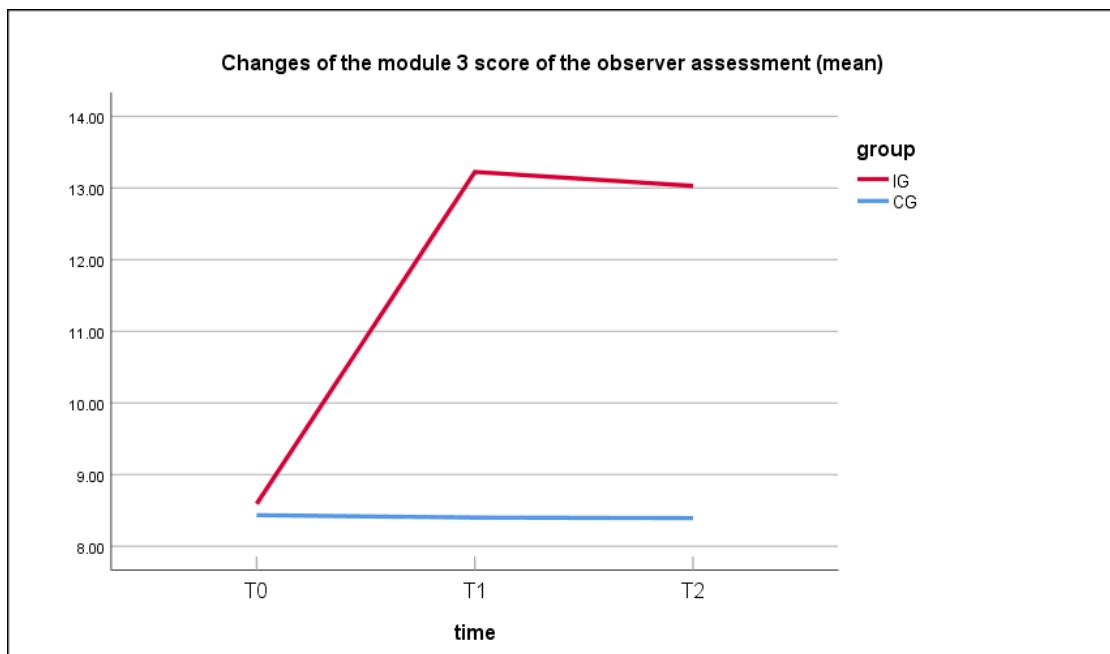


Figure 8.12 Comparison of the module 3 score of the observer assessment between groups over the three time points



Figure 8.13 Comparison of the module 4 score of the observer assessment between groups over the three time points

8.3.3 Effects on secondary outcomes (self-efficacy and outcome expectancy belief)

8.3.3.1 Effects on self-efficacy

In the GEE analysis of self-efficacy (Table 8.10 and Figure 8.14 – 8.16), group-by-time interaction effects were statistically significant on the overall scale (Wald $\chi^2 = 19.93$, $p < .001$) and two sub-scales (Wald $\chi^2 = 8.66$, $p = .013$; Wald $\chi^2 = 11.10$, $p = .004$). The effect sizes were small (Cohen's $d = 0.12 \sim 0.41$). Group effects and time effects did not show statistically significant across variables. The post-hoc pairwise comparisons of time points in IG and CG are shown in Tables 8.11 and 8.12. In the IG (Table 8.11), the self-efficacy on the overall ($p = .017$, $p < .001$) and the sub-scale of the family care ($p = .004$, $p < .001$) were significantly improved at T1 and T2 than those at baseline. The self-efficacy on the sub-scale of the mental and spiritual care of dying patients was significantly improved at T2 ($p = .025$) compared to the baseline. Moreover, the overall self-efficacy ($p = .005$) and two sub-scales ($p = .052$; $p = .031$) were significantly or nearly significantly improved from T1 to T2, indicating a sustained effect of the intervention. The CG (Table 8.12) showed no significant improvements from T0 to T1. The self-efficacy on the overall ($p = .007$) and the sub-scale of the mental and spiritual care of dying patients ($p = .043$) at T2 decreased significantly compared with the baseline. The results of the GEE analysis and the post-hoc pairwise comparisons revealed that the IG exhibited significant improvements in self-efficacy compared with the CG. Following the intervention, the IG demonstrated a statistically significant increase in self-efficacy at T1 and T2, while the CG showed minimal changes, including some undesired decreases in self-efficacy.

Table 8.10 Self-efficacy at three time points between IG and CG

Hospice Care Self-efficacy Scale on Nurses	Time points	IG (n =79)		CG (n =80)		GEE analysis	Statistics value		Effect size
		M	SE	M	SE		Wald χ^2	<i>p</i>	
● Overall self-efficacy	T0	3.72	0.06	3.69	0.06	Group effect	1.71	.191	
	T1	3.76	0.06	3.66	0.05	Time effect	0.36	.833	0.20
	T2	3.80	0.05	3.62	0.06	Group x Time effect	19.93	<.001	0.41
● Mental and spiritual care of dying patients	T0	3.74	0.06	3.71	0.06	Group effect	0.84	.360	
	T1	3.76	0.06	3.70	0.05	Time effect	0.93	.627	0.12
	T2	3.80	0.05	3.68	0.06	Group x Time effect	8.66	.013	0.27
● Family care	T0	3.69	0.06	3.66	0.06	Group effect	1.98	.159	
	T1	3.75	0.06	3.61	0.06	Time effect	4.72	.095	0.29
	T2	3.80	0.07	3.62	0.06	Group x Time effect	11.10	.004	0.31

Table 8.11 Pairwise comparison of self-efficacy between time points in IG (n = 79)

Hospice Care Self-efficacy Scale on Nurses	Pairwise comparison	Mean Difference	Standard Error	95% Confidence Interval		<i>p</i>
● Overall self-efficacy	T0 – T1	-0.04	0.02	-0.08	-0.01	.017
	T0 – T2	-0.08	0.02	-0.13	-0.04	<.001
	T1 – T2	-0.04	0.01	-0.07	-0.01	.005
● Mental and spiritual care of dying patients	T0 – T1	-0.03	0.02	-0.07	0.02	.245
	T0 – T2	-0.07	0.03	-0.13	-0.01	.025
	T1 – T2	-0.04	0.02	-0.08	0.00	.052
● Family care	T0 – T1	-0.06	0.02	-0.10	-0.02	.004
	T0 – T2	-0.11	0.03	-0.16	-0.05	<.001
	T1 – T2	-0.05	0.02	-0.09	0.00	.031

Table 8.12 Pairwise comparison of self-efficacy between time points in CG (n = 80)

Hospice Care Self-efficacy Scale on Nurses	Pairwise comparison	Mean Difference	Standard Error	95% Confidence Interval		<i>p</i>
● Overall self-efficacy	T0 – T1	0.03	0.02	-0.02	0.07	.239
	T0 – T2	0.07	0.02	0.02	0.11	.007
	T1 – T2	0.04	0.02	-0.01	0.09	.111
● Mental and spiritual care of dying patients	T0 – T1	0.01	0.02	-0.03	0.05	.635
	T0 – T2	0.03	0.02	0.00	0.07	.043
	T1 – T2	0.02	0.03	-0.03	0.08	.421
● Family care	T0 – T1	0.05	0.04	-0.02	0.12	.195
	T0 – T2	0.04	0.03	-0.03	0.10	.262
	T1 – T2	-0.01	0.02	-0.06	0.03	.573

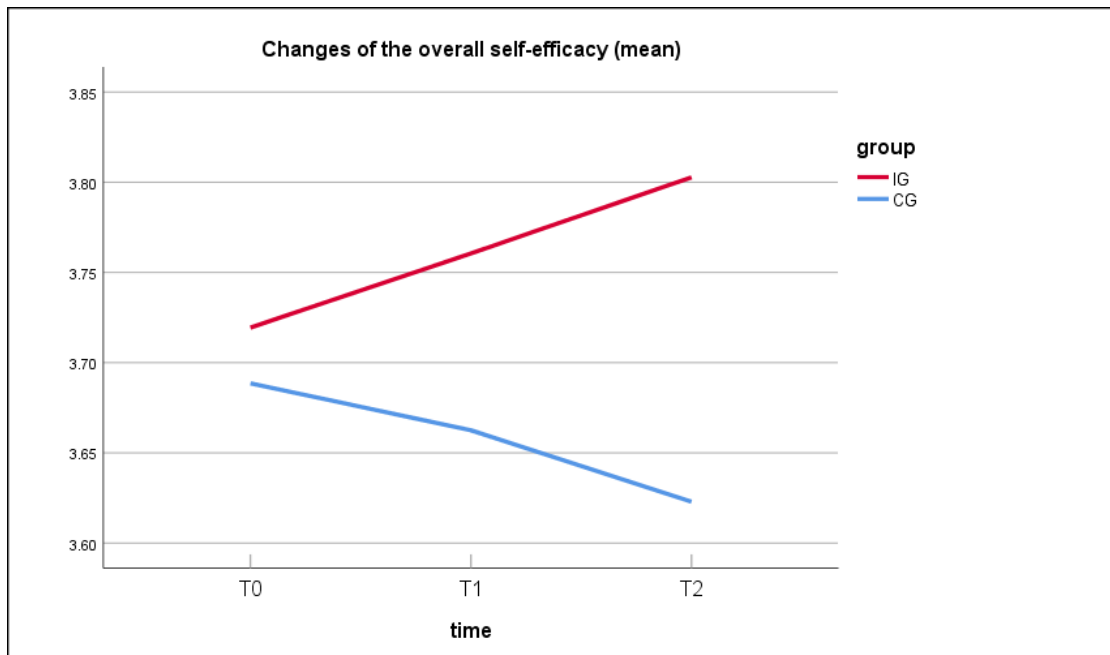


Figure 8.14 Comparison of the overall self-efficacy between groups over the three time points

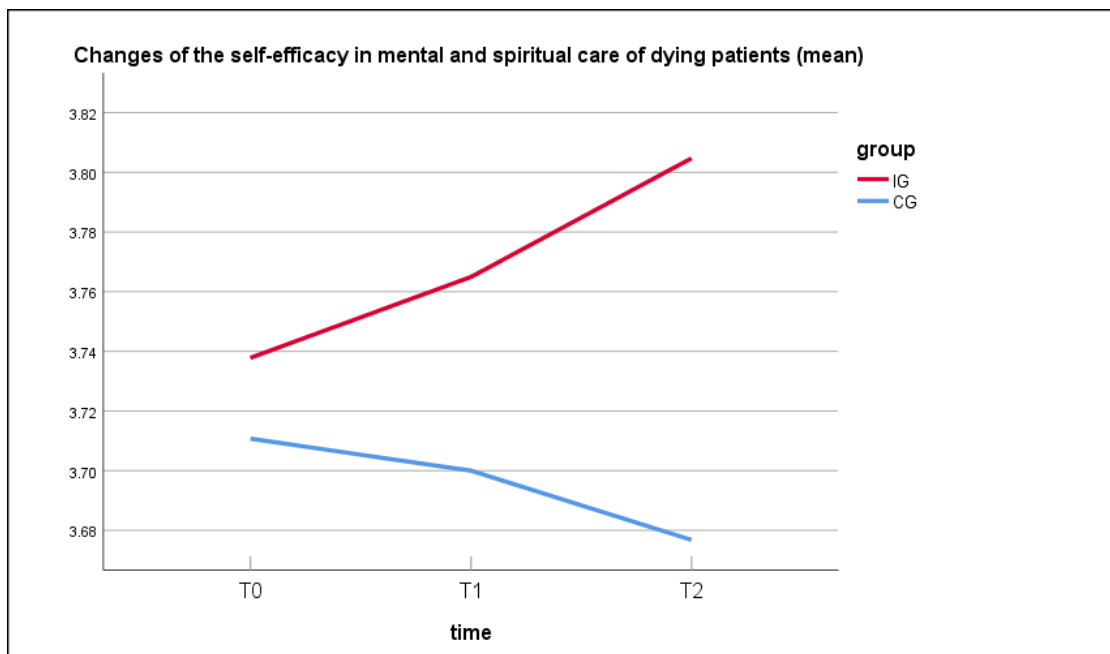


Figure 8.15 Comparison of the self-efficacy in the mental and spiritual care of dying patients between groups over the three time points

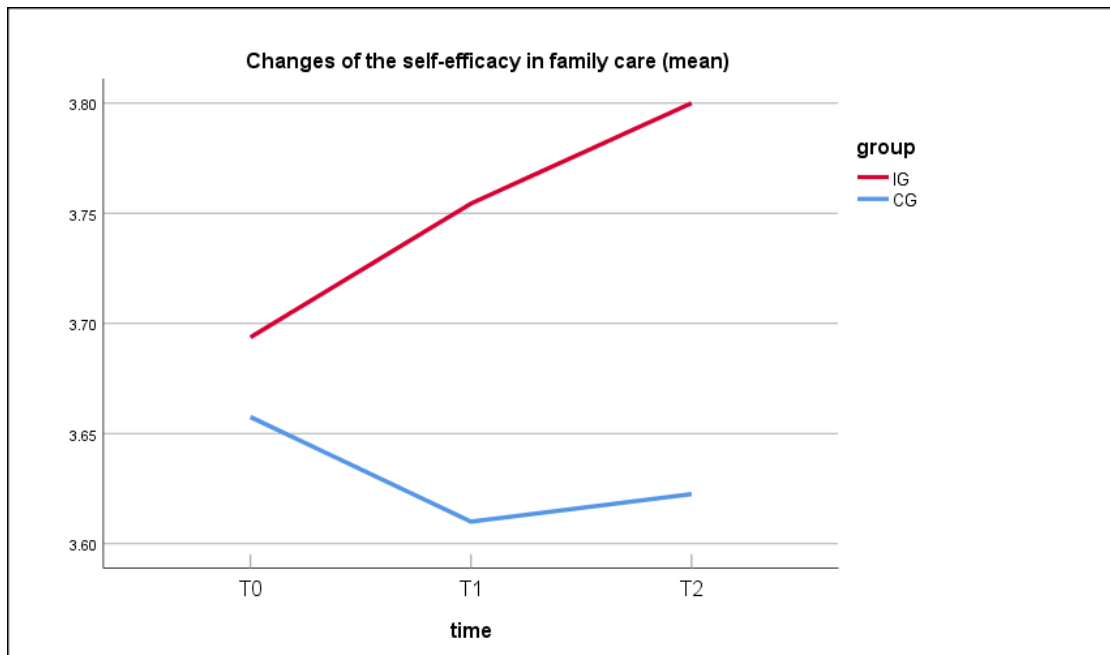


Figure 8.16 Comparison of the self-efficacy in family care between groups over the three time points

8.3.3.2 Effects on outcome expectancy belief

In the GEE analysis of outcome expectancy beliefs (Table 8.13 and Figure 8.17- 8.19), group-by-time interaction effects were statistically significant on the total score (Wald $\chi^2 = 29.89, p < .001$), positive outcome (Wald $\chi^2 = 22.00, p < .001$) and negative outcome (Wald $\chi^2 = 15.13, p = .001$). The effect sizes were small (Cohen's $d = 0.01 \sim 0.19$). Group effects and time effects did not show statistically significant across variables. The post-hoc pairwise comparisons of time points in IG and CG are shown in Tables 8.14 and 8.15. In the IG (Table 8.14), the total score (both $p < .001$), positive outcome (both $p < .001$), and negative outcome ($p = .017$; $p = .038$) were significantly improved from T0 to T1 and from T0 to T2. There were non-significant changes from T1 to T2 on the total score (MD = -0.37, 95% CI -1.39, 0.65, $p = .481$) and negative outcome (MD = -0.14, 95% CI -1.12, 0.85, $p = .782$). For positive outcomes within the IG, a small but significant increase from T1 to T2 was observed (MD = -0.23, 95% CI -0.43, -0.02, $p = .029$). In the CG (Table 8.15), almost all outcomes decreased significantly in the paired time points, except the negative outcome from T1 to T2 ($p = .129$). The results of the GEE analysis and the post-hoc pairwise comparisons revealed that the IG exhibited significant improvements in outcome expectancy beliefs compared with the CG. Following the intervention, the IG demonstrated a statistically significant increase in outcome expectancy beliefs at T1 and T2, while the CG showed undesired decreases in outcome expectancy beliefs.

Table 8.13 Outcome expectancy beliefs at three time points between IG and CG

Communication Outcomes Questionnaire	Time points	IG (n =79)		CG (n =80)		GEE analysis	Statistics value		Effect size
		M	SE	M	SE		Wald χ^2	<i>p</i>	
● Total score	T0	121.94	2.86	122.95	2.33	Group effect	0.18	.675	
	T1	123.75	2.77	121.44	2.38	Time effect	0.28	.867	0.10
	T2	124.11	2.76	120.84	2.38	Group x Time effect	29.89	<.001	0.14
● Positive outcome	T0	32.57	0.89	34.49	1.01	Group effect	0.17	.680	
	T1	33.59	0.90	33.69	0.96	Time effect	0.34	.842	0.01
	T2	33.82	0.88	33.43	0.97	Group x Time effect	22.00	<.001	0.05
● Negative outcome	T0	89.37	2.38	88.46	2.11	Group effect	0.42	.519	
	T1	90.15	2.34	87.75	2.22	Time effect	0.13	.937	0.19
	T2	90.29	2.32	87.41	2.25	Group x Time effect	15.13	.001	0.14

Table 8.14 Pairwise comparison of outcome expectancy beliefs between time points in IG (n = 79)

Communication Outcomes Questionnaire	Pairwise comparison	Mean Difference	Standard Error	95% Confidence Interval		<i>p</i>
● Total score	T0 – T1	-1.81	0.45	-2.69	-0.93	<.001
	T0 – T2	-2.18	0.55	-3.26	-1.09	<.001
	T1 – T2	-0.37	0.52	-1.39	0.65	.481
● Positive outcome	T0 – T1	-1.03	0.28	-1.57	-0.48	<.001
	T0 – T2	-1.25	0.30	-1.85	-0.66	<.001
	T1 – T2	-0.23	0.10	-0.43	-0.02	.029
● Negative outcome	T0 – T1	-0.78	0.33	-1.43	-0.14	.017
	T0 – T2	-0.92	0.45	-1.80	-0.05	.038
	T1 – T2	-0.14	0.50	-1.12	0.85	.782

Table 8.15 Pairwise comparison of outcome expectancy beliefs between time points in CG (n = 80)

Communication Outcomes Questionnaire	Pairwise comparison	Mean Difference	Standard Error	95% Confidence Interval		<i>p</i>
● Total score	T0 – T1	1.51	0.54	0.46	2.57	.005
	T0 – T2	2.11	0.59	0.95	3.27	<.001
	T1 – T2	0.60	0.25	0.11	1.09	.017
● Positive outcome	T0 – T1	0.80	0.35	0.12	1.48	.022
	T0 – T2	1.06	0.40	0.28	1.85	.008
	T1 – T2	0.26	0.13	0.01	0.51	.041
● Negative outcome	T0 – T1	0.71	0.33	0.07	1.35	.029
	T0 – T2	1.05	0.37	0.33	1.77	.004
	T1 – T2	0.34	0.22	-0.10	0.77	.129

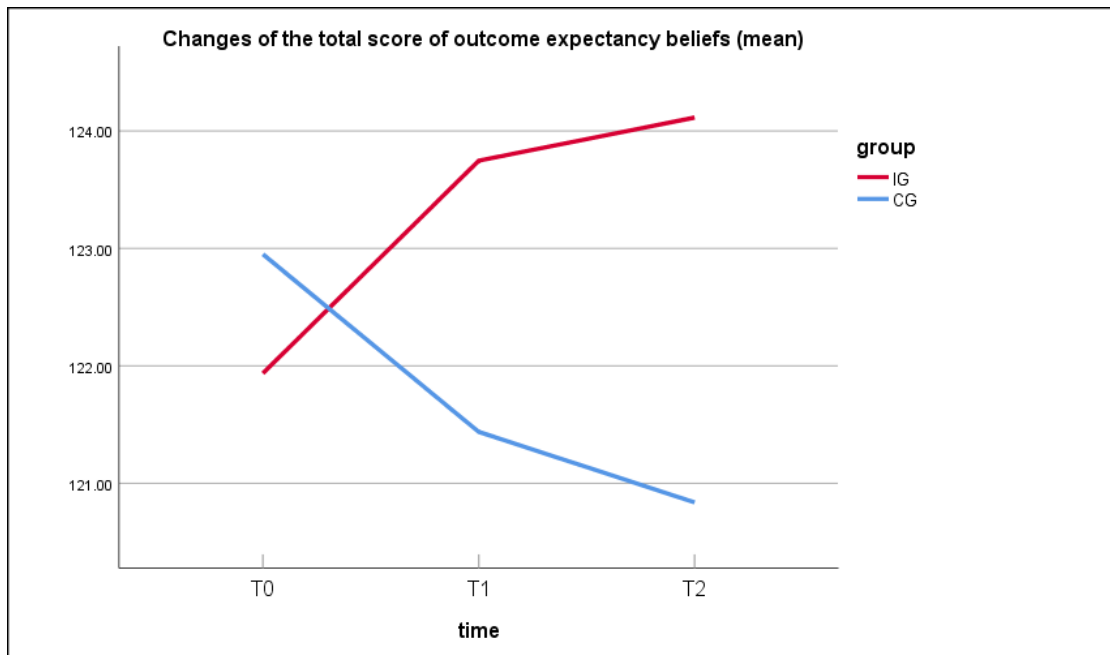


Figure 8.17 Comparison of the total score of outcome expectancy beliefs between groups over the three time points

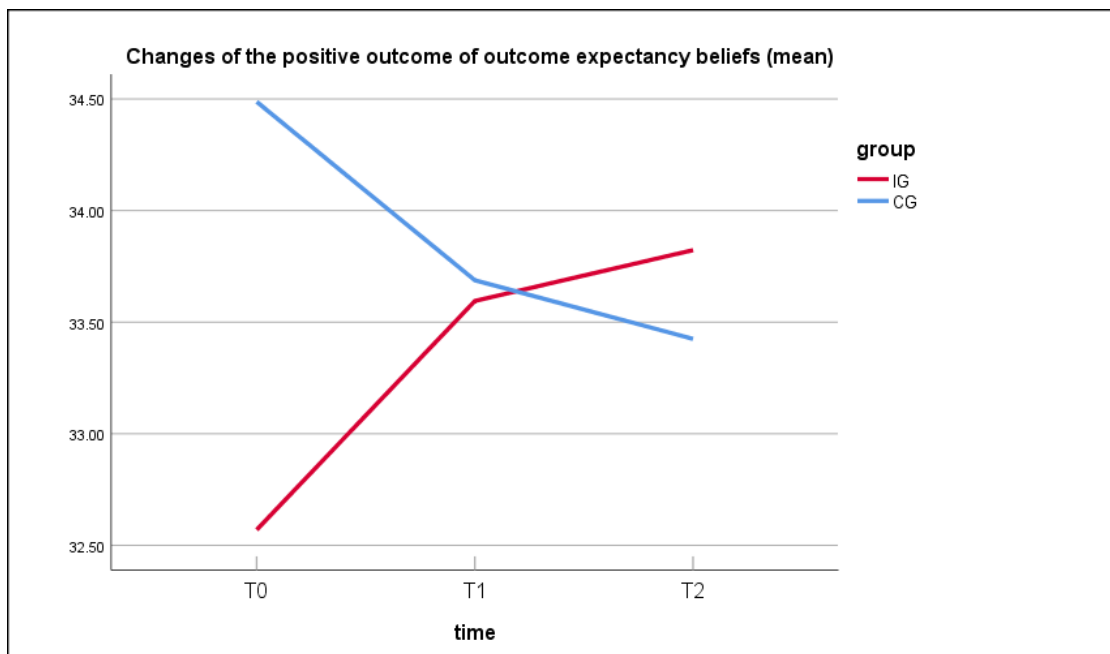


Figure 8.18 Comparison of the positive outcome of outcome expectancy beliefs between groups over the three time points

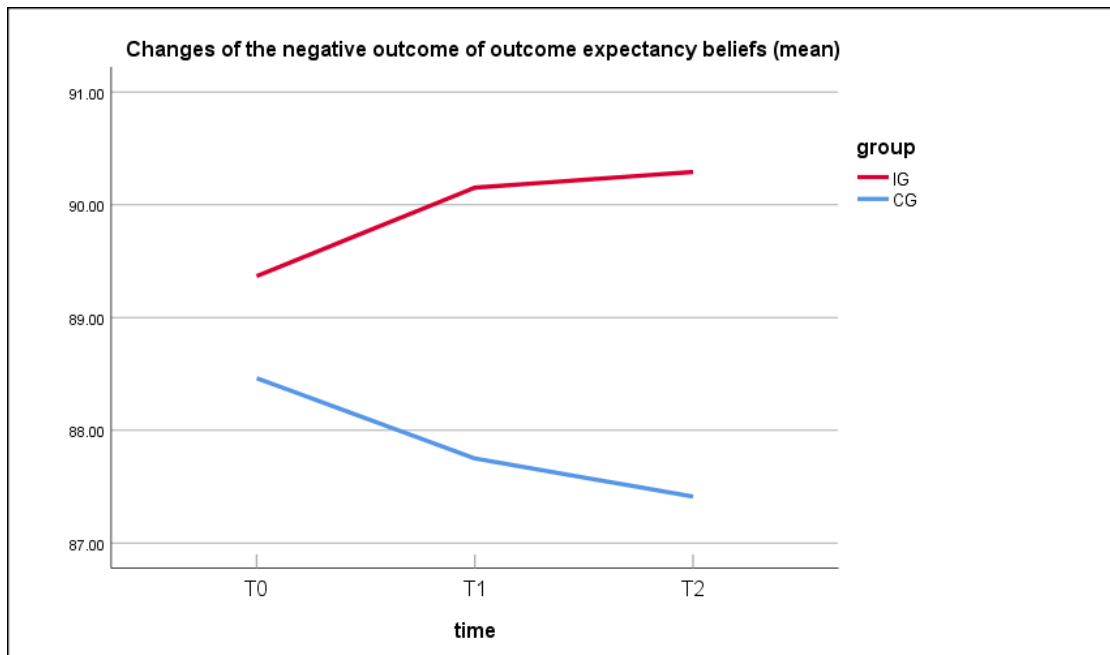


Figure 8.19 Comparison of the negative outcome of outcome expectancy beliefs between groups over the three time points

8.3.4 Post-hoc analysis results of contamination

In total, 25 participants reported that they had read another participant's training material or had discussed the training contents with other participants (14 participants reported at T1 and 11 at T2), which is marked as contaminated data in the current study. Table 8.16 shows the outcome comparisons in the paired groups (i.e., IG vs contaminated CG, IG vs non-contaminated CG, and contaminated CG vs non-contaminated CG).

For self-reported communication skills, in comparison with the contaminated CG and the non-contaminated CG, the IG showed significant improvements in overall communication skills ($p = .015$; $p = .002$), basic non-verbal communication skills ($p = .002$; $p < .001$), emotional perception skills ($p = .012$; $p = .002$) and communication skills in difficult clinical situations ($p = .002$; $p = .003$). However, there were no significant differences between the contaminated CG and the non-contaminated CG in these domains, indicating that although contamination may have reduced the difference between CG and IG, it did not significantly affect the overall communication skills, basic non-verbal communication skills, emotional perception skills and communication skills in difficult clinical situations of the CG. In basic verbal communication and emotional support skills, IG significantly improved compared to the non-contaminated CG ($p = .022$; $p = .047$). However, there were no significant improvements compared to the contaminated CG. This suggests contamination may have improved CG's basic verbal communication and emotional support skills (Figure 8.20 – 8.21). However, there were also no significant differences between contaminated CG and non-contaminated CG in these two domains.

In the total score and modular scores of the observer-assessed communication skills, IG showed significant improvements compared to both contaminated CG and non-contaminated CG (all $p < .001$, except IG vs contaminated CG on module 1, $p = .015$ and IG vs contaminated CG on module 2, $p = .003$). There was no significant difference between the contaminated CG and the non-contaminated CG on the total and modular scores, except for module 2 ($p = .037$). This suggests that contamination may have improved the module 2 score in CG (Figure 8.22).

In self-efficacy and outcome expectancy beliefs, there were no significant differences between the IG and CG subgroups or between the two CG subgroups.

In summary, contamination appeared to impact some outcomes for the CG. Nevertheless, IG improved in most areas more than the two CG subgroups, indicating that the intervention effectively enhanced communication skills, self-efficacy and outcome expectancies.

Table 8.16 Change in outcomes from T0 to T2 in the IG vs "contaminated" and "non-contaminated" CG subgroups

Outcomes	Pairwise comparison	Mean Difference	Standard Error	95% Confidence Interval		<i>p</i>
Self-report communication skill						
● Overall skills	IG – Contaminated CG	0.22	0.09	0.04	0.41	.015
	IG – Non-contaminated CG	0.25	0.08	0.09	0.41	.002
	Contaminated CG – Non-contaminated CG	0.03	0.11	-0.19	0.24	.814
● Basic verbal communication skills	IG – Contaminated CG	0.12	0.12	-0.11	0.34	.323
	IG – Non-contaminated CG	0.24	0.11	0.03	0.45	.022
	Contaminated CG – Non-contaminated CG	0.13	0.14	-0.15	0.40	.368
● Basic non-verbal communication skills	IG – Contaminated CG	0.31	0.10	0.11	0.51	.002
	IG – Non-contaminated CG	0.34	0.08	0.18	0.51	<.001
	Contaminated CG – Non-contaminated CG	0.03	0.12	-0.20	0.27	.779
● Emotional perception skills	IG – Contaminated CG	0.27	0.11	0.06	0.48	.012
	IG – Non-contaminated CG	0.27	0.09	0.09	0.44	.002
	Contaminated CG – Non-contaminated CG	0.00	0.12	-0.24	0.23	.968
● Emotional support skills	IG – Contaminated CG	0.06	0.12	-0.18	0.30	.626
	IG – Non-contaminated CG	0.21	0.11	0.00	0.43	.047
	CG					

● Communication skills in difficult clinical situations	Contaminated CG – Non-contaminated CG	0.15	0.15	-0.13	0.44	.288
	IG – Contaminated CG	0.29	0.09	0.11	0.47	.002
	IG – Non-contaminated CG	0.23	0.08	0.08	0.37	.003
	Contaminated CG – Non-contaminated CG	-0.06	0.10	-0.26	0.14	.549
Observer-assessed communication skill						
● Total score	IG – Contaminated CG	8.26	1.28	5.74	10.77	<.001
	IG – Non-contaminated CG	10.06	1.13	7.84	12.29	<.001
● Module 1	Contaminated CG – Non-contaminated CG	1.81	1.36	-0.86	4.47	.184
	IG – Contaminated CG	1.37	0.56	0.26	2.47	.015
	IG – Non-contaminated CG	2.05	0.42	1.24	2.87	<.001
	Contaminated CG – Non-contaminated CG	0.69	0.59	-0.47	1.84	.244
● Module 2	IG – Contaminated CG	1.69	0.57	0.57	2.82	.003
	IG – Non-contaminated CG	2.94	0.50	1.97	3.92	<.001
	Contaminated CG – Non-contaminated CG	1.25	0.60	0.07	2.43	.037
	IG – Contaminated CG	3.29	0.86	1.61	4.97	<.001
● Module 3	IG – Non-contaminated CG	3.17	0.70	1.79	4.55	<.001
	Contaminated CG – Non-contaminated CG	-0.12	0.99	-2.06	1.81	.902

● Module 4	IG – Contaminated CG	1.91	0.45	1.03	2.78	<.001
	IG – Non-contaminated CG	1.90	0.43	1.06	2.74	<.001
	Contaminated CG – Non-contaminated CG	0.01	0.44	-0.88	0.86	.985
Self-efficacy						
● Overall self-efficacy	IG – Contaminated CG	0.05	0.11	-0.16	0.26	.672
	IG – Non-contaminated CG	0.09	0.09	-0.08	0.26	.299
	Contaminated CG – Non-contaminated CG	0.05	0.11	-0.17	0.27	.686
● Mental and spiritual care of dying patients	IG – Contaminated CG	0.04	0.11	-0.18	0.25	.748
	IG – Non-contaminated CG	0.07	0.09	-0.10	0.25	.409
	Contaminated CG – Non-contaminated CG	0.04	0.12	-0.19	0.27	.747
● Family care	IG – Contaminated CG	0.06	0.11	-0.16	0.28	.601
	IG – Non-contaminated CG	0.11	0.09	-0.07	0.30	.221
	Contaminated CG – Non-contaminated CG	0.06	0.12	-0.17	0.28	.631
Outcome expectancy beliefs						
● Total score	IG – Contaminated CG	-1.33	4.76	-10.67	8.01	.780
	IG – Non-contaminated CG	-0.07	3.95	-7.81	7.67	.986
	Contaminated CG – Non-contaminated CG	1.26	4.78	-8.12	10.64	.792
● Positive outcome	IG – Contaminated CG	-0.68	2.04	-4.68	3.32	.738
	IG – Non-contaminated CG	-1.88	1.44	-4.70	0.94	.192

		CG					
● Negative outcome		Contaminated CG –	-1.20	2.18	-5.48	3.08	.583
		Non-contaminated CG					
		IG – Contaminated CG	-0.65	4.00	-8.50	7.20	.871
		IG – Non-contaminated	1.81	3.50	-5.05	8.67	.605
		CG					
		Contaminated CG –	2.46	4.17	-5.72	10.64	.556
		Non-contaminated CG					

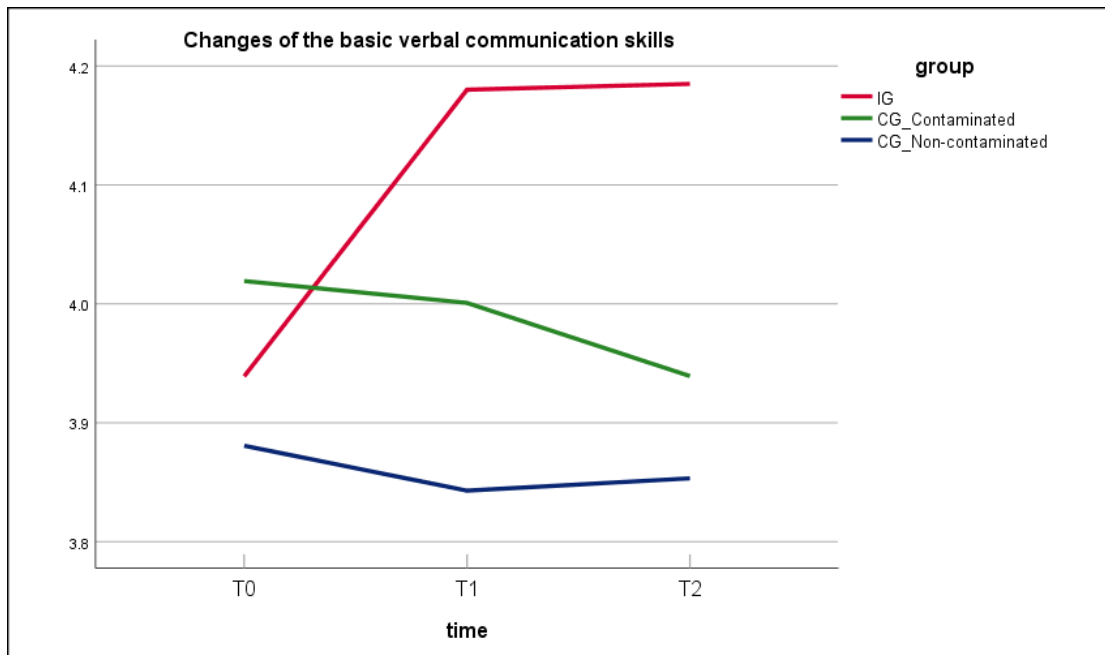


Figure 8.20 Comparison of the basic verbal communication skill between IG and CG subgroups over the three time points

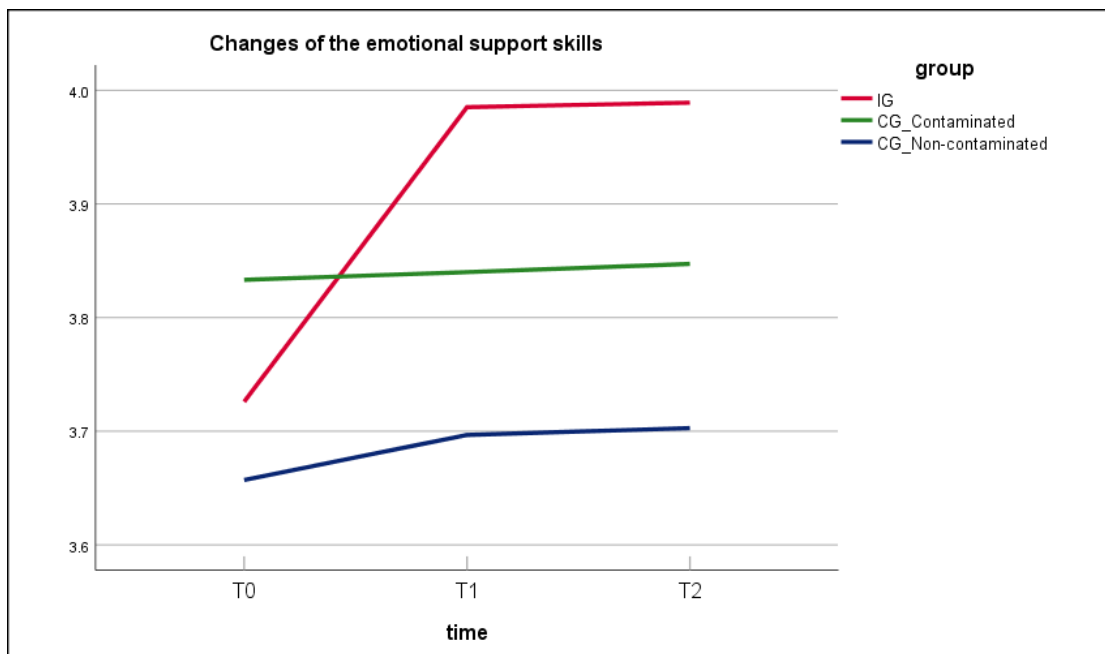


Figure 8.21 Comparison of the basic verbal communication skill between IG and CG subgroups over the three time points

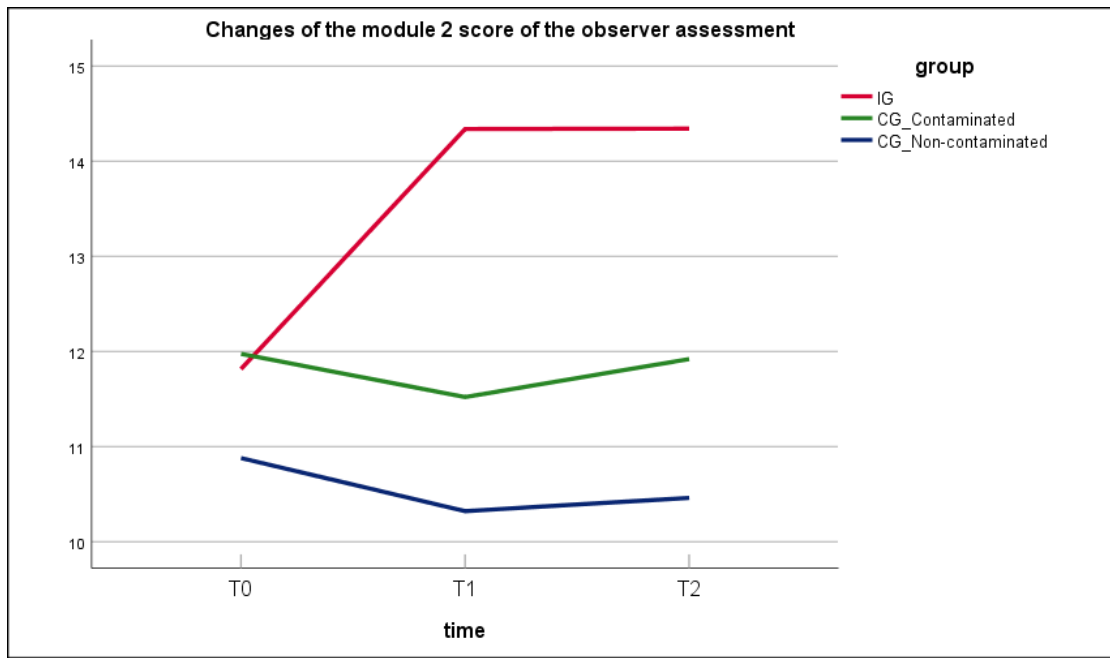


Figure 8.22 Comparison of the module 2 score of the observer assessment between IG and CG subgroups over the three time points

8.3.5 Results of process evaluation

8.3.5.1 Acceptability and satisfaction

8.3.5.1.1 Retention rate

The overall retention rate of the study was 91.82% (146/159). Specifically, the retention rate of participants in the IG was 94.94% (75/79). Two participants were unable to participate in the sessions due to time conflicts (2.53%, 2/79), and the other two participants did not participate in the T1 and T2 assessments. The retention rate of participants in the CG was 88.75% (71/80). Three participants dropped out during the training due to time conflict or health issues (3.75%, 3/80). Six participants were absent in the T1 and T2 assessments.

8.3.5.1.2 Attendance and adherence

Table 8.17 shows the attendance rates of IG and CG in each session. The average attendance rates in IG and CG were 91.30% and 91.88%, respectively. The attendance rate in IG ranged from 78.48% to 100%; in CG, it ranged from 85.00% to 100%. The adherence rate (i.e., the attendance rate was equal to or greater than 75%) was 78.48% (62/79) in IG and 85.00% (68/80) in CG. Among the participants who dropped out during the training, two drop-outs in IG completed 6 and 5 sessions, respectively. In CG, two drop-outs completed three sessions, and one participant completed four sessions.

Table 8.17 The attendance rates of IG and CG in each session

Module	Session	Attendance	
		IG (n = 79)	CG (n = 80)
Module 1	Session 1	79 (100%)	80 (100%)
	Session 2	79 (100%)	80 (100%)
Module 2	Session 3	79 (100%)	72 (90.00%)
	Session 4	70 (88.61%)	77 (96.25%)
Module 3	Session 5	67 (84.81%)	71 (88.75%)
	Session 6	62 (78.48%)	70 (87.50%)
Module 4	Session 7	72 (91.14%)	68 (85.00%)
	Session 8	69 (87.34%)	70 (87.50%)

8.3.5.1.3 Self-reported satisfaction

Seventy-seven participants from the IG rated their satisfaction with the training. The scores were: training structure ($M = 6.56$, $SD = 1.04$, Range 5~10); training content ($M = 7.19$, $SD = 0.71$, Range 5~9); training methods ($M = 6.32$, $SD = 0.70$, Range 6~9); work relevance ($M = 7.38$, $SD = 1.10$, Range 4~10); and overall satisfaction ($M = 7.42$, $SD = 0.78$, Range 6~10).

8.3.5.1.4 Adverse events

No participants reported dropping out of the training because it covered topics related to death, dying, or other emotional issues.

8.3.5.1.5 Cost

The training staffing consists of 2 trainers, 2 SPs and three observers. The training costs approximately 10,000 yuan, with the majority allocated towards the salaries of the invited nurse trainer, external observers, and SPs.

8.3.5.2 Experience and suggestions

Three focus group discussions were arranged within one month after the IG received the intervention to share participants' experiences and suggestions. Seventeen participants joined the focus group discussions (6, 5 and 6 participants in each group). Participants' characteristics are shown in Table 8.18. The average age of the participants was 32.64. Most participants were female (94.12%), had medium professional titles (64.71%), had bachelor's degrees (82.35%) and had no religious belief (94.12%).

Analysis of the focus group discussions revealed three themes and 14 categories of participants' experiences and suggestions (Table 8.19).

Table 8.18 Participants' characteristics (N = 17)

Characteristics	Mean/ Frequency	SD/ Percentage (%)
Age (years)	32.64	3.21
Gender		
● Male	1	5.88
● Female	16	94.12
Professional title		
● Junior	3	17.64
● Medium	11	64.71
● Senior	3	17.65
Education level		
● Undergraduate	14	82.35
● Master	3	17.65
Working years	7.46	5.41
Number of years involved in the care of advanced patients	7.21	4.37
Religion		
● None	16	94.12
● Buddhism	1	5.88
Department		
● Surgical oncology	4	23.53
● Radiation oncology	6	35.29
● Medical oncology	4	23.53
● Other	3	17.65

Table 8.19 Themes and categories of participants' experiences and suggestions

Themes	Categories
An innovative training for professional and personal growth	<ul style="list-style-type: none"> ● Uncommon training topics ● Context-relevant training contents ● Improved knowledge and skills ● Enhanced confidence ● Increased reflections on life and death
Facilitators and barriers in the learning process	<ul style="list-style-type: none"> ● Facilitators: well-designed modules ● Facilitators: clear guidance ● Facilitators: responsible organisation ● Barriers: limitations of training format ● Barriers: inadequate exposure to the real interaction
Suggestions and expectations for future training	<ul style="list-style-type: none"> ● Increase direct interaction with patients and families ● Combination structure of online and offline ● Multidisciplinary training ● Connect to available local resources

8.3.5.2.1 *An innovative training for professional and personal growth*

Most participants said this was their first time attending end-of-life CST, and they believed that training on this topic was uncommon. They reported having had few opportunities to participate in systematic CST in their previous training experiences. They thought the training's close integration with Chinese culture and the situation of Chinese hospitals was a distinctive feature and advantage.

The training was interesting and unique, and I had not participated in similar training before, which made me feel very innovative. (Focus group 1, N4)

The combination of training and culture allows us to delve into many topics about our country, which makes the training different. We rarely discuss these things regularly, even if we encounter communication problems in this area at work. (Focus group 2, N5)

Most participants emphasised the practicability of training and affirmed its guiding role in practice. The good usefulness of the training was mainly due to the inclusion of real clinical cases, many of which participants believed they had encountered similar situations in their work. Most participants felt that the modules covered the questions and confusion they often encountered in communicating with terminally ill patients and their families. In addition, the training gave practical guidance and suggestions on these cases, combined with video demonstrations, to increase practical communication skills.

Overall, the content of the training was very practical, and many cases and stories shared by the teachers were very impressive, which made me feel closely connected with my work. The training was not metaphysical or unrealistic. (Focus group 2, N3)

The teacher gives practical communication guidance, which is valuable and worth chewing repeatedly after class. (Focus group 1, N1)

The case analysis is excellent and super detailed at the communication level, listing strategies, skills, etc. It's conducive for me to understand and better connect theory with practice. (Focus group 3, N1)

Participants reported that the training increased their knowledge of end-of-life communication and improved their communication skills. They believed that it is essential to better care for terminally ill patients and their families. Some participants reported increasing end-of-life discussions with colleagues and looking for opportunities to practice the knowledge and skills they had learned at work.

Specific content has given me new perspectives, such as the second module on engaging in discussions with family members, which had not previously crossed my mind. I believe it is crucial to respect the viewpoints of family members, and I had never considered ways to influence their opinions. However, through practical experience, I have realised that actively communicating with family members can be beneficial. Therefore, I intend to make a greater effort in future endeavours by fostering dialogue with them. (Focus group 1, N1)

The combination of case study and role-play allows me to practice. With the deepening of the training, I think I have become familiar with some general skills. (Focus group 2, N2)

I previously had limited familiarity with this aspect and had minimal knowledge about it. However, I find the training content remarkably comprehensive, incorporating simulation exercises. Additionally, each practice session is accompanied by valuable feedback from the instructor, which significantly enhances its effectiveness. This enables me to identify my communication characteristics and weaknesses more clearly, facilitating improvements in my professional performance. (Focus group 2, N4)

We should increase such discussions in the department and set communication goals so that the knowledge and skills we have learned can truly care for patients. (Focus group 3, N5)

Several participants reported that the training made them less worried and more confident about discussing end-of-life topics than before. This enhanced confidence stems from the comprehensive content covered in the training, engaging class discussions, practical role-play exercises, and prompt feedback. The role-play simulations allowed participants to gain insight into and prepare for potential patient and family reactions regarding end-of-life communication.

The training comprehensively covered our everyday clinical situations. Through extensive discussions and practical exercises, I gained a heightened sense of confidence in initiating end-of-life communication. (Focus group 1, N5)

In the past, like many people, I may have felt that it is not good to talk about this, and I do not know how to say it, and there are always a lot of concerns, but this training makes me feel like I know how to do it. (Focus group 3, N5)

In addition, some participants reported that the training increased their reflection on life

and death; some even felt that it changed their outlook on life and death. They thought this training improved their communication skills and provided a personal growth experience.

I love our class discussions. It's interesting to see how people's opinions collide and how different they are. I think this is a humanistic feature of this training, which subtly affects our ideas. (Focus group 1, N2)

Initially, I wanted to participate in this training because of my family's illness, and I have communication needs in this aspect, so I wanted to know about this knowledge. These courses also made me reflect more on life and death. (Focus group 2, N2)

I think the training will also be helpful for my personal growth. These are topics that we may not usually discuss and will not be covered in the school, and this training is an excellent complement to this shortcoming. Some of the discussions about death were powerful but realistic, and they prompted me to reflect on my purpose and meaning in life. (Focus group 2, N4)

8.3.5.2.2 Facilitators and barriers in the learning process

Participants felt that the training was well designed, with each module being a separate topic but the topics being related to each other. The moderate difficulty of the course and the training method can combine theory with practice; these factors promote their persistence in the learning process. In particular, they mentioned some course designs that appealed to them, such as classroom reflections, discussions on common clinical communication practices, and the humanistic stories shared in the self-study materials.

I think the layout and design of the whole course are relatively reasonable. The class focuses on solving four everyday communication situations in our clinical work. The four modules are interrelated, and some communication skills can be learned and consolidated repeatedly. I think the learning difficulty is relatively moderate, allowing learners to get into the state quickly. (Focus group 1, N1)

The first thing that attracted me was the content of the training. I think this topic is interesting, and I want to continue learning to see how these topics are communicated. These cases give me a lot of inspiration. (Focus group 2, N2)

Each class allows us to discuss different topics with colleagues and reflect on our communication practices (Focus group 2, N1)... Yes, and the teacher will share a humanistic story about the theme after each class. I think these designs are

excellent. Communication is a matter that varies from person to person; it is not to dictate what to do but to let us feel and think in the learning process. (Focus group 2, N4)

Many participants felt that the facilitator's clear explanations, detailed video presentations, and immediate feedback during role-play exercises gave them clear guidance.

The teachers spoke very clearly and were able to answer our questions promptly... Whether in class or in practice, the teachers can give us more detailed feedback, which is the most helpful for me. (Focus group 1, N3)

Clear explanations and guidance help me understand these knowledge points better. (Focus group 2, N4)

I thought the teacher spoke very well and clearly, connecting complex concepts, such as grief, to our daily lives so that I could understand them immediately. (Focus group 3, N1)

The cases and videos are the most effective for me. The knowledge points about communication are clearly presented in the videos, and the teachers will take us to practice together. (Focus group 3, N2)

In addition, responsible organisation, including flexible scheduling, responding to trainees' needs, answering trainees' questions, etc., keeps participants more motivated during the learning process.

The training organisation demonstrates great attention to detail, starting from the initial promotion of the training program and extending to each module's instruction and simulation exercises. Every aspect is handled with utmost responsibility by the instructors, which has significantly enhanced my commitment towards this training (Focus group 1, N2) ... Additionally, the course schedule considers the practical circumstances of nurses and offers a certain level of flexibility, fostering greater engagement among participants. (Focus group 1, N5)

Whenever I have questions, the teachers can provide prompt answers, which motivates me to complete the self-study content. (Focus group 2, N5)

The teacher can assist us in coordinating our schedules, which is highly beneficial in time management and demonstrates their friendliness towards us. (Focus group 3, N2)

The offline-only format may restrict participants' learning opportunities and impact

their overall learning experience, particularly for those unable to attend in person.

Because the training was all offline, I felt a little inconvenienced, so I missed a theoretical course and only attended the practical one. Although I went to read the materials shared by the teacher before attending the practice class, I still felt a little confused without the teacher's explanation. So I was a little lost in the practice class. I thought it would be nice if I had a taped course that I could watch repeatedly. (Focus group 2, N2)

The offline training facilitated communication but imposed additional scheduling demands that necessitated prior negotiation with my supervisor. (Focus group 3, N2)

Another obstacle to learning mentioned by participants was a lack of sufficient hands-on opportunities, particularly in limited interaction with patients and their families. This resulted in uncertainty regarding the actual response of patients and families towards these communication strategies. Although simulation exercises were conducted with colleagues, participants expressed concerns about encountering more intricate communication scenarios in real-life work situations.

The simulation exercises mainly enable me to apply the communication strategies and skills I have learned. Still, these exercises may not be enough for me to cope with the changing communication situations in clinical work. For example, the patient's family situation may be more complicated, or the patients and their families with different education levels still need constant adjustment of my language and communication skills. Of course, this is a characteristic of communication: there is no one-size-fits-all formula. But I think if we can get more exposure to patients and families, it will help us more. (Focus group 3, N4)

8.3.5.2.3 Suggestions and expectations for future training

Regarding the recommendations for future training, participants emphasised the necessity of incorporating direct interaction with patients and families. This can be achieved by inviting patients and families to share their communication experiences with trainees, engaging in simulation exercises, and expressing their perspectives on trainees' communication.

I think involving terminally ill patients and families in training can be challenging, and it's not an easy thing to do when they're dealing with their challenges in life. However, for some patients who have had cancer experiences, as well as bereaved

family members, if they can participate in the interaction with the students and share their knowledge, it may give us a better learning experience and achieve better learning results. (Focus group 2, N4)

The development of additional online learning resources, integrating online and offline training, is eagerly anticipated by numerous participants. This integration is believed to enhance the flexibility of learning, broaden the accessibility of educational materials, and extend training opportunities to a broader population.

Some of the theoretical aspects can be implemented online. Of course, live communication with teachers is beneficial, but online resources may allow me to organise my studies more freely. (Focus group 1, N1)

I'm excited about having more awesome learning resources and methods in the future, like setting up online forums to discuss each topic, just like how people interact on the internet. I'll be even more eager to share my ideas. (Focus group 2, N1)

The teacher has unreservedly shared many valuable resources and learning materials with us. If there is an online platform like a website or public account in the future, we can get the learning resources at any time and share them with more people in need. (Focus group 2, N4)

Participants also recommended multidisciplinary training, particularly involving physicians. It is worth considering incorporating training on interprofessional care and effective team communication. They expressed their anticipation for further discussions and simulation exercises with other healthcare professionals to enhance their understanding of end-of-life communication perspectives during the training.

It might be interesting to include doctors, and that's the kind of communication we need to strengthen. How doctors assess the life expectancy of patients, how we negotiate with doctors, set communication goals, etc., are aspects of team communication that may need more practice. I also wonder about the doctor's perspectives on these cases since their viewpoint differs from ours. (Focus group 1, N3)

The participants also desired additional training content about local resources, including local end-of-life care professionals who can share their communication experiences and provide information on local end-of-life care resources and policies. They believe incorporating these aspects will enhance the overall quality

and practicality of the training program.

Is it possible to invite professionals from other institutions, such as the staff of hospice centres? I think they may have experience in this field, and their practice-based sharing may give us a greater harvest. (Focus group 3, N3)

In recent years, there has been significant progress in the field of hospice care, leading to the establishment of several hospice service centres. These service facilities and corresponding policy advancements can be incorporated into the training program to enhance trainees' understanding of these developments. (Focus group 3, N2)

8.4 Discussion

8.4.1 Summary of the study findings

The results of the study showed that communication skills, self-efficacy, and outcome expectancy beliefs among IG oncology nurses after receiving CST were significantly improved compared to those of CG on the waitlist without receiving CST during the same period. The process evaluation findings indicated that the training exhibited high retention, attendance, and adherence levels. Participants expressed high satisfaction with the training program and displayed good acceptance towards the training structure, methods, content, and relevance of the training to their work. Furthermore, the results of focus group discussions revealed that participants recognized the novelty and benefits of this training experience. They also identified facilitators and obstacles encountered during the learning process while providing recommendations for future training.

8.4.2 Discussion on the effects of skills

The culturally specific CST program significantly enhanced nurses' communication skills, as evidenced by self-reports from the participating nurses and external evaluations conducted by observers. The observed improvements in the overall, dimensional (i.e., non-verbal, emotional perception, difficult clinical situation, verbal and emotional support) and modular communication skills (i.e., responding to patient cues, negotiating with the family, nurturing hope, and bereavement support) were immediate and sustained in the short term, lasting for one month.

The significant positive changes in communication skills may be attributed, on the one hand, to the fact that the training program addressed the inadequacy of nursing education and training resources in end-of-life communication skills (X. Chen, Y. X. Zhang, et al., 2022). The CST provided participating nurses valuable opportunities to

learn and practice end-of-life communication skills. On the other hand, the training program's content may fulfil or respond to nurses' longstanding need for culture-related end-of-life communication training. In a qualitative study (Zheng et al., 2015), oncology nurses have elucidated that a prevalent communication challenge pertains to the lack of disclosure regarding terminally ill patients' condition and their consequent inability to engage in discussions concerning end-of-life matters. This communication challenge is believed to be closely intertwined with cultural factors, such as prevailing taboos surrounding conversations about death and the influence of family-oriented decision-making in Chinese context (Turnbull et al., 2023). The CST utilized two modules with four sessions to thoroughly discuss and practice culturally relevant communication. This included understanding how to identify and respond to patient cues regarding end-of-life discussions and consulting with family members to inform patients about their condition and foster comprehension and consensus. By incorporating reflective discussions on usual daily clinical practice, explaining helpful communication strategies, and employing case-based video demonstrations and role plays, nurses' comprehension of end-of-life communication within the Chinese socio-cultural context may have been significantly deepened. In comparison to a previous workshop on breaking bad news in Mainland China (Wuensch et al., 2013), the current training encompasses end-of-life communication topics that extend beyond the process of breaking bad news. Furthermore, reflections, discussions and exercises on culturally relevant communication practices are more systematic and in-depth in this CST.

A similar CST program in the US offers a one-day workshop training for oncology nurses, which is also based on the Comskil model (Brown & Bylund, 2008) and includes three modules: empathizing with patients, interacting with family members, and discussing death, dying, and goals of care (Coyle et al., 2015). After the training, participants reported improved empathic and clarifying skills (Banerjee et al., 2017;

Pehrson et al., 2016). These findings align with the results of this study, which showed enhancements in verbal, non-verbal, emotional perception, and emotional support skills. However, it should be noted that none of these studies of the CST in the US (Banerjee et al., 2017; Coyle et al., 2015; Pehrson et al., 2016) employed a rigorous RCT design, which may have limited the quality of research evidence. Despite using different assessment tools that hinder direct comparison between studies, both this CST and the training above in the US demonstrate how module development based on the Comskil model can effectively improve communication skills among oncology nurses. The model offers a comprehensive and valuable framework for developing CST for nurses.

The observer external evaluation results in this study demonstrated congruent changes in communication skills with the nurses' self-evaluation. Specifically, the trained nurses exhibited significant improvement on the 4-module simulation assessment. One possible explanation for this finding is that the external assessment tool used was study-specific, developed from the training module and closely related to the training content, making it more sensitive to detect changes in communication performance among trained nurses. As there is a lack of standard outcome measurement tools in nurses' CSTs (Kerr et al., 2020), the study-specific checklist is valuable and offers an approach to directly observe and assess how training content impacts nurses' communication performance. Future studies could adopt a similar checklist while also considering multi-perspective assessments. A German CST (Harnischfeger et al., 2022) incorporates participants' self-reports, SP ratings and investigator assessments, emphasising the necessity of blind measures for external evaluation. In addition, it is essential to note that multi-perspective assessments may require additional workforce, material resources, and time costs. Therefore, exploring cost-effective approaches for such evaluations should be considered a vital direction for developing CST evaluation tools or methods. Computational linguistic analysis shows significant potential in

optimizing resource allocation and time efficiency (Ali et al., 2023; Singy et al., 2012). It enables communication performance evaluation and offers trainees repeatable practice opportunities and immediate feedback. The training content developed in this study can provide valuable support for the future development of computational linguistic analysis software and online dialogue systems.

8.4.3 Discussion on the effects of self-efficacy

Self-efficacy is an individual's estimate of self-confidence in one's ability to successfully perform a specified task (Bandura, 1977). The results of this study show that trained nurses experienced significant improvements in their self-efficacy in the mental and spiritual care of dying patients and family care. Similarly, prior studies concerning end-of-life CST for nurses (Banerjee et al., 2017; Brown et al., 2018; S. H. Chen et al., 2021; Coyle et al., 2015; Kerr et al., 2021; Pehrson et al., 2016; Wilkinson et al., 2008) also found improvements in self-efficacy. In contrast, minor changes and undesirable declines in self-efficacy were observed in the CG. Since clinical experience and time alone do not alleviate healthcare providers' communication problems in the field of cancer care (Fallowfield et al., 2002), compulsory CST may be necessary, and resources should be allocated to support such training.

Effective communication is the fundamental skill required for providing high-quality end-of-life care (National Consensus Project for Quality Palliative Care, 2018). The current CST enhanced participating nurses' communication skills in providing family and mental and spiritual care may increase their self-efficacy in such care. For instance, during sessions 3 to 4 (module 2), end-of-life communication with families in the Chinese context was well discussed, including some common communication challenges reported by nurses, e.g., the family's preference to conceal the truth from the patient (Zheng et al., 2015). Module 4 explained the communication strategies and skills regarding bereavement support for the family. Patients' and families' emotional

expression and meaning construction after the possible prognosis and goals of care discussions were trained in module 3. Creating space for expressing emotions and encouraging meaning-based coping were identified as spiritually sensitive communication strategies (Reblin et al., 2014). These training contents may enhance participants' confidence in providing mental, spiritual and family care for terminally ill patients and their families.

Although the participants' actual communication behaviour changes were not evaluated in the current study, self-efficacy is believed to be a vital predictor of communication behaviours, according to Parle's training model (Parle et al., 1997). Studies show that learners with high levels of self-efficacy are more willing to take on challenging tasks, work more, and persevere longer when faced with challenges (Bandura & Locke, 2003; Liénard et al., 2010). The findings suggest that nurses who received training in this study may exhibit enhanced communication performance in clinical practice, particularly when faced with challenging end-of-life communication scenarios. However, further research is required to validate this hypothesis. Furthermore, nurses' perceived confidence in providing end-of-life care may prove advantageous in mitigating stress levels and enhancing job satisfaction (Wilkinson et al., 2008). More research is needed to assess the effects of the CST on nurses' psychological and occupational health.

8.4.4 Discussion on the effects of outcome expectancy beliefs

Similar to self-efficacy, outcome expectancy belief is also an integral component of Bandura's social learning theory (Bandura, 1977). Parle et al. (1997) include outcome expectancy beliefs in the integrated training model and explain it as the individual's belief in the anticipated consequences of performing a specific task. In previous studies, nurses reported uncertainty about end-of-life communication (Alshammari et al., 2022; Libo-On & Nashwan, 2017). Moreover, cultural taboos and social attitudes towards

death and dying contribute to nurses' avoidance towards end-of-life communication (Tu et al., 2022), which manifests their negative communication outcome expectancies. The current study found a significant positive change in participating nurses' outcome expectancies in IG after the training, compared to CG. The CST program may enhance the awareness and preparedness of nurse participants regarding potential communication behaviours exhibited by patients and families in various end-of-life communication scenarios, thereby resulting in positive communication outcome expectancies. The finding aligns with previous training programs (Connolly et al., 2014; Reese et al., 2019).

Liu's CST on generic communication skills for oncology nurses (Liu et al., 2007) did not yield significant changes in nurses' negative outcome expectancies, suggesting that beliefs on negative outcome expectancies may be influenced by their prior experiences and it might be challenging to alter the beliefs on negative outcome expectancies in a short period of training. In contrast, this study demonstrated a noteworthy improvement in nurses' negative outcome expectancies (Wald $\chi^2 = 15.13$, $p = .001$), potentially attributable to the incorporation of role-play simulation and immediate feedback. The simulation allows participants to repeat and improve on possible responses of patients and families in end-of-life communication. Immediate feedback from facilitators and observers aids in identifying areas for improvement as well as strengths in participants' communication. These training methods may help participants accumulate positive communication experiences and improve their outcome expectancies.

Both self-efficacy and outcome expectancy beliefs predict actual clinical practice behaviours (Mason & Ellershaw, 2004; Parle et al., 1997). Thus, the positive changes in nurses' outcome expectancy beliefs indicate that the participants are more likely to adopt the learned communication strategies and skills to communicate end-of-life

topics with patients and families. The small effect size should be noted (Cohen's $d = 0.01\sim0.19$), and a larger effect size may be observed by increasing the sample size (Sullivan & Feinn, 2012).

8.4.5 Discussion on participants' acceptability and satisfaction

The overall retention rate and average attendance rates across sessions exceeded 90%, indicating a high level of acceptability for the training program. The lower attendance rate observed in module 3 (less than 85%) can be attributed to the time conflicts with hospital activities during the training period. The certification and credits provided by the training program should not be overlooked in fostering acceptance.

The participants' satisfaction with the training structure, content, methods, work relevance, and overall training averaged between 6 and 8 on a scale of 10. The results of a systematic review on end-of-life CST revealed a significant disparity in the duration of the training, ranging from as short as 40 minutes to as long as 16 months (Brighton et al., 2017). Wong et al. (2022) compared training programs of varying durations and proposed that longer duration, precisely at least four sessions lasting 4 hours each, may be necessary for effective training for improving communication skills. In this study, the majority of participants found a total of 12 hours of training to be satisfactory, as reflected by their ratings, while a small number of participants highlighted during the focus group discussion that enhancing flexibility and accessibility through online courses could potentially lead to a reduction in offline training duration. The design of the modules took into consideration both the cultural context of end-of-life communication and the nurse's role, potentially enhancing participants' perception of the work relevance of the training program.

The training program did not elicit any adverse events, as evidenced by the absence of participant attrition due to sensitive or emotional topics. Conversely, the outcomes of

focus group discussions indicated that these end-of-life-related topics evoked positive introspection among participants. Adverse events in previous studies on end-of-life CST have not been reported (Brighton et al., 2017); thus, it is unknown what training content in previous training may trigger adverse events. This lack of information hinders comparison between studies and discussion on training content. Reporting on adverse events in future end-of-life CST may be required to assist researchers and educators in optimizing training content.

Implementing effective CST projects can be resource-intensive, encompassing various aspects such as staffing, scenarios, implementation strategies, and evaluation procedures (Ammentorp et al., 2014). However, it is noteworthy that a meta-analysis revealed that only 3% of CST initiatives reported their associated costs (Brighton et al., 2017), thereby leaving the cost-effectiveness of these projects largely unknown. This lack of information regarding costs could potentially impact the generalizability and sustainability of such endeavours. Vergo et al. (2022) introduced a three-hour program with low-cost and low-resource requirements, which involved replacing part of the lecture component with video materials, substituting SP simulation with role-playing activities among trainees, and single facilitator support throughout. Nevertheless, it should be acknowledged that this program had a relatively small sample size consisting of only 20 participants. Furthermore, its effectiveness was limited to basic rather than complex skills improvements. The main expenditure for this study primarily pertained to staffing requirements. Implementing a train-the-trainer program may prove beneficial in reducing costs (Wittenberg, Ferrell, et al., 2018).

8.4.6 Discussion on participants' experience and suggestions

The implementation of context-relevant or context-sensitive end-of-life CST enhances the training experience for participants. In this study, context-relevant training refers to the training components that consider the Chinese sociocultural and institutional

context, as explained by the participants. For instance, the modules were specifically designed to address challenging communication scenarios commonly encountered by nurses in their workplace context, which may explain why participants perceive the training as highly relevant. Moreover, each module incorporates group discussions reflecting context-sensitive communication challenges and common but undesired clinical practice. These components offer participants benefits beyond improving their communication skills, fostering increased reflexivity to effectively navigate evolving clinical interactions rather than relying solely on communication techniques (Stiefel & Bourquin, 2016).

Compared to previous end-of-life CSTs, such as those based on SICG (Adaji et al., 2024), COMFORT (Wittenberg, Reb, & Kanter, 2018), SPIKES (Kurji et al., 2021), etc., the communication strategies employed in this training also place a strong emphasis on exploring patients' understanding of prognosis and providing empathetic responses to their emotional reactions. In essence, the communication strategies for end-of-life communication share some commonalities (Bloom et al., 2022). The development of modules in this training adheres to these shared principles based on our prior work - the previous scope review (Chen et al., 2023). The difference is that the contextual relevance, including considerations of end-of-life communication within the Chinese sociocultural environment and hospital oncology care setting, contributes to this CST's distinctive advantages and differences compared to its predecessors. A previous end-of-life CST among undergraduate nursing students in China is grounded on the COMFORT and SPIKES models, aiming to enhance nursing students' attitudes towards death and their confidence in end-of-life communication (Li et al., 2023). Notably, the current CST distinguishes itself by incorporating communication strategies identified through qualitative research with Chinese stakeholders, rather than relying solely on Western-based communication models, such as the COMFORT and SPIKES

models.

The focus group discussions revealed a perception benefit that was not captured in the quantitative assessment: end-of-life CST increased participants' reflections on life and death. This finding aligns with previous simulation training studies conducted among nursing students (Bobianski et al., 2016; Wang & Yuan, 2022). Prior qualitative research has demonstrated that while nurses' professional values are congruent with those of end-of-life care, their personal values may be influenced by cultural and social contexts characterized by traditional death taboos (Tu et al., 2022). The enhancement of personal values observed among participants in this study underscores the additional advantages of end-of-life CST. It highlights the necessity to reinforce such education and training for nurses.

Participants highly praised the clear guidance provided in this CST. Immediate feedback after role-play simulations enables facilitators and observers to adopt the learner's perspective and propose alternative communication strategies to guide the conversation rather than overwhelming the learner with new information. This personalized approach may have contributed to a tailored experience that facilitated participants in achieving their individual learning objectives (Lavecchia et al., 2024). Personalization elements are often recognized as advantageous for facilitating knowledge absorption and skills transfer (Bylund et al., 2022; Roze des Ordon et al., 2017).

Participants expressed the belief that solely implementing offline training may offer limited learning opportunities and emphasized the need for increased exposure to real-world scenarios. Online or blended CST approaches (Berg et al., 2021; Frydman et al., 2021; Gautier et al., 2022; Papadakos et al., 2021) have shown potential in enhancing

trainees' self-reported outcomes, such as communication skills and confidence, as well as objective knowledge acquisition. Further research is required to improve patient outcomes. The findings of the meta-analysis by Selman et al. (Selman et al., 2017) revealed that trainees exhibited inferior communication skills during real patient interactions compared to simulations. Studies incorporating patient-reported outcomes were scarce, leaving CST's impact on patient outcomes inconclusive. Including outcomes and communication experiences reported by patients and family members in the CST assessment may provide a more reliable indication of the effectiveness of CST, as these are the populations directly impacted by end-of-life communication.

However, evaluations conducted during real interactions can be more complicated and insensitive. For instance, Curtis et al. (2013) found that untrained patients or family caregivers may struggle to accurately evaluate healthcare providers' communication quality, potentially leading to non-significant outcomes of the CST. Further exploration is needed on how to involve patients and families in assessments, including whether they should receive training similar to SPs and identifying sensitive measurement tools for evaluation purposes. Additionally, research is required to elucidate other clinically relevant outcomes associated with healthcare professionals' communication behaviour, along with mechanisms, outcome indicators, and reliable evaluation tools. An outcome-based training design can enhance the integration of clinically relevant outcomes to achieve a comprehensive assessment of communication skills (Lavecchia et al., 2024). Multifocal Interventions, such as the combined communication intervention of healthcare provider CSTs and patient and family education, may be more effective in overcoming barriers in actual end-of-life communication in hospital settings (Lord et al., 2016).

8.5 Strength and limitation

8.5.1 Strength

The study has several strengths as follows:

(1) A robust RCT and objective assessments enhance the quality of evidence.

The effects of CST interventions on enhancing nurses' communication skills show promise and previous concerns regarding existing training interventions primarily stem from limited high-quality research evidence, including a scarcity of RCTs and reliance solely on self-reported assessments by trainees (Kerr et al., 2020). As recognized by the Medical Education Research Study Quality Instrument (MERSQI), non-RCT studies indicate lower research quality (Reed et al., 2007). Self-reported outcomes are susceptible to bias, often exhibiting an optimistic bias (Dickson et al., 2012; Moore et al., 2018). The current study employed a well-designed and rigorous RCT methodology with external objective evaluation conducted by independent observers. Moreover, it is the first attempt to develop a study-specific checklist for evaluating training intervention programs in China. It supplements previous sole self-assessment methods and provides an alternative objective perspective for nursing training programs. The strengths of the study design and outcome measurement reinforce the quality of evidence presented in this study.

(2) Stakeholders' views were incorporated in the development of CST.

The use of patient and family input to develop CST is rare (Brighton et al., 2017). Although patients and families were not directly involved in developing the current CST, the training protocol and modules are based on the findings of the qualitative study conducted in the previous phase. The qualitative research offers stakeholders' perspectives (patients, families, and healthcare providers) on end-of-life communication in the Chinese context, including their experiences, perceptions, and preferred communication strategies. This valuable information is the foundation for constructing a well-structured, contextually relevant, and practical Chinese culture-

specific end-of-life CST. The current study represents the first instance in a Chinese context where stakeholder perspectives have been incorporated into developing content for an end-of-life CST. This approach also enhanced the trainees' learning experience and satisfaction.

(3) The training goals and contents were conceptually linked to outcomes.

The mismatch between the training content and the desired outcome may undermine the efficacy of the training (Tharenou et al., 2007). Moreover, trainees might only acquire basic skills and struggle to connect new information with their existing knowledge and abilities, impeding enhancing their communication skills and transferability (Saunders & Wong, 2020). The Comskil model (Brown & Bylund, 2008) and the integrated training model (Parle et al., 1997) offered theoretical support for module development, implementation, and evaluation of this training program. There was a clear conceptual connection and integration between the different elements of the training program.

(4) The CST can be generalized to other healthcare provider groups.

The CST program has been designed and implemented for oncology nurses. However, the training contents and pedagogical approach of the CST are generalizable in that they can be extended, tailored and applied to train other disciplines of healthcare workers as well. This is because the four modules encompass communication scenarios that professionals may encounter while providing care for terminally ill patients and their families. The fundamental skills and competencies developed through the CST may be broadly applicable across various healthcare disciplines. In light of the inadequate education on end-of-life care and communication in China (Willemsen et al., 2021), the CST is a potentially valuable program for a broader spectrum of healthcare providers.

8.5.2 Limitation

The study has several noteworthy limitations:

(1) Participant selection bias.

Participating nurses are likely to possess a higher interest in communication and have advanced communication skills than their colleagues, potentially leading to self-selection bias. The implementation of randomized grouping could have mitigated the impact of this bias. All participants were recruited exclusively from two hospitals in one city (an emerging first-tier city in mainland China with relatively high levels of economic development). Although this recruitment strategy offered time and cost advantages, it may have resulted in a sample that lacks representativeness of the broader population, thereby weakening the generalizability of the findings. When introducing end-of-life communication CST to participants in other cities, special attention should be given to their baseline communication skills, initial knowledge and attitude towards end-of-life communication, and necessary adjustments based on available training resources. Recruiting post-intervention focus group discussion members through convenient sampling has the potential risk of selecting only highly active participants who might provide more positive feedback; however, data saturation was achieved at a theoretical level (Green & Thorogood, 2018). Furthermore, those participants who did not complete the intervention were not included in focus group discussions and may hold different experiences and perspectives.

(2) Study design of the waiting control group.

Some researchers argue that including a waiting control group may introduce bias and inflate estimates of the intervention's effectiveness (Sima et al., 2021). However, designing a placebo training program that appears convincing yet imparts no useful knowledge or skills is challenging. Moreover, providing participants with such ineffective training would be unethical as it could hinder their career development.

(3) Blinding and contamination.

In this study, only the evaluators and data collectors were blinded. Failure to blind participants can trigger the Hawthorne effect, where study participants become aware of being observed and influence their behaviour (McCambridge et al., 2014). Given

this, participants in the IG were likely to report more positive assessment results due to being observed. At the same time, those in the waiting CG were likely to have negative assessment results because they were assigned to the waiting group, which might discourage their learning motivation. However, it was not possible to blind participants in this study as it was challenging to avoid communicating the content and progress of the intervention with colleagues who could then guess possible groupings.

Although efforts have been made to reduce contamination (Section 8.2.6), it is challenging to eliminate it due to educational interventions' easily transmitted nature (Keogh-Brown et al., 2007). Measuring contamination allows us to analyze its impact on the results and carefully interpret their validity. The extent of contamination among individuals in the CG remains unclear. Since acquiring and improving complex communication skills takes longer (Vergo et al., 2022), any impact from contamination on this study's effectiveness is minimal. Future location-based cluster randomized controlled trials may help mitigate contamination (Hemming & Taljaard, 2023).

(4) Lack of measurement of medium and long-term effects and actual communication behaviour.

This training only assessed the immediate and one-month post-training results, leaving the maintenance level of the training effect in the medium- and long-term unknown. Drawing conclusions regarding whether additional or enhanced training is necessary becomes challenging. Furthermore, although a combination of self-reporting and external assessment was employed, it still does not capture nurses' real-life communication behaviour. According to the model (Parle et al., 1997), as self-efficacy and outcome expectancies are crucial predictors of behaviour, trainees are likely to perform better in authentic communication scenarios in the workplace; however, further evaluation is required in future studies.

8.6 Implications for clinical practice, education, policy, and research

This study demonstrates the efficacy of Chinese culturally specific end-of-life CST in enhancing oncology nurses' communication skills, self-efficacy, and outcome expectancies. Interpreted through the employed theoretical model (Parle et al., 1997), improved self-efficacy and outcome expectancies will result in behavioural change, leading to improved practice and better patient care. Trained nurses are more likely to excel in discussing end-of-life topics with patients and their families. However, nurses must adapt their communication strategies and skills based on individual needs and specific communication situations rather than relying on a fixed script. To promote effective end-of-life communication behaviours among nurses, institutional support at the workplace level may be necessary, including manageable workloads that allow for the increased time dedicated to communicating with patients and families as well as counselling services and psychological care measures aimed at addressing potential adverse effects such as emotional or psychological distress experienced by nurses during these conversations.

This training programme has the potential to be expanded to a broader range of nurses and other healthcare providers. It is imperative to integrate it into the continuing education of nurses. There is a significant dearth of education and training in end-of-life care and communication skills for non-specialist palliative care nurses (Q. Q. Cheng et al., 2021). Hence, this project can offer valuable training opportunities for more nurses. Additionally, multidisciplinary healthcare professionals and social workers can benefit from this training since many communication strategies and skills are universally applicable.

Research evidence will contribute to developing evidence-based end-of-life communication guidelines. The findings of this research can inform the development

of contextual end-of-life communication guidelines tailored to Chinese clinical practice and those countries or regions with a similar cultural background. For instance, healthcare providers withhold information from patients while communicating with their families, which is commonly observed in societies where family ties are strong (Sarafis et al., 2013).

Longitudinal studies are necessary to assess the retention of knowledge and skills (Lavecchia et al., 2024) and evaluate the sustainability of training effects. It is essential to incorporate outcomes reported by patients and families and other clinically relevant measures to accurately gauge participants' communication behaviour in clinical settings. Initiating projects aimed at training trainers to facilitate the implementation of this program in resource-limited areas would be highly valuable. Additionally, employing blended training may enhance the trainee experience.

8.7 Conclusion

This study implemented a culturally specific end-of-life CST for nurses in China and demonstrated its effectiveness in improving nurses' communication skills, self-efficacy, and outcome expectancy beliefs. The training program showed good acceptance and satisfaction among participants. The focus group discussion results highlighted the benefits of the training in promoting nurses' professional and personal growth. Additionally, participants identified facilitating and hindering factors in the learning process and proposed suggestions and expectations for future training. Improvements in nurses' communication skills, self-efficacy, and outcome expectancy beliefs may help promote end-of-life communication with patients and families in practice. Still, more research is needed to evaluate this. The training can be essential to nurses' continuing education by providing structured, systematic CST to enhance nurses' end-of-life communication competence.

Chapter 9: Conclusion

This study developed a culturally specific end-of-life CST program and evaluated its effectiveness in improving communication skills, self-efficacy, and outcome expectancy beliefs among Chinese oncology nurses.

The literature review has identified two significant research gaps. Firstly, there is a shortage of empirical evidence regarding end-of-life communication strategies within the Chinese context. Secondly, there is a lack of culturally specific end-of-life CST for Chinese oncology nurses.

The first sub-study of this research synthesized available end-of-life communication strategies into seven themes through a scoping review, including (a) preparation, (b) exploration and assessment, (c) family involvement, (d) provision and tailoring of information, (e) empathic emotional responses, (f) reframing and revisiting the goals of care, and (g) conversation closure. The study findings contribute to the training program's development and underscore the necessity of exploring end-of-life communication in non-Anglo-Saxon countries, including China.

The second sub-study then explored the end-of-life communication experiences, perceptions, suggestions and strategies of key stakeholders (patients, families, and healthcare professionals) in China. The qualitative study involved interviews with 19 patients, 22 family caregivers, and 8 healthcare providers. Additionally, three focus group discussions were held with healthcare providers. The two states of end-of-life communication in the Chinese context are determined by the experiences and perceptions of stakeholders: protection and openness. The former is characterized by dominant family involvement, truth concealment and restricted end-of-life topics. The main characteristics of the latter are dominant patient participation, truth disclosure and

rich end-of-life topics. Patient factors (comfort level of talking about the end of life, burden and treatment engagement), family factors (comfort level of talking about the end of life, burden, expectation, value and trust in healthcare providers), and healthcare provider factors (comfort level of talking about the end of life, available time and priority in practice, end-of-life communication awareness, end-of-life care knowledge and communication skills) may influence the dynamic transition from protective to open end-of-life communication state. Participants provided recommendations for enhancing end-of-life communication, including clarifying the responsibilities of hospital-based healthcare providers, evaluating the quality of end-of-life communication and providing end-of-life communication training. The suggested communication strategies proposed by participants were organized into an acronym, IGNITE, i.e., a) **Identify** the primary communicator(s) and prepare the family if necessary; b) Initiate end-of-life communication in a **Gradual** and **Natural** manner; c) **Navigate** realistic expectations; d) **Inner** healing with emotional support and meaning reconstruction; and e) **Timing** and **Environment**. These findings contribute to a deeper understanding of end-of-life communication practices, particularly from a Chinese perspective that complements existing evidence on strategies dominated by Anglo-Saxon countries, thus addressing the first research gap identified in the literature review. Moreover, these findings laid the foundation for developing a culturally specific end-of-life CST program in the Chinese context.

The third sub-study developed a comprehensive Chinese culturally specific end-of-life CST program and implemented and evaluated it among Chinese oncology nurses, filling the second research gap as the first known end-of-life CST program incorporating stakeholder perspectives in the Chinese context. Guided by the five communication components in the Comskil model, the communication goals, strategies, skills, process tasks, and cognitive appraisals of the Chinese culturally specific end-of-

life CST were developed. The four modules of this training program, i.e., (1) Respond to patient cues, (2) Negotiate with the family, (3) Nurture hope, and (4) Bereavement support, were informed by the qualitative research findings. The final training program was developed as an 8-week, 8-session, 12-hour program, delivered by lectures, video demonstrations, and role-play simulations.

A total of 159 oncology nurses participated in the training and its evaluation, with an IG (n = 79) and a wait-list CG (n = 80). The IG showed significantly improved communication skills, self-efficacy, and outcome expectancy beliefs compared to the CG. Process evaluation results indicated good acceptability and satisfaction with the program. Participants considered this a novel training program beneficial for professional and personal growth and identified facilitating and hindering factors in the learning process. They desired future training programs to increase direct interactions with patients and families, develop blended formats and multidisciplinary participation, and link training content to locally available resources.

The primary findings are presented with the conceptual framework in Figure 9.1. This research is a promising part of continuing nursing education. It has the potential to be expanded to a broader range of healthcare professionals, benefiting more practitioners and applying the learned strategies and skills to end-of-life communication with patients and families, thereby promoting end-of-life communication practices in the Chinese context. The findings of this study enrich the current understanding of end-of-life communication. They can help improve the cultural considerations in existing end-of-life communication guidelines and develop evidence-based end-of-life communication guidelines for the Chinese context. However, it remains unclear how nurses transfer these strategies and skills to their actual work settings and how they impact patient and family outcomes, requiring further research.

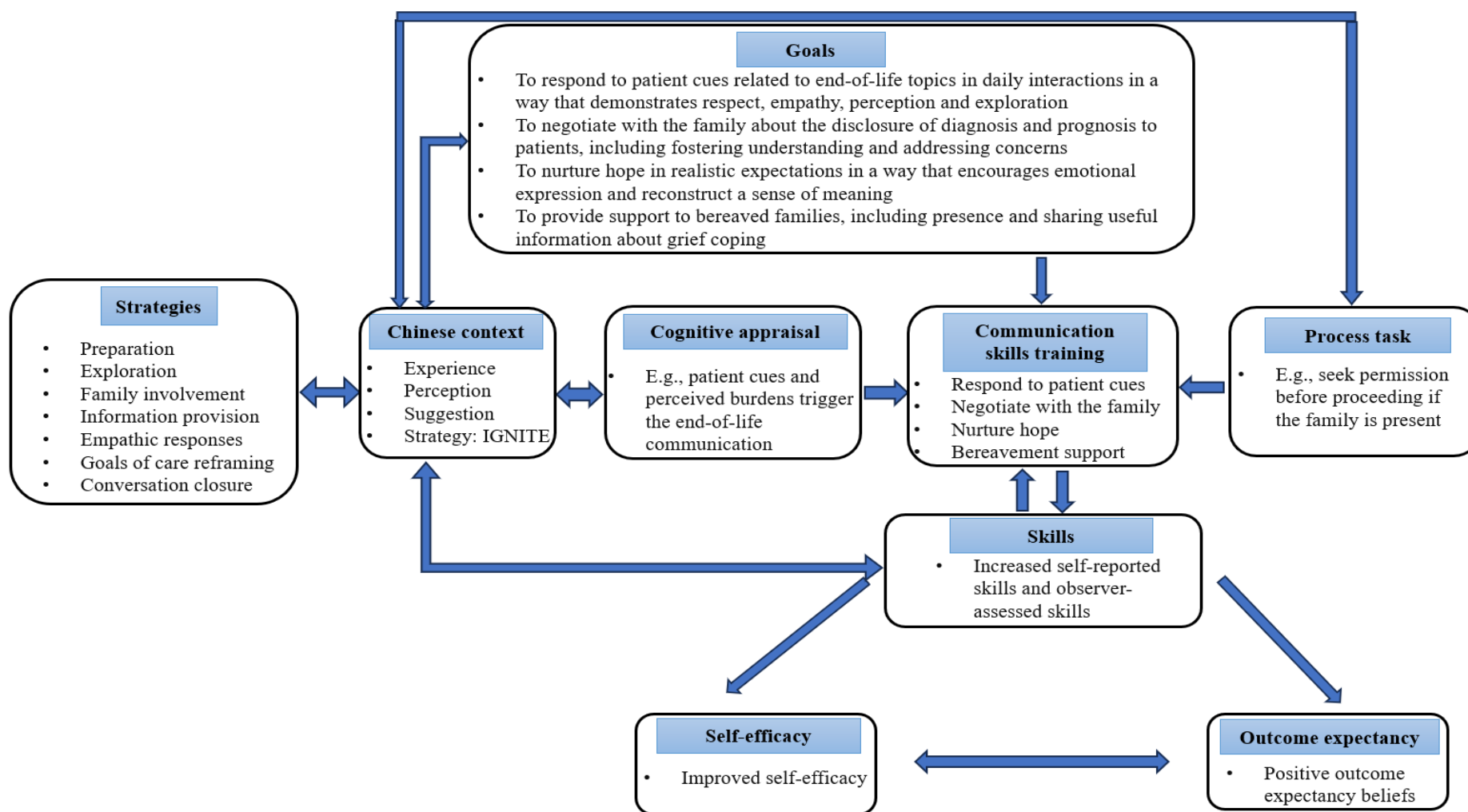


Figure 9.1 Main study findings presented with the conceptual framework of the current study

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APPENDICES

Appendix 1: Ethical approval of Hong Kong Polytechnic University

(1) The qualitative study



To	Chung Oi Kwan (School of Nursing)		
From	Pang Marco Yiu Chung, Chair, PolyU Institutional Review Board		
Email	marco.pang@	Date	26-Apr-2023

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 01-Jan-2023 to 01-Jan-2024:

Project Title:	Development and Evaluation of a Culturally Specific End-of-life Communication Skills Training for Chinese Oncology Nurses
Department:	School of Nursing
Principal Investigator:	Chung Oi Kwan
Project Start Date:	01-Jan-2023
Project type:	Human subjects (clinical)
Review type:	Expedited Review
Reference Number:	HSEARS20221217002

You will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In case the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the PolyU Institutional Review Board in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

Pang Marco Yiu Chung
Chair
PolyU Institutional Review Board

(2) The RCT



To	Chung Oi Kwan (School of Nursing)		
From	Leung Yee Man Angela, Chair, Departmental Research Committee		
Email	angela.ym.leung@	Date	11-Aug-2023

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 01-Jul-2023 to 31-Dec-2023:

Project Title:	Effects of a Culturally Specific End-of-life Communication Skills Training for Chinese Oncology Nurses
Department:	School of Nursing
Principal Investigator:	Chung Oi Kwan
Project Start Date:	01-Jul-2023
Project type:	Human subjects (non-clinical)
Reference Number:	HSEARS20230525002

You will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In case the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the PolyU Institutional Review Board in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

Leung Yee Man Angela

Chair

Departmental Research Committee (on behalf of PolyU Institutional Review Board)

Appendix 2: Ethical approval of study sites

浙江大学医学院附属邵逸夫医院伦理审查批件

Ethics Committee Approval Letter of Sir Run Run Shaw Hospital,
Zhejiang University School of Medicine

批件号 Approval NO.: 邵逸夫医院伦审 2023 研第 0163 号

项目名称 Study Title	基于中国社会文化背景的生命末期沟通技能培训的开发及其在中国肿瘤护士中的评价		
申办方 Sponsor	无		
受理号 Acceptance Number	2023-527-01		
主要研究者 Principal Investigator	项敏利	承担科室 Responsible Department	护理部
审查类别 Category of Review	初始审查	审查方式 Type of Review	快速审查
审查日期 Date of Review	2023.04.20	审查地点 Location of Review	/
审查文件清单 Items Reviewed	见附件		
审评意见 Evaluation	本伦理委员会认为递交的审查材料符合伦理规范，同意开展临床研究。		
审查决定 Decision	委员会对该项目的审查决定为： 同意		
主任/副主任委员签字 Chair Signature			
签发日期 Date of issue	2023.4.20		
伦理审查委员会 Stamp of EC	伦理审查委员会盖章		
批件有效期 Period of Validity	自本伦理审查委员会初始审查批准之日起一年内，本临床研究应在本院启动。逾期未启动的，本批件自行废止。		
年度/定期跟踪审查 Continue Review	审查频率为该研究批准之日起每 12 个月一次，首次 2024 年 04 月 19 日，请于批件到期前 1 个月递交研究进展报告。 伦理审查委员会有根据实际进展情况改变跟踪审查频率的权利。		
声明 Statement	本伦理审查委员会的职责、人员组成、操作程序及记录遵循《涉及人的生物医学研究伦理审查办法》、《涉及人的健康相关研究国际伦理准则》、《赫尔辛基宣言》、GCP 和 ICH-GCP 等国际伦理指南和国内相关法律法规。		
注意事项:			

第 1 页 共 2 页

1. 请遵循我国相关法律、法规和规章中的伦理原则。
2. 请遵循经本伦理审查委员会批准的临床研究方案、知情同意书、招募材料等开展本研究，保护受试者的健康与权利。对研究方案、知情同意书和招募材料等的任何修改，均须得到本伦理审查委员会审查同意后方可实施。
3. 在本院发生的 SAE/SUSAR 以及研发期间安全性更新报告须按照 NMPA/GCP 最新要求及时递交本伦理审查委员会，国内外其它中心发生的 SAE/SUSAR 需定期汇总、评估后递交本伦理审查委员会。
4. 根据报告情况，本伦理审查委员会有权对其评估做出新的决定。
5. 无论研究开始与否，请在跟踪审查日到期前 1 个月提交研究进展报告。
6. 申办方应当向组长单位伦理审查委员会提交中心研究进展报告汇总；当出现任何可能显著影响研究进行或增加受试者危险的情况时，请申请人及时向本伦理审查委员会提交书面报告。
7. 研究纳入了不符合纳入标准或符合排除标准的受试者，符合中止研究规定而未让受试者退出研究，给予错误治疗或剂量，给予方案禁止的合并用药等没有遵从方案开展研究的情况；或可能对受试者的权益或健康以及研究的科学性造成不良影响等违背 GCP 原则的情况，请申办方、监查员或研究者提交违背方案报告。
8. 申请人暂停或提前终止临床研究，请及时提交暂停或终止研究报告。
9. 完成临床研究，请申请人提交结题报告。
10. 凡涉及中国人类遗传资源采集标本、收集数据等研究项目，必须获得中国人类遗传资源管理办公室批准后方可在本中心开展研究。
11. 凡经本伦理审查委员会批准的研究项目在实施前，申请人应按相关规定在国家卫健委、药审中心等临床研究登记备案信息系统平台登记研究项目相关信息。

附件（审查文件清单）：

1. 初始审查申请表（科研专用）
2. 主要研究者责任声明
3. 主要研究者履历
4. 研究方案（V1.0；2023.02.28）
5. 知情同意书（V1.0；2023.02.28）

浙江省肿瘤医院医学伦理委员会
伦理审查批件

伦理批件号: IRB-2023-526 号 (科)

项目名称	基于中国社会文化背景的生命末期沟通技能培训的开发及其在中国肿瘤护士中的评价		
申办方/项目来源	香港理工大学研究者发起		
主要研究者	傅晓炜	研究科室	护理部
审查类别	<input checked="" type="checkbox"/> 初始审查 <input type="checkbox"/> 修正案审查 <input type="checkbox"/> 年度/定期跟踪审查 <input type="checkbox"/> 其他:		
审查方式	<input type="checkbox"/> 会议审查 <input checked="" type="checkbox"/> 简易审查 <input type="checkbox"/> 紧急会议审查		
审查日期	2023 年 6 月 12 日	审查地点	行政科研楼
审查文件	1. 研究者发起的临床研究初始审查申请表 2. 无资助说明 3. 主要研究者简历、GCP 证书、研究人员列表 4. 研究方案 (版本号: V1.0, 日期: 2023 年 5 月 23 日) 5. 知情同意书 (版本号: 1.0, 日期: 2023 年 5 月 23 日) 6. 数据收集表 7. 临床研究委托书 8. 参加临床研究各单位名称及联系方式 9. 组长单位伦理批件、其他合作单位伦理批件		
审查决定	同意 回避情况: <input checked="" type="checkbox"/> 无 <input type="checkbox"/> 有		
审查意见	经审查, 本伦理委员会认为该项目基本符合伦理要求, 同意开展研究。 跟踪审查频率为: 12 个月 请于每 11 月递交年度/定期跟踪审查申请。		
主任/副主任委员签字: <div>浙江省肿瘤医院医学伦理委员会 (盖章)</div> <div>日期: 2023 年 6 月 13 日</div>			
声明	本伦理委员会的职责、人员组成、操作程序及记录遵循《涉及人的生命科学和医学研究伦理审查办法》、《药物临床试验质量管理规范》和 ICH-GCP 等国际伦理指南和国内相关法律法规。		

联系电话: 0571-88122564 邮箱地址: ec@zjcc.org.cn
地址: 浙江省杭州市拱墅区半山东路 1 号 浙江省肿瘤医院行政科研楼 316 室 邮编: 310022

注意事项:

1. 请遵循我国相关法律、法规和规章中的伦理原则。
2. 请遵循经本伦理委员会批准的临床研究方案、知情同意书、受试者招募材料等开展研究, 保护受试者的安全与权益。对研究方案、知情同意书和受试者招募材料等的任何修改, 均须得到本伦理委员会再次审查同意后方可实施。
3. 在本院发生的 SAE/SUSAR, 研究期间安全性更新报告须及时递交本伦理委员会, 国内外其它中心发生的 SAE/SUSAR 需定期汇总、评估后递交本伦理委员会。
4. 自本伦理委员会初始审查批准之日起一年, 研究未启动的, 本批件自行废止。
5. 凡是涉及人类遗传资源审批或者按照国家规定必须经有关部门专项审批的内容, 均需在开展研究前获得批准。



联系电话: 0571-88122564 邮箱地址: ec@zjcc.org.cn
地址: 浙江省杭州市拱墅区半山东路1号 浙江省肿瘤医院行政科研楼316室 邮编: 310022

Appendix 3: Information sheet

(1) The qualitative study

INFORMATION SHEET

Development and Evaluation of a Culturally Specific End-of-life Communication Skills Training for Chinese Oncology Nurses

Dear **patient**,

You are invited to participate in the above project supervised by Dr Chung Oi Kwan Joyce, who is a staff member of the School of Nursing in The Hong Kong Polytechnic University, and conducted by Weilin Chen, who is a post-graduate student of the School of Nursing in The Hong Kong Polytechnic University. The project has been approved by the PolyU Institutional Review Board (PolyU IRB) (or its Delegate) (Reference Number: HSEARS20221217002).

This project aims to develop an end-of-life communication skills training based on Chinese social-cultural context and to evaluate the effectiveness of the training in the Chinese oncology nurses. We sincerely invite you to participate in the research. The data collected will be used to design the training program and will eventually contribute to quality end-of-life care. Please read the below information carefully. If you have any questions, please contact us.

Why we invite you to participate in the study:

The data collected in this study will help us study the situation regarding end-of-life communication and design related training programs so that we can improve the quality of end-of-life care for patients and families.

Personal preference:

It is voluntary to participate in this study; if you decide to participate, please sign the consent form and return it with the questionnaire. You can keep this information sheet for reference in the future. You have the right to refuse or withdraw from the study. Your participation or not will not cause any negative consequences.

Research procedure:

If you decide to participate, you will have an interview with the researcher. The interview aims to understand your experience and perceptions of end-of-life communication (including disease-related information, expression of preferences,

treatment decision-making, etc.) with healthcare providers. You can select a location which suits you or receive the interview in our interview room. The interview is expected to take 30 to 60 minutes. It will be audio-recorded for data analysis. Besides, we will collect your personal data.

Privacy:

The information you provide as part of the project is the research data. Any research data from which you can be identified is known as personal data. Personal data does not include data where the identity has been removed (anonymous data). We will minimize our use of personal data in the study as much as possible. The researcher and her supervisors (including Professor Alex Molassiotis of the University of Derby outside Hong Kong) will have access to personal data and research data for the purposes of the study. Responsible members of The Hong Kong Polytechnic University may be given access for monitoring and/or audit of the research.

All information related to you will remain confidential and will be identifiable by codes only known to the researchers. The information collected will be kept for 5 years after project completion. The Hong Kong Polytechnic University takes reasonable precautions to prevent the loss, misappropriation, unauthorized access or destruction of the information you provide.

Rights of the Subject

You have the right to refuse to participate or withdraw at any time for any reason without penalty of any kind and to request access to and correction of the personal data supplied for the project.

Benefits:

You will not have any benefit after the research, but the information you provide may help us to design the end-of-life communication skills training for healthcare providers.

Risk:

The interview may remind you of experiences related to the illness. If you feel uncomfortable, you can seek help from the researcher. We will contact your family caregivers and healthcare providers with your consent, and transfer you to professional psychological consultants or social work services. Your caregiver is allowed to accompany you through the interview.

If you have any enquiries about this study, including the following cases:

- a. if you have any other questions in relation to the study; or
- b. if, under very rare conditions, you become injured as a result of your participation in the study; or

c. if you want to get access to/or change your personal data before (the expiry date).
Please contact the principal investigator:

Dr Chung Oi Kwan Joyce (Principal investigator)
Assistant Professor, School of Nursing, the Hong Kong Polytechnic University
(Tel: XXX/ email: okjoyce.chung@polyu.edu.hk)
Weilin Chen
PhD candidate, School of Nursing, the Hong Kong Polytechnic University
(Tel: XXX/ email: wei-lin.chen@polyu.edu.hk)

In the event you have any complaints about the conduct of this research study, you may contact the Secretary of the PolyU Institutional Review Board in writing (institutional.review.board@polyu.edu.hk) stating clearly the responsible person and department of this study as well as the HSESC Reference Number.

Report of serious adverse event (SAE)

In case of a serious adverse event¹, please report to the Principal Investigator immediately and the Principal Investigator will be required to report it to the PolyU IRB within 48 hours upon the receipt of your report.

Thank you for your interest in participating in this study.

Dr Chung Oi Kwan Joyce
Principal Investigator
Assistant Professor, School of Nursing, The Hong Kong Polytechnic University

¹SAE is any adverse event that:

- Results in death
 - Is life threatening, or places the participant at immediate risk of death from the event as it occurred
 - Requires or prolongs hospitalization
 - Causes persistent or significant disability or incapacity
 - Results in congenital anomalies or birth defects
 - Is another condition which investigators judge to represent significant hazards
- (Reference: NIA Adverse Event and Serious Adverse Event Guidelines.

<https://www.nia.nih.gov/sites/default/files/2018-09/nia-ae-and-sae-guidelines-2018.pdf>)

INFORMATION SHEET

Development and Evaluation of a Culturally Specific End-of-life Communication Skills Training for Chinese Oncology Nurses

Dear **family caregivers**,

You are invited to participate in the above project supervised by Dr Chung Oi Kwan Joyce, who is a staff member of the School of Nursing in The Hong Kong Polytechnic University, and conducted by Weilin Chen, who is a post-graduate student of the School of Nursing in The Hong Kong Polytechnic University. The project has been approved by the PolyU Institutional Review Board (PolyU IRB) (or its Delegate) (Reference Number: HSEARS20221217002).

This project aims to develop an end-of-life communication skills training based on Chinese social-cultural context and to evaluate the effectiveness of the training in the Chinese oncology nurses. We sincerely invite you to participate in the research. The data collected will be used to design the training program and will eventually contribute to quality end-of-life care. Please read the below information carefully. If you have any questions, please contact us.

Why we invite you to participate in the study:

The data collected in this study will help us study the situation regarding end-of-life communication and design related training programs so that we can improve the quality of end-of-life care for patients and families.

Personal preference:

It is voluntary to participate in this study; if you decide to participate, please sign the consent form and return it with the questionnaire. You can keep this information sheet for reference in the future. You have the right to refuse or withdraw from the study. Your participation or not will not cause any negative consequences.

Research procedure:

If you decide to participate, you will have an interview with the researcher. The interview aims to understand your experience and perceptions of end-of-life communication (including disease-related information, expression of preferences, treatment decision-making, etc.) with the patient's healthcare providers. You can select a location which suits you or receive the interview in our interview room. The interview

is expected to take 30 to 60 minutes. It will be audio-recorded for data analysis. Besides, we will collect your personal data.

Privacy:

The information you provide as part of the project is the research data. Any research data from which you can be identified is known as personal data. Personal data does not include data where the identity has been removed (anonymous data). We will minimize our use of personal data in the study as much as possible. The researcher and her supervisors (including Professor Alex Molassiotis of the University of Derby outside Hong Kong) will have access to personal data and research data for the purposes of the study. Responsible members of The Hong Kong Polytechnic University may be given access for monitoring and/or audit of the research.

All information related to you will remain confidential and will be identifiable by codes only known to the researchers. The information collected will be kept for 5 years after project completion. The Hong Kong Polytechnic University takes reasonable precautions to prevent the loss, misappropriation, unauthorized access or destruction of the information you provide.

Rights of the Subject

You have the right to refuse to participate or withdraw at any time for any reason without penalty of any kind and to request access to and correction of the personal data supplied for the project.

Benefits:

You will not have any benefit after the research, but the information you provide may help us to design the end-of-life communication skills training for healthcare providers.

Risk:

The interview may remind you of experiences related to your family's illness. If you feel uncomfortable, you can seek help from the researcher. We will contact your families and healthcare providers with your consent, and transfer you to professional psychological consultants or social work services, if necessary.

If you have any enquiries about this study, including the following cases:

- a. if you have any other questions in relation to the study; or
- b. if, under very rare conditions, you become injured as a result of your participation in the study; or
- c. if you want to get access to/or change your personal data before (the expiry date).

Please contact the principal investigator:

Dr Chung Oi Kwan Joyce (Principal investigator)
Assistant Professor, School of Nursing, the Hong Kong Polytechnic University
(Tel: XXX/ email: okjoyce.chung@polyu.edu.hk)
Weilin Chen
PhD candidate, School of Nursing, the Hong Kong Polytechnic University
(Tel: XXX/ email: wei-lin.chen@polyu.edu.hk)

In the event you have any complaints about the conduct of this research study, you may contact the Secretary of the PolyU Institutional Review Board in writing (institutional.review.board@polyu.edu.hk) stating clearly the responsible person and department of this study as well as the HSESC Reference Number.

Report of serious adverse event (SAE)

In case of a serious adverse event¹, please report to the Principal Investigator immediately and the Principal Investigator will be required to report it to the PolyU IRB within 48 hours upon the receipt of your report.

Thank you for your interest in participating in this study.

Dr Chung Oi Kwan Joyce
Principal Investigator
Assistant Professor, School of Nursing, The Hong Kong Polytechnic University

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INFORMATION SHEET

Development and Evaluation of a Culturally Specific End-of-life Communication Skills Training for Chinese Oncology Nurses

Dear **healthcare providers**,

You are invited to participate in the above project supervised by Dr Chung Oi Kwan Joyce, who is a staff member of the School of Nursing in The Hong Kong Polytechnic University, and conducted by Weilin Chen, who is a post-graduate student of the School of Nursing in The Hong Kong Polytechnic University. The project has been approved by the PolyU Institutional Review Board (PolyU IRB) (or its Delegate) (Reference Number: HSEARS20221217002).

This project aims to develop an end-of-life communication skills training based on Chinese social-cultural context and to evaluate the effectiveness of the training in the Chinese oncology nurses. We sincerely invite you to participate in the research. The data collected will be used to design the training program and will eventually contribute to quality end-of-life care. Please read the below information carefully. If you have any questions, please contact us.

Why we invite you to participate in the study:

The data collected in this study will help us study the situation regarding end-of-life communication and design related training programs so that we can improve the quality of end-of-life care for patients and families.

Personal preference:

It is voluntary to participate in this study; if you decide to participate, please sign the consent form and return it with the questionnaire. You can keep this information sheet for reference in the future. You have the right to refuse or withdraw from the study. Your participation or not will not cause any negative consequences.

Research procedure:

If you decide to participate, you will have a focus group discussion with other healthcare providers organized by the researcher. If you are unwilling or unable to join the discussion, you may choose to have a one-on-one interview with the researcher. The discussion (or the interview) aims to understand your experience and perceptions of end-of-life communication (including disease-related information, expression of preferences, treatment decision-making, etc.) with patients and families. The focus

group discussion (or the interview) will be conducted in the conference room (or the interview room) and expected to take 30 to 60 minutes. It will be audio-recorded for data analysis. Besides, we will collect your personal data.

Privacy:

The information you provide as part of the project is the research data. Any research data from which you can be identified is known as personal data. Personal data does not include data where the identity has been removed (anonymous data). We will minimize our use of personal data in the study as much as possible. The researcher and her supervisors (including Professor Alex Molassiotis of the University of Derby outside Hong Kong) will have access to personal data and research data for the purposes of the study. Responsible members of The Hong Kong Polytechnic University may be given access for monitoring and/or audit of the research.

All information related to you will remain confidential and will be identifiable by codes only known to the researchers. The information collected will be kept for 5 years after project completion. The Hong Kong Polytechnic University takes reasonable precautions to prevent the loss, misappropriation, unauthorized access or destruction of the information you provide.

Rights of the Subject

You have the right to refuse to participate or withdraw at any time for any reason without penalty of any kind and to request access to and correction of the personal data supplied for the project.

Benefits:

You will not have any benefit after the research, but the information you provide may help us to design the end-of-life communication skills training for healthcare providers.

Risk:

The discussion/interview may remind you of experiences caring terminally ill patients and their families. If you feel uncomfortable, you can seek help from the researcher. We will contact your families and other healthcare providers with your consent, and transfer you to professional psychological consultants or social work services.

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请与研究人员联系：

钟爱群博士（主要研究员）

香港理工大学护理学院助理教授

(电话号码: XXX / email: okjoyce.chung@polyu.edu.hk)

陈炜琳

香港理工大学护理学院博士研究生

(电话号码: XXX / email: wei-lin.chen@polyu.edu.hk)

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报告严重不良事件(SAE)

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香港理工大学护理学院博士研究生

(电话号码: XXX / email: wei-lin.chen@polyu.edu.hk)

如果您对这项研究有任何的不满，可随时与香港理工大学研究伦理委员会秘书联络（电邮: institutional.review.board@polyu.edu.hk），清楚说明负责人、部门以及参考编号。

报告严重不良事件(SAE)

如有严重不良事件¹，请立即向主要研究员报告，主要研究员须在收到报告后 48 小时内向理大伦理委员会报告。

谢谢您有兴趣参与这项研究。

¹SAE 是任何不良事件:

- 导致死亡
- 威胁生命, 或使参与者在事件发生时立即面临死亡风险
- 需要或延长住院时间
- 导致持续或严重残疾或丧失能力
- 导致先天性异常或出生缺陷
- 是调查人员判断为代表重大危险的另一种情况

(参考:NIA 不良事件和严重不良事件指南。

<https://www.nia.nih.gov/sites/default/files/2018-09/nia-ae-and-sae-guidelines-2018.pdf>)

(2) The RCT

INFORMATION SHEET

Effects of a Culturally Specific End-of-life Communication Skills Training for Chinese Oncology Nurses

You are invited to participate in the above project supervised by Dr Chung Oi Kwan Joyce, who is a staff member of the School of Nursing in The Hong Kong Polytechnic University, and conducted by Weilin Chen, who is a post-graduate student of the School of Nursing in The Hong Kong Polytechnic University. The project has been approved by the PolyU Institutional Review Board (PolyU IRB) (or its Delegate) (Reference Number: HSEARS20230525002).

This project aims to evaluate the effectiveness of a culturally specific end-of-life communication skills training in Chinese oncology nurses. It is hoped that this information will help to enhance end-of-life communication skills training and eventually contribute to quality end-of-life care.

It is voluntary to participate in this study; if you decide to participate, please sign the consent form and return it with the questionnaire. You can keep this information sheet for reference in the future. You have the right to refuse or withdraw from the study. Your participation or not will not cause any negative consequences.

If you decide to participate, you will be assigned to the control group or the intervention group through random sampling. Participants in the intervention group will be invited to participate in end-of-life communication skills training. Participants will be required to join an eight-week training program. The training modules contain communication strategy, skills, process tasks, barriers and cues on a series of end-of-life topics (prognosis; death and dying; advance care planning; goals of care and decision-making; palliative and hospice care introduction and referral; and bereavement support). Training methods include lectures, video demonstrations, and simulation in small groups (4-5 trainees per group with multidisciplinary roles). Written and audiovisual learning materials will be offered. Each session will be 150 minutes, including lectures and video demonstration (90 min/session) and simulation and feedback (60 min/session). One session will be conducted in two weeks. Totally there will be four sessions completed in 8 weeks. Participants in the control group will be a waitlist group and receive the training after the end of data collection.

In order to further understand the participants' experience in the training program, we will randomly invite 10 participants in the intervention group to participate in a one-to-one interview that takes about 20 to 30 minutes after the training is completed. Will be

invited to comment on the experience, suggestions and expectations of this training. Interviews will be conducted on-site and will be recorded for research purposes. If you do not wish to be interviewed, please let the researcher know at any time and we will keep it on file. Even if you decline access, you can continue to participate in the study.

Participants in the control or intervention groups will be required to complete the questionnaire twice (before the program begins and in the third month after the program begins). The questionnaire consists of six pages and a personal data sheet. It takes about fifteen to twenty minutes.

The information you provide as part of the project is the research data. Any research data from which you can be identified is known as personal data. Personal data does not include data where the identity has been removed (anonymous data). We will minimize our use of personal data in the study as much as possible. The researcher and her supervisors (including Professor Alex Molassiotis of the University of Derby outside Hong Kong) will have access to personal data and research data for the purposes of the study. Responsible members of The Hong Kong Polytechnic University may be given access for monitoring and/or audit of the research.

All information related to you will remain confidential and will be identifiable by codes only known to the researchers. The information collected will be kept for 5 years after project completion. The Hong Kong Polytechnic University takes reasonable precautions to prevent the loss, misappropriation, unauthorized access or destruction of the information you provide.

The possible harmful effects derived from participating in this study may include: a. The clinical cases of end-stage patients involved in the training may trigger memories of past work or personal experiences that may have been painful or stressful. If you experience any distress, discomfort, or other psychological conditions while participating in the study, please feel free to contact the investigator, who will assist you with professional psychological counseling in the hospital, or assist you with family or peer support; b. Participating in the study may require additional time and effort from you outside of work, you may need to discuss with your supervisors or related seniors and adjust your working schedule if necessary, and may affect your work performance. However, participating in the training program is expected to benefit your work.

You have every right to withdraw from the study before or during the measurement without penalty of any kind.

If you have any questions, you may ask our helpers now or later, even after the study has started.

You may contact Dr Chung Oi Kwan Joyce (tel. no.: XXX/ email: okjoyce.chung@polyu.edu.hk) or Ms Weilin Chen (tel. no.: XXX/ email: wei-lin.chen@polyu.edu.hk) of PolyU under the following situations:

- a. if you have any other questions in relation to the study;
- b. if, under very rare conditions, you become injured as a result of your participation in the study; or
- c. if you want to get access to/or change your personal data before (the expiry date).

In the event you have any complaints about the conduct of this research study, you may contact Secretary, PolyU Institutional Review Board in writing (institutional.review.board@polyu.edu.hk) stating clearly the responsible person and department of this study as well as the Reference Number.

In case of a serious adverse event¹, please report to the Principal Investigator/Chief Investigator immediately and the Principal Investigator/Chief Investigator will be required to report it to the PolyU IRB within 48 hours upon the receipt of your report.

Thank you for your interest in participating in this study.

Dr Chung Oi Kwan Joyce
Principal Investigator
Assistant Professor, School of Nursing, The Hong Kong Polytechnic University

¹SAE is any adverse event that:

- Results in death
 - Is life threatening, or places the participant at immediate risk of death from the event as it occurred
 - Requires or prolongs hospitalization
 - Causes persistent or significant disability or incapacity
 - Results in congenital anomalies or birth defects
 - Is another condition which investigators judge to represent significant hazards
- (Reference: NIA Adverse Event and Serious Adverse Event Guidelines.
<https://www.nia.nih.gov/sites/default/files/2018-09/nia-ae-and-sae-guidelines-2018.pdf>)

有关资料

基于中国社会文化背景的生命末期沟通技能培训的开发及其在中国肿瘤护士中的评价

诚邀您参加钟爱群博士（香港理工大学助理教授）负责监督，陈炜琳（香港理工大学研究生）负责执行的上述研究课题。该项目已获得香港理工大学研究伦理委员会（或其代表）的批准（参考编号：HSEARS20230525002）。

本项目旨在评估中国肿瘤护士生命末期沟通技能培训的有效性。希望这些信息将有助于提高生命末期沟通技能培训，并最终有助于提高终末期照护质量。

参加这项研究与否，纯属自愿。如您决定参与，请填妥同意书，并与问卷一并交回，您可保留这份函件，以作日后参考。您亦有权拒绝参加或中途退出此研究。您的参加与否并不会产生任何负面的后果。

如决定参与，您将通过随机抽样被分配到对照组或干预组。干预组的参与者将被邀请参加生命末期沟通技能培训。参与者将被要求参加为期八周的培训项目。培训模块包括沟通策略、技巧、流程任务、障碍和线索，涉及一系列临终主题（预后；死亡和濒死；预立医疗照护计划；护理和决策目标；缓和和临终关怀的介绍和转介；以及丧亲支持）。培训方法包括讲座、视频演示和小组模拟（每组 4-5 名学员担任多学科角色）。将提供书面和视听学习材料。每节课 150 分钟，包括讲座和视频演示（90 分钟/节）以及模拟和反馈（60 分钟/节）。两周内完成一次课程。总共有四个课程将在 8 周内完成。对照组为等待组，在数据收集结束后接受培训。

为了进一步了解参与者在培训项目中的体验，我们将在培训结束后随机邀请 10 名干预组参与者进行一对一的访谈，访谈时间约为 20-30 分钟。将被邀请评论这次培训的经验、建议和期望。访谈将在现场进行，并将被记录下来用于研究目的。如果您不希望接受采访，请随时告知研究人员，我们会记录在案。即使您拒绝访谈，您也可以继续参与研究。

对照组或干预组的参与者将被要求填写两次问卷（在项目开始前和项目开始后的第三个月）。问卷由六页和一份个人资料表组成。大约需要 15 到 20 分钟。

你作为项目的一部分所提供的信息就是研究数据。任何可以识别你身份的研究数据都被称为个人数据。个人数据不包括身份已被删除的数据（匿名数据）。我们会尽量减少在研究中使用个人数据。研究人员及其导师（包括英国德比大学的 Alex Molassiotis 教授）将为研究目的访问个人数据和研究数据。香港理工大学的负责成员可获准参与监察及/或审核有关研究。

所有与您有关的信息将被保密，并将通过只有研究人员知道的代码识别。收集的信息将在项目完成后保存 5 年。香港理工大学采取合理的预防措施，以防止你所提供的资料被遗失、盗用、未经授权的查阅或损毁。

参加本研究可能带来的影响包括：a. 培训中涉及到的一些终末期患者的案例，可能会引发您对过去工作或个人经历的回忆，这些经历可能是痛苦的或者有压力的。如果您在参与研究的过程中出现任何痛苦、不适或其他心理状况，请随时联系研究者，研究者将协助您联系医院内专业的心理辅导，或协助您获得家庭或同伴支持；b. 参与该研究可能需要您在工作之外额外付出时间和精力，您可能需要和您的上级协调工作时间，有可能影响您的工作表现，但参与该培训项目被期待有益于您的工作。

您有权在研究前或研究过程中退出研究，而不会受到任何惩罚。

如果您有任何问题，您可以现在或以后，甚至在研究开始后，问我们的助手。

如有下列情形，您可以联系香港理工大学的钟爱群博士(电话号码：XXX / email: okjoyce.chung@polyu.edu.hk)或陈炜琳女士(电话号码：XXX / email: weilin.chen@polyu.edu.hk):

1. 如果您有研究相关的其他问题，或者
2. 如果，在非常罕见的情况下，您会因为参与研究而受伤，或者
3. 如你想在(有效期)届满前查阅或更改你的个人资料。

如果您对这项研究有任何的不满，可随时与香港理工大学研究伦理委员会秘书联络（电邮：institutional.review.board@polyu.edu.hk），清楚说明负责人、部门以及参考编号。

如有严重不良事件¹，请立即向主要研究员报告，主要研究员须在收到报告后 48 小时内向理大伦理委员会报告。

感谢您有兴趣参与这项研究。

钟爱群博士
主要研究员（PI）
香港理工大学护理学院助理教授

¹SAE 是任何不良事件：
-导致死亡

- 威胁生命，或使参与者在事件发生时立即面临死亡风险
- 需要或延长住院时间
- 导致持续或严重残疾或丧失能力
- 导致先天性异常或出生缺陷
- 是调查人员判断为代表重大危险的另一种情况

(参考:NIA 不良事件和严重不良事件指南。

<https://www.nia.nih.gov/sites/default/files/2018-09/nia-ae-and-sae-guidelines-2018.pdf>)

Appendix 4: Consent form

(1) The qualitative study

CONSENT TO PARTICIPATE IN RESEARCH
Development and Evaluation of a Culturally Specific End-of-life Communication
Skills Training for Chinese Oncology Nurses

I _____ hereby consent to participate in the captioned research supervised by __ Dr Chung Oi Kwan Joyce__ and conducted by _Weilin Chen_____.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e., my personal details will not be revealed.

The researcher has thoroughly explained to me the procedures of the study written on the information sheet. I understand the benefit and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind. Participation or not will not cause any negative consequences.

Name of participant

Signature of participant

Date

Dr Chung Oi Kwan Joyce
Weilin Chen

Name of researcher

Signature of researcher

Date

参 与 研 究 同 意 书

基于中国社会文化背景的生命末期沟通技能培训的开发及其在中国 肿瘤护士中的评价

本人_____同意参与由钟爱群博士负责监督，陈炜琳执行的上述研究。

本人知悉此研究所得的资料可能被用作日后的研究及发表，但本人的私隐权利将得以 保留，即本人的个人资料不会被公开。

研究人员已向本人清楚解释列在所附资料上的研究程序，本人明白当中涉及的利益及风险；本人自愿参与研究项目。

本人明白本人有权就程序的任何部分提出疑问，亦有权随时退出此研究。参加与否将不会产生任何负面后果。

_____	_____	
_____	_____	
参与者姓名	参与者签署	日期
钟爱群博士 陈炜琳	_____	
_____	_____	
研究者姓名	研究者签署	日期

(2) The RCT

CONSENT TO PARTICIPATE IN RESEARCH

Effects of a Culturally Specific End-of-life Communication Skills Training for Chinese Oncology Nurses

I _____ hereby consent to participate in the captioned research supervised by __ Dr Chung Oi Kwan Joyce__ and conducted by _Weilin Chen_____.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e., my personal details will not be revealed.

The researcher has thoroughly explained to me the procedures of the study written on the information sheet. I understand the benefit and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind. Participation or not will not cause any negative consequences.

Name of participant

Signature of participant

Date

Dr Chung Oi Kwan Joyce
Weilin Chen

Name of researcher

Signature of researcher

Date

参 与 研 究 同 意 书

基于中国社会文化背景的生命末期沟通技能培训在中国肿瘤护士中的有效性

本人_____同意参与由钟爱群博士负责监督，陈炜琳执行的上述研究。

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本人明白本人有权就程序的任何部分提出疑问，亦有权随时退出此研究。参加与否将不会产生任何负面后果。


_____	_____	
参与者姓名	参与者签署	日期
钟爱群博士 陈炜琳	_____	
研究者姓名	研究者签署	日期

Appendix 5: The recruitment posters

(1) The qualitative study



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學



School of
Nursing

香港理工大学伦理批号: HSEARS20221217002
省肿瘤医院伦理批号: IRB-2023-526号 (科)
主要研究者: 香港理工大学钟爱群博士, 助理教授
省肿瘤医院傅晓辉护士长, 副主任护师

患者、家属、医务人员生命末期沟 通经历、认知和建议的研究

研究详情

目的: 了解利益相关者关于“生命末期事宜”的沟通经历、认知、态度和建议, 为改善中国文化环境中疾病晚期患者的沟通提供依据

内容: 患者、家属、医务人员将被邀请参与30分钟左右的访谈;
部分医务人员在访谈后将被邀请参与60~90分钟的焦点小组讨论

时间: 参与者弹性安排时间 (2023年5~8月)

地点: 线下 (如医院内) 或线上均可

招募对象

1、患者

- (1) 年龄 ≥ 18 岁;
- (2) 癌症晚期或非癌症疾病晚期 (如终末期肺病、终末期心力衰竭、终末期肾病等);
- (3) 正在院内接受姑息治疗 (如姑息性放、化疗、手术、靶向及免疫治疗等, 即以症状控制、缓解痛苦、提高生活质量为照护目标), 或正在院内接受临终关怀, 或近2个月内出院自行居家, 或转送至社区/当地医院/安宁疗护机构 (如临终关怀中心等);
- (4) 基本了解自己的病情;
- (5) 能够说普通话并较清晰地表达

2、家属

- (1) 年龄 ≥ 18 岁;
- (2) 上述类型患者的主要家庭照顾者; 或近2个月内的丧亲家属;
- (3) 基本了解患者的病情;
- (4) 能够说普通话并较清晰地表达


3、医务人员


- (1) 医院护士、医生 (含中医师);
- (2) 至少有5年治疗或照护晚期患者的工作经历

答谢礼品


完成访谈或讨论, 可获50元购物卡

联络方法


如有兴趣参与或想获得更多相关资料,
请联系陈女士 (电话/微信: )



(2) The RCT




THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學




School of
Nursing

患者问我：“我还能活多久？”
我该怎么回答他呢.....

和患者、家属谈论死亡？别别别，
婉拒了哈！我自己还没想明白呢！




基于中国社会文化背景的生命末期沟通技能培训



本培训以沟通技能培训经典模型Comskil Model作为理论框架，内容来自讲者与60余位医务人员、晚期患者及家属的访谈，以及新近国内外研究证据，主要讲授和探讨一系列护士与晚期患者及其家属生命末期相关的沟通策略、技巧和案例，共4节课。

培训模块

- ◆ 与晚期患者的沟通
- ◆ 与晚期患者家属的沟通
- ◆ 平衡期望与现实
- ◆ 晚期患者家属支持与照护




参与者招募


- ◆ 照护晚期癌症患者的护士；对活动感兴趣人士

首次培训时间地点（培训内容相同，2选1即可）


- ◆ [Redacted] 组)
- ◆ [Redacted] 组)
- ◆ [Redacted] 示教室

完成4节课和评估
可获得《结课证书》和Ⅱ类学分2.0






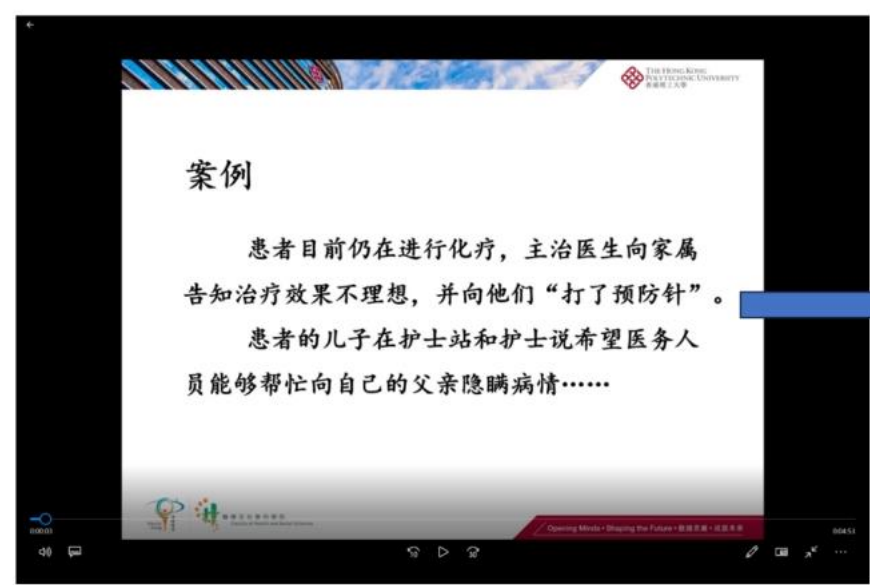
扫一扫填写报名表



扫一扫加入钉钉群



Appendix 6: The video sample




案例

患者目前仍在进行化疗，主治医生向家属告知治疗效果不理想，并向他们“打了预防针”。

患者的儿子在护士站和护士说希望医务人员能够帮忙向自己的父亲隐瞒病情……

Case background information



沟通目标：与家属协商是否向患者透露诊断和预后情况，以增进理解并解决顾虑

我爸还不知道他现在病的这么严重

Communication goal

Subtitles

过程任务: 环境; 坐位 → Process task

沟通策略: 检查家庭成员间的沟通 → Communication strategy

您和其他的家人有商量过怎么办吗

认知评价: 家属对披露真相的误解 → Cognitive appraisal

沟通技巧: 开放式问题 积极倾听 → Communication skill

但是我们还是认为先得瞒着

Appendix 7: Training completion certificate sample



Appendix 8: The observer-used assessment checklist

(1) English version

Observer-used assessment checklist

Participant number:

Note: Observers should check the following list item by item based on the nurse's performance in the simulated communication, including the application or completion of communication strategies, skills, process tasks, and communication goals. Please use "√" (completed or identified) or "×" (uncompleted or unidentified).

Module 1: RESPOND TO PATIENT CUES			
	Items	“√”(Completed or Identified)	“×”(Uncompleted or Unidentified)
Communication strategies	1. Recognize the cues based on the understanding of the patient's information and situation		
	2. Acknowledge the patient's willingness to express and appreciate the trust		
	3. Explore underlying concerns		
	4. Normalize discussions about death and dying		
	5. Elicit the patient's thoughts, preferences and wishes hypothetically		
	6. Respond to emotional reactions with empathy		
	7. Check previous discussions between the patient and family about these topics		

	8. Introduce advance care planning		
	9. Make a closure		
Communication skills	1. Express feelings		
	2. Express gratitude		
	3. Express a willingness to help		
	4. Ask open questions		
	5. Active listening		
	6. Check understanding		
	7. Clarify		
	8. Restate		
	9. Validate		
	10. Normalize		
	11. Hypothetical questions		
	12. Encourage the expression of thoughts and feelings		
	13. Make a “take stock” statement		
	14. Empathize		
	15. Acknowledge		
	16. Simplify		
	17. Praise the patient’s efforts		
	18. Review previous discussions, if any		
	19. Summarize		
	20. Information giving		
	21. Offer the choice		
	22. Check understanding		
	23. Invite questions		
	24. Endorse question asking		
	25. Reinforce joint decision-making		
	26. Review next steps		
Process tasks	1. Careful observation		
	2. Use eye contact		

3. Use appropriate body language, such as an open posture		
4. Understand the patient's cues		
5. Make time, or at least tell the patient what time is available		
6. Seek permission before proceeding if the family is present		
7. Understand non-verbal language (e.g., facial expressions the family doesn't want to talk)		
8. Use appropriate body language, such as sitting close to the patient (at eye level)		
9. Ensure the patient's privacy		
10. Avoid interruptions		
11. Make notes if necessary		
12. Correct any misunderstandings		
13. Avoid making the patient think that discussing death and dying is a taboo		
14. Use examples or stories to explain the benefits of discussions of death and dying		
15. Allow time to process		
16. Offer tissues		
17. Understand the family end-of-life		

	communication		
	18. Use simple language and avoid technical terms		
	19. Use available documents, educational materials, or explanatory videos to explain advance care planning		
	20. Address all questions		
	21. Prepare the patient for the next communication about advance care planning if the patient is interested		
	22. Allow the patient not to discuss, and provide opportunities for addressing these topics at a later time		
	23. Invite family members/ significant others/ physician/ other healthcare providers with informed consent of the patient		
Communication goal	1. To respond to patient cues related to end-of-life topics in daily interactions in a way that demonstrates respect, empathy, perception and exploration.		
Module 2: NEGOTIATE WITH THE FAMILY			
	Items	“√”(Completed or Identified)	“×”(Uncompleted or Unidentified)
Communication strategies	1. Tailor the negotiation to the family’s needs		

2. Explore the family's concerns about the disclosure		
3. Check previous family communication around end-of-life topics; acknowledge the cultural taboo if appropriate		
4. Respond to the family's concerns: Explore the underlying reasons for the family's reluctance to disclose the truth		
5. Respond to the family's concerns: Discuss with the family about potentially concealing information from the patient while highlighting the challenges associated with doing so		
6. Respond to the family's concerns: Guide the family to empathize with the patient's perspective		
7. Respond to the family's concerns: Discuss with the family the potential consequences or outcomes of withholding information from patients while emphasizing the negative impacts		
8. Respond to the		

	family's concerns: Indicate the responsibilities of surrogate decision-makers, highlight discrepancies between familial preferences and those of patients themselves, and the importance of understanding patients' wishes		
	9. Propose a plan if there are persistent concerns or disagreements among family members		
	10. Propose a plan for the disclosure		
	11. Tailor the disclosure to the family's needs		
	12. Make a closure		
Communication skills	1. Declare your agenda items		
	2. Invite family agenda items		
	3. Negotiate agenda		
	4. Ask open questions		
	5. Encourage expression of feelings		
	6. Active listening		
	7. Invite questions		
	8. Endorse question asking		
	9. Clarify		
	10. Restate		
	11. Review previous discussions, if any		
	12. Validate		
	13. Normalize		

	14. Empathize		
	15. Acknowledge		
	16. Information giving		
	17. Analyze		
	18. Summarize		
	19. Check understanding		
	20. Reinforce joint decision-making		
	21. Review next steps		
Process tasks	1. Ensure a quiet and privacy environment		
	2. Greet appropriately		
	3. Make introductions		
	4. Sit at eye level		
	5. Check the family's understanding of the patient's prognosis and their family plans		
	6. Explore the family preferences concerning disclosure of diagnosis and prognosis to patients		
	7. Avoid the bias that all families prefer to non-disclosure		
	8. Allow time to process		
	9. Avoid interruptions		
	10. Make notes if necessary		
	11. Understand the family end-of-life communication		
	12. Understand the underlying reasons for the family's reluctance to disclose the truth		
	13. Use examples or stories to explain the risks of concealment		
	14. Use survey data to		

	explain differences in end-of-life preferences between patients and their families		
	15. Correct misunderstandings		
	16. Address all questions		
	17. Acquire further input from specialists		
	18. Prepare for the next steps (e.g., ask who should be involved in the family meeting and invite them)		
	19. Use examples or stories to describe the disclosure process Prepare for next steps		
	20. Allow time for consideration and leave open for further communication		
	21. Repeat		
Communication goal	1. To negotiate with the family about the disclosure of diagnosis and prognosis to patients, including fostering understanding and addressing concerns		
Module 3: NURTURE HOPE			
	Items	“√”(Completed or Identified)	“×”(Uncompleted or Unidentified)
Communication strategies	1. Review physician’s discussion		
	2. Explore the patient/family's thoughts and needs		
	3. Respond to emotional		

	reactions with empathy		
	4. Analyze the progress and emphasize the positive aspects of the previous discussion		
	5. Emphasize what can be done and reassure available ongoing support, if it is possible; otherwise, make reliable alternative arrangements		
	6. Discuss and facilitate day-to-day coping		
	7. Follow-ups (e.g., provide opportunities for emotional exchanges between the patient and the family/ significant others; introduce the Four Principles of Life)		
Communication skills	1. Check understanding		
	2. Explain in plain language		
	3. Acknowledge the (unrealistic) expectations		
	4. Reinforce the efforts of both sides		
	5. Ask open questions		
	6. Active listening		
	7. Encourage expression of feelings		
	8. Invite questions		
	9. Empathize		
	10. Validate		
	11. Acknowledge		
	12. Normalize		
	13. Simplify		
	14. Praise the efforts		
	15. Express a		

	willingness to help		
	16. Analyze		
	17. Summarize		
	18. Encourage optimism		
	19. Use metaphor to explain palliative care		
	20. Reinforce joint decision-making		
	21. Make partnership statements		
	22. Information giving		
	23. Identify areas where control can be fostered (e.g., advance care planning, tidying up unfinished business, focusing on important relationships, involving the family in end-of-life care for patients, etc.)		
	24. Praise the diverse ways of the expression of emotion		
Process tasks	1. Greet patient appropriately		
	2. Make introduction		
	3. Sit at eye level		
	4. Ensure a quiet and privacy environment		
	5. Seek realistic expectations		
	6. Follow up of the physician's discussion (what has already been discussed and reactions)		
	7. Invite a third party if necessary (e.g., psychologist and social worker)		
	8. Maintain eye contact		

9. Show compassion by using a warm, caring, and respectful manner		
10. Allow time to integrate		
11. Offer tissues		
12. Allow time to process		
13. Avoid over-assurance		
14. Avoid making the patient feel abandoned		
15. Facilitate realistic goals and reframe the patient's and family's expectations		
16. Use examples, stories or educational materials to provide information		
17. Use simple language and avoid technical terms		
18. Understand the patient's and the family's coping style		
19. Make appropriate environmental modifications to accommodate the patient's preference		
20. Careful observation		
21. Arrange activities like memorial days and life reviews with family involvement		
22. Document significant moments (e.g., photographs, videos, and other		

	mementoes)		
Communication goal	1. To nurture hope in realistic expectations in a way that encourages emotional expression and reconstructs a sense of meaning		
Module 4: BEREAVEMENT SUPPORT			
	Items	“√”(Completed or Identified)	“×”(Uncompleted or Unidentified)
Communication strategies	1. Tailor the support to the family's needs		
	2. Express grief appropriately		
	3. Elicit descriptions of personal experience of loss		
	4. Respond to emotional reactions with empathy		
	5. Assist the family in relaxing		
	6. Review the family efforts and help focus on the positive impact		
	7. Normalize through education by explaining the normal range of grief experiences		
	8. Provide useful information for ongoing support and make a closure		
Communication skills	1. Express a willingness to help		
	2. Ask permission for the accompanying		
	3. Express feelings		
	4. Encourage expression of feelings		
	5. Active listening		

	6. Empathize		
	7. Validate		
	8. Acknowledge		
	9. Normalize		
	10. Encourage expression of feelings		
	11. Demonstrate		
	12. Review		
	13. Praise the efforts		
	14. Normalize (emphasize that others experience similar symptoms)		
	15. Information giving		
	16. Acknowledge that although it doesn't feel normal, grief is normal		
	17. Invite questions		
	18. Check understanding		
	19. Summarize		
Process tasks	1. Greet the family appropriately		
	2. Make introduction		
	3. Ensure a quiet and privacy environment		
	4. Maintain eye contact		
	5. Show compassion by using a warm, caring, and respectful manner		
	6. Respect and cooperate with the family's beliefs (e.g., pray or chant)		
	7. Careful observation		
	8. Listen carefully for any metaphors used by the family and explore the meaning		
	9. Maintain eye contact		
	10. Show compassion		

	by using a warm, caring, and respectful manner		
	11. Allow time to integrate		
	12. Offer tissues		
	13. Avoid interruptions		
	14. Allow time to process		
	15. Review the documentation of significant moments if appropriate		
	16. Use simple language and avoid technical terms		
	17. Invite an appropriate third party		
	18. Address all questions		
	19. Provide information in a medium that can be reviewed repeatedly if possible		
	20. Facilitate access to professional and community resources if necessary		
Communication goal	To support bereaved families, including presence and sharing useful information about grief coping		

Modular score (for statistical purposes; 1 point for each "√") :

Module 1 (0-59) :

Module 2 (0-55) :

Module 3 (0-54) :

Module 4 (0-48) :

Total score (0-216) :

(2) Chinese version

观察者清单

被评估者编号：

说明：请观察者根据护士在模拟沟通中的表现，逐一检查下列清单，包括每一模块考核中的沟通策略、技巧和过程任务的应用或完成情况，以及沟通目标的达成情况，并用“√”（完成或可识别）或“×”（未完成或未识别）。

模块 1：回应患者暗示			
	清单条目	“√”（完成或可识别）	“×”（未完成或未识别）
沟通策略	1.根据对患者信息和情况的理解来识别线索		
	2.确认患者愿意表达并感谢他们的信任		
	3.深入探究潜在的问题		
	4.让关于死亡和临终的讨论变得正常化		
	5.诱导患者说出他们的想法、偏好和愿望（假设性的）		
	6.用同理心回应情感反应		
	7.检查患者和家属之前关于这些话题的讨论		
	8.介绍预立医疗照护计划		
	9.结束对话		
沟通技巧	1.表达感受		
	2.表达感激		
	3.表达帮助的意愿		
	4.提出开放性问题的		
	5.积极倾听		
	6.检查理解		
	7.澄清		
	8.复述		
	9.验证		
	10.正常化		
	11.假设性问题		

	12.鼓励表达想法和感受		
	13.做出“盘点”陈述		
	14.共情		
	15.承认		
	16.简化		
	17.赞扬努力		
	18.回顾之前的讨论（如果有的话）		
	19.总结		
	20.提供信息		
	21.提供选择		
	22.检查理解		
	23.邀请提问		
	24.鼓励提问		
	25.强化共同决策		
	26.回顾下一步行动		
过程任务	1.仔细观察		
	2.保持眼神交流		
	3.使用适当的肢体语言，如保持开放的姿态		
	4.理解患者的暗示		
	5.安排时间，或者至少告诉患者何时有空		
	6.如果家人在场，请先征得他们的同意后再继续		
	7.理解非言语语言（例如，家人不想谈论时的面部表情）		
	8.使用适当的肢体语言，如坐在患者旁边（与患者视线平齐）		
	9.确保患者的隐私		
	10.避免干扰/中断		
	11.如有必要，做些笔记		
	12.纠正任何误解		
	13.避免让患者认为讨论死亡和临终问题是禁忌		
	14.使用例子或故事来解释讨论死亡和临终问题的益处		

	15.给时间来处理问题		
	16.提供纸巾		
	17.了解家庭临终沟通		
	18.使用简单的语言，避免使用专业术语		
	19.使用现有的文件、教育材料或解释性视频来解释预立医疗照护计划		
	20.回答所有问题		
	21.如果患者感兴趣，为下一次关于预立医疗照护计划的沟通做好准备		
	22.允许患者不参与讨论，并留下沟通的空间		
	23.在获得患者知情同意的情况下，邀请患者的家人/重要他人/医生/其他卫生保健提供者参与讨论		
沟通目标	1.在日常互动中，以尊重、同理心、洞察力和探索的态度回应与临终话题相关的患者暗示		
模块 2：与家属协商			
	清单条目	“√”（完成或可识别）	“×”（未完成或未识别）
沟通策略	1.针对家庭的需求进行协商		
	2.了解家庭成员对信息披露的担忧		
	3.检查之前关于临终话题的家庭沟通；如果合适的话，承认文化禁忌		
	4.回应家属的担忧：探究家庭不愿透露真相的深层原因		
	5.回应家属的担忧：与家属讨论可能对患者隐瞒信息的问题，同时强调这样做所带来的挑战		
	6.回应家属的担忧：引导		

	家庭成员从患者的角度去理解和感受病情		
	7.回应家属的担忧：与家属讨论向患者隐瞒信息的潜在后果或结果，同时强调负面影响		
	8.回应家属的担忧：指出代理决策者的职责，强调家庭偏好与患者自身偏好的差异，以及理解患者意愿的重要性		
	9.如果家庭成员之间存在持续的担忧或分歧，提出一个计划		
	10.提出一个披露的计划		
	11.根据家庭的需要来调整信息披露		
	12.结束对话		
沟通技巧	1.宣布你的议程事项		
	2.邀请家庭成员提出议程事项		
	3.协商议程		
	4.提出开放性问题		
	5.鼓励表达感受		
	6.积极倾听		
	7.邀请提问		
	8.鼓励提问		
	9.澄清		
	10.重述		
	11.回顾之前的讨论（如果有的话）		
	12.验证		
	13.正常化		
	14.共情		
	15.承认		
	16.提供信息		
	17.分析		
	18.总结		
	19.检查理解		
	20.强调共同决策		

	21.回顾下一步		
过程任务	1.确保环境安静、私密		
	2.适当地问候		
	3.自我介绍		
	4.使用适当的肢体语言， 如坐在患者旁边（与患者 视线平齐）		
	5.了解患者及其家人对病 情预后的理解以及他们的 家庭计划		
	6.探究家庭对于向患者透 露诊断和预后情况的偏好		
	7.避免认为所有家庭都倾 向于不透露的偏见		
	8.给时间来处理问题		
	9.避免干扰/中断		
	10.如有必要，做些笔记		
	11.了解家庭临终沟通		
	12.了解家庭不愿透露真 相的深层原因		
	13.使用例子或故事来解 释隐瞒真相的风险		
	14.利用调查数据解释患 者及其家属临终偏好的差 异		
	15.纠正误解		
	16.回答所有问题		
	17.进一步听取专家的意 见		
	18.准备下一步行动（例 如，询问谁应该参与家庭 会议并邀请他们）		
	19.使用例子或故事来描 述披露过程		
	20.留出考虑时间，并为进 一步沟通留下空间		
	21.重复		
沟通目标	1.与家属协商是否向患者 透露诊断结果和预后情 况，包括增进理解和解决		

	顾虑		
模块 3：培育希望			
	清单条目	“√”（完成或可识别）	“×”（未完成或未识别）
沟通策略	1.回顾医生的讨论		
	2.了解患者/家属的想法和需求		
	3.用同理心回应情感反应		
	4.分析前面讨论的进展情况，并强调其中的积极方面		
	5.强调可以采取的措施，并确保在可能的情况下提供持续的支持；否则，应制定可靠的替代安排		
	6.讨论并促进日常应对		
	7.跟进（例如，为患者与家人/重要他人之间提供情感交流的机会；介绍“四道人生”）		
沟通技巧	1.检查理解		
	2.用通俗易懂的语言解释		
	3.承认（不切实际的）期望		
	4.强调双方的努力		
	5.提出开放式问题		
	6.积极倾听		
	7.鼓励表达感受		
	8.邀请提问		
	9.共情		
	10.验证		
	11.承认		
	12.正常化		
	13.简化		
	14.赞扬努力		
	15.表达帮助的意愿		
	16.分析		
	17.总结		
	18.鼓励乐观		
	19.用比喻来解释姑息治疗		

	20.强调共同决策		
	21.做出合作声明		
	22.提供信息		
	23.确定可以促进控制感的领域（例如，讨论预立医疗照护计划、处理未完成的事宜、关注重要的关系，让家属参与患者的临终护理等）		
	24.赞美表达情感的多种方式		
过程任务	1.适当地问候		
	2.自我介绍		
	3.使用适当的肢体语言，如坐在患者旁边（与患者视线平齐）		
	4.确保环境安静、私密		
	5.寻求现实的期望		
	6.跟进医生的讨论（已经讨论过的内容和反应）		
	7.如有必要，邀请第三方（例如心理治疗师和社会工作者）		
	8.保持眼神交流		
	9.用温暖、关怀、尊重的态度表达同情		
	10.留出时间让对方消化吸收		
	11.提供纸巾		
	12.给时间来处理问题		
	13.避免过度保证		
	14.避免让患者感到被抛弃		
	15.协助制定切实可行的目标，重塑患者及其家人的期望		
	16.使用例子、故事或教育材料提供信息		
	17.使用简单的语言，避免使用专业术语		

	18.了解患者和家属的应对方式		
	19.根据患者的偏好对环境进行适当的改善		
	20.仔细观察		
	21.安排有家人参与的纪念日和生活回顾等活动		
	22.记录重要时刻（如照片、视频和其他纪念品）		
沟通目标	1.以一种鼓励情感表达和重建意义感的方式，在现实的期望中培养希望		
模块 4：丧亲支持			
	清单条目	“√”（完成或可识别）	“×”（未完成或未识别）
沟通策略	1.针对家庭需求提供帮助		
	2.适当地表达哀伤		
	3.引出对失去亲人的个人经历的描述		
	4.用同理心回应情感反应		
	5.帮助家人放松		
	6.回顾家庭的努力，帮助聚焦于积极的影响		
	7.通过教育来正常化，即解释悲伤体验的正常范围		
	8.提供有用的信息以进行持续的支持，并结束对话		
沟通技巧	1.表达帮助的意愿		
	2.请求允许陪伴		
	3.表达感受		
	4.鼓励表达情感		
	5.积极倾听		
	6.共情		
	7.验证		
	8.承认		
	9.正常化		
	10.鼓励表达感受		
	11.演示		
	12.回顾		
	13.赞扬努力		

	14.正常化（强调其他人也有类似的症状）		
	15.提供信息		
	16.承认虽然感觉不正常，但悲伤是正常的		
	17.邀请提问		
	18.检查理解		
	19.总结		
过程任务	1.适当地问候		
	2.自我介绍		
	3.确保环境安静、私密		
	4.保持眼神交流		
	5.用温暖、关怀、尊重的态度表达同情		
	6.尊重并配合家属的信仰（例如祈祷或吟唱）		
	7.仔细观察		
	8.仔细聆听家庭成员使用的任何隐喻，并探究其含义		
	9.保持眼神交流		
	10.用温暖、关怀、尊重的态度表达同情		
	11.留出时间让对方消化吸收		
	12.提供纸巾		
	13.避免干扰/打断		
	14.给时间来处理问题		
	15.如果合适的话，回顾重要时刻的记录		
	16.使用简单的语言，避免使用专业术语		
	17.邀请合适的第三方参与		
	18.回答所有问题		
	19.尽可能以可反复查阅的媒介提供信息		
	20.必要时提供专业和社区资源		
沟通目标	1.为丧亲的家庭提供支		

	持，包括陪伴和分享有关 应对悲伤的有用信息		
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模块得分（统计用；每个“√”记1分）：

模块1（0-59）：

模块2（0-55）：

模块3（0-54）：

模块4（0-48）：

总分（0-216）：

Appendix 9: Nurses' Clinic Communication Skill Scale

(1) Chinese version

护士临床沟通能力量表

请对您以下方面的表现进行评价,并在您的答案上打“√”。

条目	很差 1	较差 2	一般 3	较好 4	很好 5
1.见到患者,能主动与其打招呼	1	2	3	4	5
2.平时能使用亲切的名词来称呼患者如老李,小张等等	1	2	3	4	5
3.平时与患者交谈时,能注意语音、语速,使患者听清所讲的内容	1	2	3	4	5
4.平时与患者交谈时,能注意语调,不让语调伤害患者	1	2	3	4	5
5.平时与患者交谈时,能根据患者的文化层次,选择其易懂的词语	1	2	3	4	5
6.平时与患者交谈时,能应用礼貌性语言,如请,您好,对不起等	1	2	3	4	5
7.在给患者进行各项操作时,能积极地与患者进行沟通,如讲解操作的目的、了解患者的感受等	1	2	3	4	5
8.即使工作繁忙,也能耐心地与患者交流	1	2	3	4	5
9.当患者向我咨询我不了解的信息时,能主动向患者介绍其他合适的咨询对象或途径	1	2	3	4	5
10.平时与患者交谈时,能表现出与当时的情景相适应的表情,如患者痛苦时,表现出关切的表情;患者高兴时,则面带微笑	1	2	3	4	5
11.平时与患者交谈时,能用关切的目光注视患者	1	2	3	4	5
12.平时与患者交谈时,能适时使用幽默话语,以营造良好的氛围	1	2	3	4	5
13.当患者倾诉其情感体验时,能将我的感受及时告知患者,以核实感知到的是否正确	1	2	3	4	5
14.对情绪不好的患者,能主动进行心理疏导	1	2	3	4	5
15.对情绪不好的患者,能提供合适的安慰,使患者的心理需求得以满足,缓解其负性情绪	1	2	3	4	5
16.对情绪不好的患者,能通过一些非语言的方式(如触摸、眼神),来表达对患者的情感	1	2	3	4	5

支持					
17.对情绪不好的患者,能通过合适的语言表达对其的支持和关心,如赞许、夸奖、鼓励、安慰或开导患者	1	2	3	4	5
18.与情绪不好的患者交谈时,患者能从我的语言和非语言行为中感受到我对其情感的理解和支持	1	2	3	4	5
19.面对患者或家属对我的不满时,能心平气和地与他们进行沟通,并想办法平息他们的不满情绪	1	2	3	4	5
20.对死亡患者的家属,能及时了解其需求并提供帮助	1	2	3	4	5
21.对有老年痴呆的患者,能与其有效沟通并了解其需求	1	2	3	4	5
22.第一次和患者见面时,能主动自我介绍	1	2	3	4	5
23.平时在给患者进行护理操作时,能根据不同的情景和患者谈论合适的话题	1	2	3	4	5
24.平时与患者交谈过程中,不会突然终止交谈去做其他事情	1	2	3	4	5
25.当与患者交谈时,能排除工作之外的事情的影响	1	2	3	4	5
26.与患者见面时,能保持大方得体的着装	1	2	3	4	5
27.平时与患者交谈时,能举止优雅、稳重	1	2	3	4	5
28.平时与患者交谈时,能与患者保持合适的距离,让患者觉得亲切而不疏远	1	2	3	4	5
29.当患者在发泄情绪时,能在适当的时候沉默,让患者感受到无声的支持	1	2	3	4	5
30.与悲观的患者交谈时,能鼓励患者表达自己的感受,并对其表示理解、关心和支持,使其尽快恢复平静	1	2	3	4	5
31.与发怒或哭泣患者交谈时,能尽量让患者发泄不满,从中了解他们的需求,使其身心尽快恢复平衡	1	2	3	4	5
32.当患者表现出孤单无助时,能多抽空陪伴患者并积极提供帮助	1	2	3	4	5
33.对治疗表现出痛苦情绪的患者,能通过适当的方式(鼓励性的话)让患者感受到被理解、支持和鼓励	1	2	3	4	5
34.对焦虑、恐惧中的患者,能通过合适的解释及安慰缓解其情绪	1	2	3	4	5

35.当患者对治疗或护理表现出质疑时,能耐心解释,直至取得其理解	1	2	3	4	5
36.对传染病患者如艾滋病、肝炎患者,能与其有效沟通并了解其需求	1	2	3	4	5
37.对临终或癌症患者,能主动评估其心理需要,为患者提供针对性心理护理	1	2	3	4	5
38.对有文化差异的患者(外国患者,少数民族患者),能与其有效沟通并了解其需求	1	2	3	4	5
39.在护理患者的过程中,能注意观察患者的情绪变化	1	2	3	4	5
40.在护理患者的过程中,能通过患者的非语言行为(患者的表情、目光等)了解患者的情绪状态	1	2	3	4	5
41.遇到要求过高的患者,能对患者表示理解、关心和重视的同时对其不合理要求进行一定限制	1	2	3	4	5
42.能将治疗或护理的不良消息(如手术被取消,治疗效果不好等消息)以一种患者能接受的方式告知患者	1	2	3	4	5
43.对于不配合的患者,能先了解原因,然后有针对性地与患者沟通,取得其配合	1	2	3	4	5
44.对于一些语言不通的患者(如气管插管者,讲方言者),能通过画图、手势等方式与其进行有效沟通,了解患者的需求并及时提供帮助	1	2	3	4	5
45.当询问涉及患者隐私问题时,能选择合适的方式使患者能自然地诉说	1	2	3	4	5
46.在抢救患者的过程中,能用恰当言语及时与家属进行沟通,安抚患者家属的情绪	1	2	3	4	5
47.与情绪不好的患者交谈时,能引导患者表达其内心感受	1	2	3	4	5
48.当患者诉说其情感体验时,能耐心倾听	1	2	3	4	5
49.当患者诉说其情感体验时,不会随意打断患者,给患者足够的时间说出他的想法	1	2	3	4	5
50.当患者诉说其情感体验时,能表现出对其所讲内容的兴趣并鼓励患者讲下去	1	2	3	4	5
51.当患者诉说其情感体验时,能通过适当的方式(如点头等)给予及时反馈	1	2	3	4	5
52.与情绪不好的患者交谈时,能从患者的角度出发,体会患者的感受,理解患者	1	2	3	4	5

(2) English version (The scale is originally Chinese and does not have English versions.

This English version is only a translation for reference)

Nurses' Clinic Communication Skill Scale

Please rate your performance in the following areas and tick "√" on your answers.

Items	Very poor 1	Poor 2	General 3	Good 4	Very good 5
1. Greet patients when I see them	1	2	3	4	5
2. I can address patients friendly, such as Lao Li, Xiao Zhang and so on	1	2	3	4	5
3. When talking with patients, I can pay attention to voice and speed so that patients can hear what is said clearly	1	2	3	4	5
4. When talking with the patients, I can pay attention to the intonation and don't let tone hurt patients	1	2	3	4	5
5. When talking with patients, I can choose words that are easy to understand according to the patient's cultural level	1	2	3	4	5
6. When talking with patients, I can use polite language, such as please, hello, sorry, etc	1	2	3	4	5
7. When performing various procedures on patients, I can actively communicate with the patient, such as to explain the purpose of the operation, understand the feelings of the patients, etc	1	2	3	4	5
8. Even if the work is busy, I also communicate with patients patiently	1	2	3	4	5
9. When a patient consults me about information I am unfamiliar with, I can proactively introduce them to other suitable consultation targets or channels	1	2	3	4	5
10. During conversations with patients, I can display appropriate facial expressions that match the situation. For example, show concern when the patient is in pain, and smile when the patient is happy	1	2	3	4	5
11. When speaking with patients, I can look	1	2	3	4	5

at them with a concerned expression					
12. During conversations with patients, I can use humorous remarks appropriately to create a positive atmosphere	1	2	3	4	5
13. When the patient expresses their emotional experiences, I can inform them of my own feelings in a timely manner to verify whether my perceptions are accurate	1	2	3	4	5
14. For patients with bad mood, I can proactively provide psychological counseling	1	2	3	4	5
15. For patients with bad mood, I can provide appropriate comfort to meet their psychological needs and alleviate their negative emotions	1	2	3	4	5
16. For patients with bad mood, I can use non-verbal ways (such as touch, eye contact) to express emotional support	1	2	3	4	5
17. For patients with bad moods, I can use the appropriate verbal expression of support and care, such as praise, compliments, encouragement, comfort, or counseling for the patient	1	2	3	4	5
18. When I talk to a patient who is in a bad mood, the patient can feel that I understand and support their emotions through my verbal and nonverbal behaviors	1	2	3	4	5
19. When patients or family members are dissatisfied with me, I can communicate with them calmly and find ways to calm their dissatisfaction	1	2	3	4	5
20 For the families of deceased patients, I can understand their needs and assist promptly	1	2	3	4	5
21. For patients with dementia, I can communicate effectively with them and understand their needs	1	2	3	4	5
22. When meeting patients for the first time, I can take the initiative to introduce myself	1	2	3	4	5
23. During the nursing operation for	1	2	3	4	5

patients, I can talk about appropriate topics with patients according to different situations					
24. During normal conversations with patients, I do not suddenly stop the conversation to do something else	1	2	3	4	5
25. When speaking with patients, I can eliminate the influence of non-work-related matters	1	2	3	4	5
26. I can dress generously and appropriately when meeting patients	1	2	3	4	5
27. When conversing with patients, I can act with elegance and composure	1	2	3	4	5
28. During conversations with patients, I can maintain an appropriate distance so that they feel comfortable and not distant	1	2	3	4	5
29. When a patient is expressing their emotions, I can remain silent at times, allowing the patient to feel supported without words	1	2	3	4	5
30. When speaking with a pessimistic patient, I can encourage them to express their feelings, show understanding, concern, and support, which can help them regain calmness as soon as possible	1	2	3	4	5
31. When communicating with patients who are angry or crying, I can allow them to express their frustrations and understand their needs so that they can regain emotional balance as quickly as possible	1	2	3	4	5
32. When patients show signs of loneliness and helplessness, I can try to make time to be with them and offer supportive assistance	1	2	3	4	5
33. For patients who express painful emotions during treatment, I can convey understanding, support, and encouragement through appropriate means (encouraging words)	1	2	3	4	5
34. For patients with anxiety and fear, I can	1	2	3	4	5

relieve their emotions through appropriate explanation and comfort					
35. When patients show doubts about treatment or care, I can patiently explain until they understand	1	2	3	4	5
36. For infectious disease patients such as AIDS and hepatitis patients, I can effectively communicate with them and understand their needs	1	2	3	4	5
37. For terminally ill or cancer patients, I can proactively assess their psychological needs and provide targeted psychological care	1	2	3	4	5
38. For patients with cultural differences (foreign patients, ethnic minority patients), I can effectively communicate with them and understand their needs	1	2	3	4	5
39. During the process of caring for patients, I can pay attention to observing the patient's emotional changes	1	2	3	4	5
40. During the process of caring for patients, I can understand the emotional state of the patient through their nonverbal behaviors (such as their facial expressions and gaze)	1	2	3	4	5
41. When dealing with patients who have unreasonably high expectations, I can express understanding, concern, and importance while also imposing certain limitations on their unreasonable	1	2	3	4	5
42. I can convey bad news about treatment or care (such as cancelled surgery or poor treatment outcomes) to patients in a way that they can accept	1	2	3	4	5
43. For non-compliant patients, I can first understand the reason and then communicate with them in a targeted manner to obtain their cooperation	1	2	3	4	5
44. For some patients who do not speak the same language (such as those with tracheal	1	2	3	4	5

intubation or speaking a dialect), I can communicate effectively with them through drawing pictures, gestures, etc. to understand their needs and provide timely assistance					
45. When asking about sensitive issues related to a patient's privacy, I can choose an appropriate approach that allows the patient to feel comfortable and able to speak naturally	1	2	3	4	5
46. During the rescue process, I can communicate with the patient's family in a timely and appropriate manner to calm their emotions	1	2	3	4	5
47. When speaking with patients who are feeling down, I can guide them in expressing their inner feelings	1	2	3	4	5
48. When the patient expresses their emotional experiences, I can be patient and listen attentively	1	2	3	4	5
49. When the patient expresses their emotional experiences, I will not interrupt them at random, giving the patient enough time to express their thoughts	1	2	3	4	5
50. When the patient expresses their emotional experiences, I can show interest in what they are saying and encourage them to continue	1	2	3	4	5
51. When the patient expresses their emotional experiences, I can receive timely feedback through appropriate means (such as nodding)	1	2	3	4	5
52. When speaking with patients who are in a bad mood, I can empathize with them by understanding their perspective and feelings	1	2	3	4	5

Appendix 10: Hospice Care Self-efficacy Scale on Nurses

(1) Chinese version

护士安宁疗护自我效能问卷

条目	非常 不自 信 1	不自 信 2	不确 定 3	自信 4	非 常 自信 5
1.安排清醒患者与医生讨论病情	1	2	3	4	5
2.在保护患者的前提下履行病情告知义务	1	2	3	4	5
3.与患者沟通，陪伴并倾听患者心声	1	2	3	4	5
4.协助患者正确认识死亡及生命价值	1	2	3	4	5
5.尊重终末期患者信仰与文化习俗的差异	1	2	3	4	5
6.与医生讨论心肺复苏事宜和不必要的维生治疗	1	2	3	4	5
7.与患者或家属讨论心肺复苏事宜和不必要的维生治疗	1	2	3	4	5
8.指导家属参与患者的护理工作	1	2	3	4	5
9.消除家属疑虑，使之了解患者病情	1	2	3	4	5
10.尊重家属的要求，尽量少搬动患者	1	2	3	4	5
11.指导家属遗体护理及居丧准备	1	2	3	4	5
12.协助高危险哀伤的家属经历哀伤历程	1	2	3	4	5

(2) English version (The scale is originally Chinese and does not have English versions.
This English version is only a translation for reference)

Hospice Care Self-efficacy Scale on Nurses

Items	Very diffident 1	Diffident 2	Not sure 3	Confident 4	Very confident 5
1 Arrange for the conscious patient to discuss the condition with the doctor	1	2	3	4	5
2. Fulfill the obligation of disease disclosure under the premise of protecting patients	1	2	3	4	5
3. Communicate with the patient, accompany and listen to the patient	1	2	3	4	5
4. Assist the patient's correct understanding of death and life value	1	2	3	4	5
5. Respect differences in beliefs and cultural practices of end-stage patients	1	2	3	4	5
6. Discuss cardiopulmonary resuscitation (CPR) and unnecessary life-sustaining treatments with doctors	1	2	3	4	5
7. Discuss CPR and unnecessary life-sustaining treatments with patients or families	1	2	3	4	5
8. Guide the family members involved in patient care	1	2	3	4	5
9. Alleviate the family's concerns and inform them about the patient's condition.	1	2	3	4	5
10 Respect the family's request and move the patient as little as possible	1	2	3	4	5
11. Guide family members in body care and bereavement	1	2	3	4	5

preparation					
12. Help high-risk grieving families go through the grieving process	1	2	3	4	5

Appendix 11: The Communication Outcomes Questionnaire

(1) English version

Communication Outcomes Questionnaire

Note: The following statements are results or perspectives related to communicating with cancer patients (which may be correct or incorrect). Based on your own clinical experience and perspective, please select the probability of each communication result appearing using a suitable numerical value from 1 to 9, as shown below. Among them, 1 represents "very likely", and 9 represents "very unlikely":

1	2	3	4	5	6	7	8	9
Very likely		likely		neutral		unlikely		very unlikely
When you talk with cancer patients how likely is it that ...								
1. Asking them to talk about their concerns and emotions will benefit them	1	2	3	4	5	6	7	8 9
2. Your patients will become uncontrollably upset if you ask about their feelings	1	2	3	4	5	6	7	8 9
3. Asking your patients to talk about their illness and concerns will damage the way they cope	1	2	3	4	5	6	7	8 9
4. You will get too close to your patients if you ask about their feelings and concerns	1	2	3	4	5	6	7	8 9
5. You could be of some help to a patient by determining if they were depressed	1	2	3	4	5	6	7	8 9
6. Your workload will become unmanageable if you start asking patients about their psychological as well as physical concerns	1	2	3	4	5	6	7	8 9
7. Asking about concerns will give your patient false expectations	1	2	3	4	5	6	7	8 9
8. You will not ask a patient about their feelings and concerns because it is not your role	1	2	3	4	5	6	7	8 9
9. You would be criticized by colleagues if the patient gets upset	1	2	3	4	5	6	7	8 9
10. You will feel down if you talk with patients about their concerns and feelings	1	2	3	4	5	6	7	8 9
11. The way you break bad news will devastate your patient	1	2	3	4	5	6	7	8 9
12. A patient will get so overwhelmed by feelings that you will lose control of the interview	1	2	3	4	5	6	7	8 9
13. Your colleagues would be supportive if you needed to take extra time with a patient who was upset	1	2	3	4	5	6	7	8 9

14. You could say something which would harm the patient	1 2 3 4 5 6 7 8 9
15. You feel that you have been helpful when you have explored a patient's concerns	1 2 3 4 5 6 7 8 9
16. A patient will only cope if you make them feel everything will be all right	1 2 3 4 5 6 7 8 9
17. Asking a patient about their worries and fears about dying will help you identify concerns you could help with	1 2 3 4 5 6 7 8 9
18. Talking about fears and worries will distress your patients and make them cry	1 2 3 4 5 6 7 8 9
19. Your patient will show such strong emotions that you will be personally overwhelmed	1 2 3 4 5 6 7 8 9
20. If they are important patient swill bring up their concerns without you asking	1 2 3 4 5 6 7 8 9
21. Asking patients about their concerns and feelings will be useful for you in your management of the patient	1 2 3 4 5 6 7 8 9
22. You will feel unprofessional if you do not know how to respond to difficult questions	1 2 3 4 5 6 7 8 9
23. You will feel responsible to resolve all the concerns the patient bring up	1 2 3 4 5 6 7 8 9

(2) Chinese version

沟通结果问卷

说明：下面的陈述是有关与癌症病人沟通的一些结果或观点（可能正确，也可能不正确）。根据你自己的临床经验和观点，请选择你认为下面的每一种沟通结果出现的可能性有多大，并用 1~9 中的一个合适的数值表示。其中，1 代表“非常可能”，9 代表“非常不可能”，如下所示：

1	2	3	4	5	6	7	8	9
非常可能		很可能		不确定		不太可能		非常不可能

当你与癌症病人交谈时，下面这些情形或者结果发生的可能性有多大？

- | | |
|--|-------------------|
| 1.让病人谈论他们的担忧和情感将对他们有好处 | 1 2 3 4 5 6 7 8 9 |
| 2.如果你询问病人生病后的心情，会导致他们控制不住自己的悲伤情绪 | 1 2 3 4 5 6 7 8 9 |
| 3.让病人谈论他们的疾病和担忧将有损他们的应对方式 | 1 2 3 4 5 6 7 8 9 |
| 4.如果关心和询问病人生病后的感受和担忧，你会变得与病人的关系太密切 | 1 2 3 4 5 6 7 8 9 |
| 5.通过确定病人是否有抑郁情绪，你能够给病人提供一定的帮助 | 1 2 3 4 5 6 7 8 9 |
| 6.如果你开始关心病人心理上 and 身体上的担忧，你的工作量将变得难以应付 | 1 2 3 4 5 6 7 8 9 |
| 7.关心和询问病人的心理想法和顾虑只能提供给病人一些虚假的期望 | 1 2 3 4 5 6 7 8 9 |
| 8.你不要询问病人生病后的心情和担忧，因为这不是你工作范围内的事 | 1 2 3 4 5 6 7 8 9 |
| 9.如果病人变得控制不住悲伤情绪，你会受到同事的责备 | 1 2 3 4 5 6 7 8 9 |
| 10.如果你与病人谈论他们的感受和担忧，你也会变得情绪低落 | 1 2 3 4 5 6 7 8 9 |
| 11.如果由你去告诉病人他/她得了癌症，将会对病人造成伤害 | 1 2 3 4 5 6 7 8 9 |
| 12.病人将无法控制自己的情绪，你也无法将交谈继续进行下去 | 1 2 3 4 5 6 7 8 9 |
| 13.如果你需要多花费一些时间给一位情绪不好的病人以心理支持，你能够得到同事们的支持 | 1 2 3 4 5 6 7 8 9 |
| 14.你说的有些话可能会伤害病人，即：有些病人很敏感，你害怕会说错话 | 1 2 3 4 5 6 7 8 9 |
| 15.当你探讨了病人的担忧时，你觉得你对病人是有帮助的 | 1 2 3 4 5 6 7 8 9 |
-

16.如果你能够使病人感觉到任何事情都会好起来，病人才能应对	1 2 3 4 5 6 7 8 9
17.问病人对于死亡和临终的焦虑和恐惧将有助于你确定病人的担忧，从而为病人提供帮助	1 2 3 4 5 6 7 8 9
18.谈论病人恐惧和担忧的事情将会导致病人心情悲痛而哭泣	1 2 3 4 5 6 7 8 9
19.你的病人将会出现强烈的情绪反应，你个人很难控制这种局面	1 2 3 4 5 6 7 8 9
20.如果病人认为那些担忧对他们很重要的话，不需要你的询问，病人会自己倾诉出来	1 2 3 4 5 6 7 8 9
21.问病人生病后的感受和担忧有助于你对病人的管理	1 2 3 4 5 6 7 8 9
22.如果你不知道如何回答病人提出的一些难以回答的问题，你会觉得自己不够专业（即：水平不高或经验不足）	1 2 3 4 5 6 7 8 9
23.你觉得你有责任解决病人出现的所有顾虑	1 2 3 4 5 6 7 8 9

Appendix 12: Participant's information questionnaire

(1) English version

The general information

1. Department: _____
2. Age: _____ (years old)
3. Gender: _____
4. Professional and technical titles: _____
5. Working years _____; Years of participation in treatment or care of terminally ill patients _____
6. Education level: _____ (College/Bachelor/Master/Doctor)
7. Religion: _____ (Buddhism/Taoism/Christianity/others please specify)

(2) Chinese version

一般资料

1. 科室: _____
2. 年龄: _____ (岁)
3. 性别: _____
4. 专业技术职称: _____
5. 工作年限: _____; 参与晚期患者治疗或照护年限: _____
6. 受教育程度: _____ (专科/本科/硕士研究生/博士研究生)
7. 宗教信仰: _____ (佛教/道教/基督教/其他请注明)

Appendix 13: The visual analogue scales for satisfaction evaluation

(1) English version

1. How would you rate the structure of the training?

0	1	2	3	4	5	6	7	8	9	10
Very Dissatisfied										Very Satisfied

2. How would you rate the content of the training?

0	1	2	3	4	5	6	7	8	9	10
Very Dissatisfied										Very Satisfied

3. How would you rate the delivery methods of the training?

0	1	2	3	4	5	6	7	8	9	10
Very Dissatisfied										Very Satisfied

4. How would you rate the relevance of training to your work?

0	1	2	3	4	5	6	7	8	9	10
Very Dissatisfied										Very Satisfied

5. How satisfied are you with the overall training?

0	1	2	3	4	5	6	7	8	9	10
Very Dissatisfied										Very Satisfied

(2) Chinese version

1. 你对培训的组织结构如何评价？

0	1	2	3	4	5	6	7	8	9	10
非常 不满 意										非常 满意

2. 你对培训的内容如何评价？

0	1	2	3	4	5	6	7	8	9	10
非常 不满 意										非常 满意

3. 你对培训的方法如何评价？

0	1	2	3	4	5	6	7	8	9	10
非常 不满 意										非常 满意

4. 你对培训与你工作的相关性如何评价？

0	1	2	3	4	5	6	7	8	9	10
非常 不满 意										非常 满意

5. 你对培训的整体满意度如何？

0	1	2	3	4	5	6	7	8	9	10
非常 不满 意										非常 满意

Appendix 14: The interview guide for focus group discussion in the process evaluation

(1) English version

1. What are your impressions during the 8-week training period?
2. How would you evaluate this training in terms of structure, training content, training method, work relevance, and overall satisfaction?
3. What difficulties have you encountered throughout the training process?
4. Which factors have motivated you to persist in completing the training?
5. To what extent do you believe the training has met your expectations?
6. After completing this training program, how do you perceive your personal growth in end-of-life communication?
7. Do you have any suggestions or expectations for future training?
8. Additionally, is there anything else you want to add beyond our previous discussions?

(2) Chinese version

1. 在参与培训的 8 周里，你有什么感想？
2. 对于此次培训，你是如何评价的（组织机构、培训内容、培训方法、工作相关性、总体满意度）？
3. 在参与培训的过程中，你遇到过哪些困难？
4. 在参与培训的过程中，哪些因素促使你坚持下来？
5. 你觉得培训在多大程度上满足了你的期待？
6. 你觉得在培训后你在生命末期沟通方面有什么变化？
7. 你对未来的培训有什么建议或者期待？
8. 除了上述我们谈到的，你还有什么要补充的吗？