THE SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE, A PRIVATE UNIVERSITY IN KAJANG

By

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ABSTRACT

BACKGROUND: End-of-life care, a vital component of palliative care, plays a crucial role for individuals with terminal illnesses and their families. Despite growing demand, the quality of end-of-life care in Malaysian hospitals remains uncertain. This underscores the importance of exploring bereaved caregivers' perspectives to identify and address any gaps in care.

OBJECTIVES: To assess the aspects of care and the overall satisfaction level of the bereaved caregivers with the care received during the end-of-life.

METHODOLOGY: A cross-sectional survey was conducted among 107 participants from 22nd July to 20th August 2024 in a private university in Kajang. Purposive sampling method was used to enlist participants who fulfil the inclusion criteria. Data was collected using a self-administered questionnaire through face-to-face and online approach. Data analysis was performed using IBM SPSS version 29.0.

RESULTS: More than half of the participants (58.7%) expressed dissatisfaction with the overall care received during the end-of-life. Pearson's correlation test revealed a statistically significant negative correlation between the domains of end-of-life care and overall satisfaction.

Chi-square test showed no significant association between sociodemographic characteristics (participants' ethnicity, education level, religion and religiosity) and overall satisfaction of bereaved caregivers with care received during the end-of-life.

CONCLUSION: The study highlights significant gaps in end-of-life care within Malaysian hospitals, particularly in addressing unmet patient and family needs. To bridge these gaps, further specialized training for healthcare providers is essential. This upskilling would not only improve the quality of care but also enhance satisfaction among bereaved caregivers.

KEYWORDS: end-of-life care, overall satisfaction level, bereaved caregivers

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Date: 27th September 2024

PERMISSION SHEET

It is hereby certified that WONG JIA YAN (ID No: 20UMB06432) has completed this research project titled "THE SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE, A PRIVATE UNIVERSITY IN KAJANG" under the supervision of Dr. Thavamalar a/p Paramasivam (Supervisor) from M. Kandiah Faculty of Medicine and Health Sciences.

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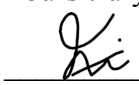

(WONG JIA YAN)

DECLARATION

I hereby declare that the research project is based on my original work except for quotations and citations which have been duly acknowledged. I also declare that it has not been previously or concurrently submitted for any other degree at UTAR or other institutions.

(WONG JIA YAN)

Date: 27th September 2024

APPROVAL SHEET

This research project entitled "THE SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE, A PRIVATE UNIVERSITY IN KAJANG" is prepared by WONG JIA YAN and submitted as partial fulfilment of the requirements for the degree of Bachelor of Nursing (Honours) at Universiti Tunku Abdul Rahman.

Approved by:

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LIST OF ABBREVIATIONS

EOL	End-of-Life
HCP	Healthcare provider
ICU	Intensive Care Unit
MoH	Ministry of Health
NCDs	Non-communicable Diseases
PhD	Doctor of Philosophy
SPSS	Statistical Package for the Social Sciences
UTAR	Universiti Tunku Abdul Rahman
U.S.	United States of America
UK	United Kingdom
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

CHAPTER 1: INTRODUCTION

1.0 CHAPTER OVERVIEW

The background, problem statement, and significance of study will be described in this chapter, followed by research objectives, hypotheses, conceptual and operational definitions.

1.1 BACKGROUND OF THE STUDY

The final phase of life, characterized by emotional vulnerability and physical decline, necessitates specialized care not only for patients but also for their families (Jurges and Hank, 2009). End-of-life care, a facet of palliative care, is tailored for individuals approaching the terminal stages of life-limiting illnesses, aiming to ensure that their transition is gentle, dignified, and comforting (NHS, 2022). Importantly, end-of-life care does not just enhance the quality of life for patients facing life-threatening illnesses by addressing physical, psychological, social, and spiritual challenges, but also extends its positive impact to their families and caregivers (Hawley, 2017; WHO, 2020).

In the Malaysian context, palliative care did not begin until around 1992 (Wright, et al., 2010). End-of-life care services are multifaceted, encompassing inpatient palliative care provided by government hospitals and community-based services predominantly offered by Non-Governmental Organizations (NGOs) like Hospis Malaysia and Charis Hospice (MoH, 2010; Hospis Malaysia, 2022; Charis Hospice, 2023). These services, delivered by highly trained professionals, span

medical, psychological, and emotional support, aiming to effectively manage suffering and improve the overall quality of life for patients and their families (MoH, 2010; Hospis Malaysia, 2022). However, home palliative care services in Malaysia remain limited and are primarily available within specific urban areas (Hospis Malaysia, 2022; Charis Hospice, 2023; Perak Palliative Care Society; n.d.). This lack of accessibility, particularly in rural regions, places a significant burden on family members, who often take on the responsibility of providing care due to the scarcity of resources. Besides, end-of-life care is also sometimes provided in acute care settings for patients with deteriorating conditions or uncontrollable symptoms as they approaching the end of life (Ho, et al., 2022).

Several studies conducted across different countries and healthcare systems underscore the positive outcomes associated with end-of-life support (Akiyama, Numata and Mikami, 2010; Hawley, 2017; Robertson, Hjörleifsdóttir, and Sigurðardóttir, 2022). These outcomes include improved symptom control and quality of life for patients, as well as reduced stress and minimized regret for caregivers (Akiyama, Numata and Mikami, 2010; Hawley, 2017; Robertson, Hjörleifsdóttir, and Sigurðardóttir, 2022). These improvements are crucial not only for the immediate well-being of the individuals involved but also for their subsequent adaptation to bereavement (Akiyama, Numata and Mikami, 2010). International research further emphasizes the profound impact of the support or lack thereof on the health of family members, manifesting in feelings of helplessness, frustration, anxiety, guilt and depression symptoms, ultimately

influencing the bereavement experience (O'Sullivan, et al., 2018; Robertson, Hjörleifsdóttir, and Sigurðardóttir, 2022).

Assessing the quality of end-of-life care emerges as a pivotal aspect in the pursuit of enhancing palliative care services (Jurges and Hank, 2009). Yet, evaluating the care experience during this phase presents notable challenges due to compromised patient health and difficulty in identifying those in their last week of life. Proxy measures, involving informal caregivers or family members, are commonly used to gain insights into patients' perspectives on care (Jurges and Hank, 2009; Phongtankuel, et al., 2020). Numerous research studies consistently focus on critical aspects to enhance end-of-life care quality, including evaluating and improving physical comfort, fostering shared decision-making, optimizing symptom management, ensuring effective advance care planning, addressing spiritual needs, and enhancing overall care coordination (Seow, et al., 2017; O'Sullivan, et al., 2018).

1.2 PROBLEM STATEMENT

Globally, an estimated 56.8 million individuals, including 25.7 million in their final year of life, require palliative care, but only 14% currently receive it (WHO, 2020). In Malaysia, escalating demand is fueled by the growing burden of non-communicable diseases (NCDs) and an ageing population, with NCDs contributed up to 71% of premature death in Malaysia (Yang, et al., 2020; DOSM, 2023). Palliative care needs in Malaysia are projected to increase by

240% by 2030 (Yang, et al., 2020). This emphasizes an increased need for palliative care, especially among the ageing population with NCDs and multiple comorbidities. Moreover, more patients are proportionally dying in hospitals, having received end-of-life care due to admission for inadequate symptom control with community resources (Bainbridge and Seow, 2017; Carey, et al., 2019). A local study found that 52.5% of those receiving end-of-life care in a hospital eventually passed away in the hospital, this further underscores the importance of quality end-of-life care being provided in hospital setting (Ho, et al., 2022).

Achieving a reasonable-quality end-of-life, free from avoidable distress and suffering, in line with patients' and families' wishes and clinical, cultural, and ethical standards is crucial. However, this is often challenging, especially in acute hospital settings (Carr and Luth, 2020; Carey, et al., 2019). Overseas studies reveal deficiencies in end-of-life care, including insufficient caregiver involvement in decision-making, lack of preparation for the dying phase, inadequate symptoms management, neglect of caregivers' needs by healthcare providers, and a lack of follow-up after death (Teno, et al., 2004; Røen, et al., 2018). Similar issues are observed in Malaysia, where local research points to a shortage of quality end-of-life care services, compounded by factors like inadequate education and negative attitudes among healthcare providers (Yang, et al., 2020; Dust, et al., 2022). Internationally, Malaysia ranks low in end-of-life care, coming in 62nd out of 81 countries, and lags behind regional peers like Thailand and the Philippines (Finkelstein, et al., 2022). In the "Global Atlas of

Palliative Care," Malaysia is categorized as a level 3A country, indicating limited integration of palliative care into the healthcare system, while neighboring countries such as Singapore and Thailand have reached higher levels of integration (Worldwide Hospice Palliative Care Alliance and WHO, 2020). This underscores the need for systemic improvements for end-of-life care in Malaysia.

Despite the critical role of quality end-of-life care, there is limited research in Malaysia which assesses the areas for improvements from the perspective of caregivers. Understanding the experiences of bereaved family members is crucial for improving end-of-life care. Family feedback offers insights into the quality of care provided and highlights areas where emotional, spiritual, and practical support can be enhanced (Jurges and Hank, 2009; Phongtankuel, et al., 2020). Studies show that family-centered care, including effective communication and grief support, promotes better coping and long-term emotional outcomes for families after a loss (Hawley, 2017; Akiyama, Numata and Mikami, 2010; Carey, et al., 2019). These perspectives can guide healthcare providers to develop compassionate, personalized care strategies that address the needs of both patients and their loved ones.

1.3 ORIGINILITY OF THE STUDY

Since the late 1990s, extensive research on end-of-life care quality from the perspective of bereaved caregivers has been conducted in Western countries (Fakhoury, 1998; Teno, et al., 2001; Casarett, Crowley and Hirschman, 2003; Carey, et al., 2017; O'Sullivan, et al., 2018). Following this trend, East Asian countries, including South Korea and Japan, have also seen a rise in studies on similar topics (Miyashita, Morita and Hirai, 2008; Akiyama, Numata and Mikami, 2010; Park, et al., 2013; Choi, et al., 2013; Katsuki, et al., 2020). However, in Malaysia, research on palliative and end-of-life care remains limited. Existing studies primarily focus on the growing need for palliative care services and its quality from healthcare providers' perspectives (Lau and Pickersgill, 2019; Yang, et al., 2020; Ho, et al., 2022; Hamdan, et al., 2023). To date, almost no research, to the best of the researcher's knowledge, has examined the quality of end-of-life care from the perspective of bereaved family members or assessed their satisfaction with such care.

1.4 RESEARCH OBJECTIVES

1.4.1 GENERAL OBJECTIVES

To assess the aspects of care and the overall satisfaction level of the bereaved caregivers with the care received during the end-of-life.

1.4.2 SPECIFIC OBJECTIVES

1. To determine the overall satisfaction level of bereaved caregivers with the care received during the end-of-life.

2. To evaluate the opportunity to improve in the perceived aspects (physical comfort and emotional support, inform and shared decision-making, focus on individual, attend to emotional and spiritual needs of family) of end-of-life care from the caregiver's perspective.

3. To evaluate the association between the aspects of end-of-life care and the overall satisfaction level of bereaved caregivers with the care received during the end-of-life.

4. To determine the association between sociodemographic characteristics (bereaved caregiver’s ethnicity, education level, religion, and religiosity) and the overall satisfaction level of bereaved caregivers with the care received during the end-of-life.

1.5 RESEARCH QUESTIONS

1. What is the overall satisfaction level of bereaved caregivers with the care received during the end-of-life?

2. What is the opportunity to improve in the perceived aspects (physical comfort and emotional support, inform and shared decision-making, focus on individual, attend to emotional and spiritual needs of family) of end-of-life care from the caregiver's perspective?

3. What is the association between the aspects of end-of-life care and the overall satisfaction level of bereaved caregivers with the care received during the end-of-life?

4. What is the association between sociodemographic characteristics (bereaved caregiver’s ethnicity, education level, religion, and religiosity) and the overall satisfaction level of bereaved caregivers with the care received during the end-of-life?

1.6 HYPOTHESIS

1.6.1 NULL HYPOTHESIS

$H_0$1: There is no statistically significant association between the aspects of end-of-life care and the overall satisfaction level of bereaved caregivers with the care received during the end-of-life.

$H_0$2: There is no statistically significant association between sociodemographic characteristics (bereaved caregiver's ethnicity, education level, religion, and religiosity) and the overall satisfaction level of bereaved caregivers with the care received during the end-of-life.

1.6.2 ALTERNATE HYPOTHESIS

H_a1: There is statistically significant association between the aspects of end-of-life care and the overall satisfaction level of bereaved caregivers with the care received during the end-of-life.

H_a2: There is statistically significant association between sociodemographic characteristics (bereaved caregiver's ethnicity, education level, religion, and religiosity) and the overall satisfaction level of bereaved caregivers with the care received during the end-of-life.

1.7 CONCEPTUAL AND OPERATIONAL DEFINITIONS

1.7.1 THE OVERALL SATISFACTION LEVEL OF BEREAVED CAREGIVERS

According to Oxford Learner's Dictionaries (2023), satisfaction level is the degree of good feeling that a person has when they achieved something or when something that the person wanted to happen does happen. Bereaved is having lost a relative or close friend who has recently died (Cambridge Dictionary, 2023). Caregiver is a person who takes care of a sick or old person informally (Cambridge Dictionary, 2023).

Operational definition: Bereaved caregiver is a staff or student at the selected private university who is a family member, relative or friend most knowledgeable regarding the hospital care received by the decedent during the end-of-life. The satisfaction level of the bereaved caregivers is the bereaved caregivers' feelings towards the care received at the hospital at that point of time. It is measured with a single item rating question that employed the 5-point Likert scale. An all point-defined scale of [1- not at all satisfied, 2- not very satisfied, 3- somewhat satisfied, 4- very satisfied, 5- completely satisfied] is used. The ratings will be further dichotomized into SATISFIED ("very satisfied" or "completely satisfied") and NOT SATISFIED ("not at all satisfied", "not very satisfied" or "somewhat satisfied").

1.7.2 ASPECTS OF CARE RECIVED DURING THE END-OF-LIFE

According to Oxford Learner's Dictionaries (2023), care is the process of caring for somebody and providing what they need for their health or protection. Received is to get or accept something that is send or given. The term "end of life" refers to the period preceding an individual's natural death, characterized by a process unlikely to be halted by medical care, usually defined as the last 6 months of a patient's life (Lamont, 2005).

Operational definition: The care received is looked at from 4 domains of end-of-life care namely, physical comfort and emotional support, inform and shared decision-making, focus on individual, attend to emotional and spiritual needs of family. Each domain consists of 5 key questions, 8 key questions, 6 key questions and 6 key questions respectively. Each key question will contribute to the problem score. The problem score is the sum of the mean score of each key question in a specific domain. A higher problem score indicates more problems and more opportunities to improve. Domain score is obtained through dividing the problem score by the number of key questions in the domain. A domain score of >0.2 indicates important opportunity to improve.

1.7.2.1 PHYSICAL COMFORT AND EMOTIONAL SUPPORT

The first domain of care received is physical comfort and emotional support. In this study, physical comfort is characterized by the absence of symptoms such as pain, dyspnea, anxiety, and sadness. Even if these symptoms are present, they are effectively addressed and managed. Emotional support is defined as having the opportunity to openly discuss one's problems.

1.7.2.2 INFORM AND PROMOTE SHARED DECISION-MAKING

The second domain of care received is inform and promote shared decision-making. In this study, this domain involves providing patients and their caregivers with relevant and comprehensive information about patient's illness, disease trajectory and prognosis. Medical decisions should reflect the patients' desired involvement and informed preferences.

1.7.2.3 FOCUS ON INDIVIDUAL

The third domain of care received is focus on individual. In this study, it is defined as the patient is treated with respect and dignity. This includes helping the patient achieve their desired level of control over their functioning and daily activities.

1.7.2.4 ATTEND TO EMOTIONAL AND SPIRITUAL NEEDS OF THE FAMILY

The fourth domain of care received is attending to emotional and spiritual needs of the family. Emotional and spiritual needs is defined as the desire for elements one currently lacks, particularly in the realms of emotions and profound beliefs. In this study, it is defined as the family receives the desired support at time prior to and after the patient's death, including appropriate referral for bereavement services.

1.7.3 SOCIODEMOGRAPHIC CHARACTERISTICS

Sociodemographic characteristics is a combination of social and demographic factors (Hatch, et al., 2011). In this study, the sociodemographic characteristics include the bereaved caregiver's ethnicity, education level, religion, and religiosity.

1.7.3.1 ETHNICITY

Ethnicity is defined as "shared culture, such as language, ancestry, practices, and beliefs" (Cambridge Dictionary, 2023). In this study, ethnicity of the bereaved caregiver is classified using nominal data, including categories such as Malay, Chinese, Indian, and Others, aligning with the major ethnic groups in Malaysia.

1.7.3.2 EDUCATION LEVEL

Education level denotes the highest formal education achievement of an individual (Cambridge Dictionary, 2023). In this study, the bereaved caregiver's education levels are categorized as follows: Less Than High School, High School Graduate, Technical School or Diploma, Bachelor's Degree, and Master's or Ph.D.

1.7.3.3 RELIGION AND RELIGIOSITY

Religion is an intricate and multifaceted concept encompassing beliefs, practices, rituals, moral values, and a connection to the sacred or transcendent (Shanmugasundaram, et al., 2014). In the context of this study, the bereaved caregiver's religion is categorized using nominal data, including options such as Islam, Buddhism, Christianity, Hinduism, Atheism, and others. The evaluation of the bereaved caregiver's religiosity employs nominal responses such as "religious," "non-religious," "not applicable," and "don't know."

1.7.4 PRIVATE UNIVERSITY

A private university is an educational institution of higher learning that is not operated or funded by a government entity. Instead, it is typically established and maintained by a private organization, often for-profit, or a non-profit entity (Cambridge Dictionary, 2023). By this definition, the selected institution of this study is a private university.

1.8 SIGNIFICANCE OF STUDY

This study underscores the importance of understanding perspectives of bereaved caregivers on the quality of end-of-life care received by the patients and their family in Malaysian hospitals. By utilizing a quality improvement framework, the research identifies areas for enhancement based on the bereaved caregivers' insights. These findings can serve as a baseline element for future intervention studies, paving the way for evidence-based practices guidelines for healthcare providers, particularly nurses. These guidelines sim to foster the development of enhanced support systems tailored to the specific needs of both patients and their families. Overall, the study's results are crucial for pinpointing care gaps, guiding initiatives to enhance service quality, and ultimately contributing to a more positive end-of-life and bereavement experience.

1.9 SUMMARY

In conclusion, a notable gap exists in the current body of research concerning the satisfaction levels of bereaved caregivers regarding the care provided at the end of life. Recognizing this void, the researcher has strategically directed the focus of this study towards a comprehensive exploration of the quality of end-of-life care, as perceived by bereaved caregivers. By delving into the caregivers' perspectives, the aim is to gain a nuanced understanding of their experiences and satisfaction levels, thereby identifying potential areas for enhancing the quality of care.

CHAPTER 2

LITERATURE REVIEW

CHAPTER 2: LITERATURE REVIEW

2.0 CHAPTER OVERVIEW

In this chapter, a comprehensive exploration of existing literature on the satisfaction level of bereaved caregivers with the care given during the end-of-life is conducted. This involves the development of a detailed search strategy and critical appraisal of relevant studies to contribute to the understanding of caregiver satisfaction in end-of-life care.

2.1 SEARCH STRATEGY

In this study, an extensive search strategy was meticulously employed, utilizing diverse databases such as UTAR Library OPAC, Google Scholar, and PubMed to gather relevant journal articles on the research topic. Keywords such as end-of-life care, bereavement care, bereaved caregivers, family, satisfaction, and perception were systematically used in the search process. Initially, a substantial 6,097 articles were retrieved from the three databases using the specified keywords. To refine and focus the search, Boolean Operators (AND, OR, NOT, or AND NOT) were strategically applied in conjunction with the keywords. The next step involved a thorough filtration process to exclude articles published before 2004, those not in the English language, non-academic articles, non-full-text articles, as well as unrelated and duplicated journals. Following this rigorous approach, a final set of 13 journal articles was chosen for in-depth review and analysis. **Diagram 2.1** provides a clear visual representation of the search strategy flowchart.

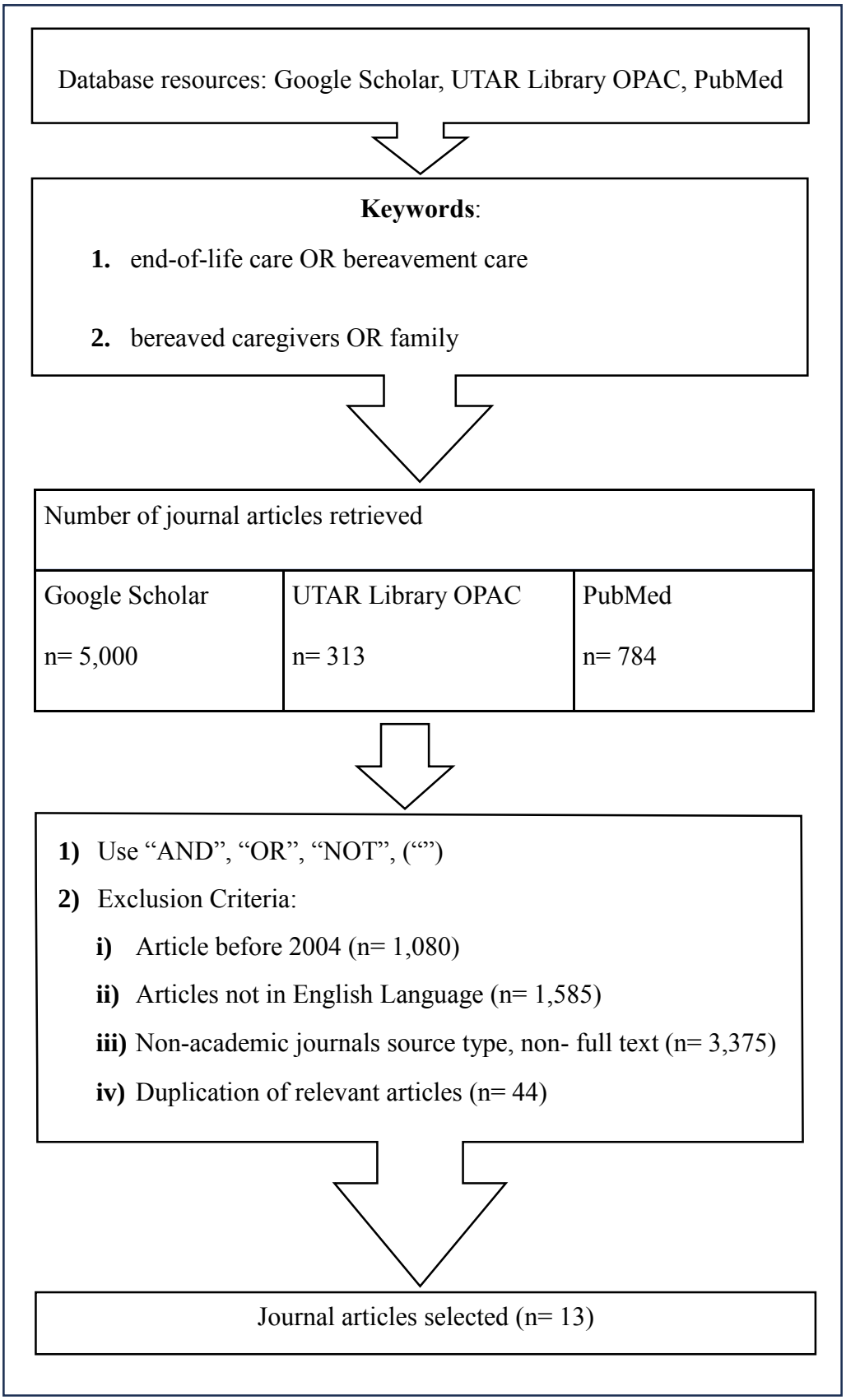

Diagram 2.1: Search strategy flowchart

2.2REVIEW OF LITERATURE

In this literature review, the quality of end-of-life care, the overall satisfaction level of bereaved caregivers with the care given during the end-of-life, as well as sociodemographic variables comprising the bereaved caregivers' ethnicity, religion and religiosity will be discussed. During the literature review, it became apparent that the existing body of research on this topic is predominantly qualitative, with a notable shortage of quantitative studies internationally. Additionally, a significant gap was identified – there is a complete absence of studies in Malaysia that investigate end-of-life care from the standpoint of bereaved caregivers.

2.2.1 THE OVERALL SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH END-OF-LIFE CARE

End-of-life care satisfaction in hospital settings is a complex and multifaceted issue, as evidenced by a synthesis of several studies with diverse perspectives. A cross-sectional study in U.S. by Carey, et al. (2017) conducted among 104 bereaved caregivers demonstrated a high overall satisfaction level with the quality of end-of-life care. Participants reported effective symptom management, sufficient nursing care, and compassionate treatment for decedents. Notably, satisfaction was significantly associated with improved communication between families and the medical team (Carey, et al., 2017; Robertson, Hjörleifsdóttir, and Sigurðardóttir, 2022). Similarly, O'Sullivan, et al. (2018) revealed 87% of the 485 bereaved caregivers were satisfaction with hospital care in Sweden, emphasizing the positive impact of well-functioning communication and being treated with respect and dignity. However, a lack of

crucial information and staff commitment were identified as negative aspects affecting satisfaction (O'Sullivan, et al., 2018). These studies similarly highlighted that even when caregivers reported high satisfaction, there were still significant unmet needs from various care aspects.

Conversely, an observational study in UK by Bainbridge and Seow (2017) reported only 37%-48% conducted among 1153 bereaved caregivers rated overall high satisfaction with end-of-life care in hospital settings. Lower satisfaction was associated with a lack of care in the domain of symptom management, respectful and compassionate care, emotional, and spiritual support (Bainbridge and Seow, 2017). A cross-sectional study in U.S. by Teno, et al. (2004) noted less than 50% of the 572 bereaved caregivers reported satisfactory end-of-life care and more than one-third of them reported insufficient emotional support for patients as well as family. Other studies further identified aspects for quality improvement, including relationships with healthcare professionals, personal care needs, privacy at the last moment and the management of anxiety or sadness for patients (Sadler, et al., 2014; Carey, et al., 2017; Robertson, Hjörleifsdóttir, and Sigurðardóttir, 2022). These findings underscore existing challenges in various aspects of end-of-life care.

A cross-sectional study in Japan by Katsuki, et al. (2020) revealed lower Good Death scores for hospital deaths compared to home deaths. Patients expressed a preference for home deaths, citing familiarity and the ability to maintain usual

habits. Comparably, specialized palliative care units were consistently rated with higher satisfaction than hospitals (O'Sullivan, et al., 2018; Bainbridge and Seow, 2017; Phongtankuel, et al., 2020). This trend suggested that the care place and type of care services significantly influence family satisfaction and end-of-life care quality. Specialized palliative care units, dedicated to providing palliative care to all patients, exhibit higher satisfaction, possibly due to staff expertise and specialization in palliative care (O'Sullivan, et al., 2018).

Overall, the existing international studies suggested critical gaps in end-of-life care delivery, which also likely exist within the Malaysian healthcare system. Hence, this study was set out to examine the bereaved caregiver's perspective with end-of-life care received in Malaysian hospitals.

2.2.2 SOCIODEMOGRAPHIC CHARACTERISTICS

2.2.2.1 ETHNICITY

An observational study by Nayfeh, et al. (2021) highlighted lower satisfaction ratings in specific population subgroups in the U.S., possibly influenced by individual and cultural expectations based on ethnic origin and/or region of birth. In a global observational cohort study across 730 ICUs in 84 countries, Lobo, et al. (2017) found variations in decisions to withhold or withdraw life-sustaining treatment, with less frequency in South Asia (10%) and the Middle East (18%), and more prevalence in Oceania (67%) and North America (65%). This aligned with population-based studies indicating higher rates of aggressive end-of-life care for recently immigrated patients from Asia (Yarnell, et al., 2017) and

patients of South Asian descent (Yarnell, et al., 2020) in Canada, suggesting that disparities in satisfaction ratings may, to some extent, be attributable to diverse individual and cultural preferences regarding end-of-life care (Nayfeh, et al., 2021).

Another study by Lee, et al. (2016) emphasized the lasting impact of patient and family minority race on satisfaction. Ethnic minority patients and family are less likely to possess living wills with their culture, indirectly experienced lower family-rated quality of dying due to increased life support at death (Lee, et al., 2016; Chan, 2019). Opioid utilization disparities were identified, revealing that dying black patients are 60–70% less likely to receive opioids than their white counterparts. This discrepancy was attributed to implicit biases among practitioners, reflecting inaccurate beliefs that black patients were more prone to painkiller abuse and possess a higher pain tolerance than whites (Burgio, et al., 2016). Additionally, a study on Chinese cancer patients highlighted their inclination to endure pain without reporting it to healthcare providers until reaching unbearable levels, further accentuating variations in end-of-life care preferences due to cultural influences (Chen, et al., 2008).

Malaysia as a multiracial and multiethnic country consisting predominantly Bumiputera (70.4%), Chinese (22.4%), Indian (6.5%), others (0.7%) (DOSM, 2024), satisfaction with end-of-life care may varies across ethnic groups due to differing cultural and religious practices. Although direct statistics are limited,

cultural norms suggest that these differences impact care experiences. Chinese culture's taboo against discussing death may conflict with medical practices requiring open communication, potentially leading to dissatisfaction (Jiao and Hussin, 2020). Conversely, Malay culture emphasizes Islamic rituals, such as reciting the Shahada and facing Mecca during death, which are crucial for patient and family satisfaction (Mahmoud, Moughrabi and Khasawneh, 2022). These highlight the need for culturally sensitive care, suggesting that gaps in such aspect may influence end-of-life care satisfaction in Malaysia. Thus, the association between ethnicity and care satisfaction was examined in current study.

2.2.2.2 EDUCATION LEVEL

In comparing findings across different studies on the association between educational attainment and satisfaction with end-of-life care, diverse perspectives emerge. A Swedish cross-sectional study by O'Sullivan, et al. (2018) indicated that bereaved family members with higher educational attainment are more likely to report lower satisfaction with overall care. Phongtankuel, et al. (2020) from the U.S. contributed to this discourse by revealing that lower satisfaction scores were associated with caregivers who have more than a high school education. This result contradicted common beliefs derived from previous research that higher educational attainment correlates with increased access to information and healthcare, thereby, elevating satisfaction (Lakin and Kane, 2022). The assumption suggested those with higher education levels may have elevated expectations, influencing their perception of the quality of healthcare (O'Sullivan, et al., 2018).

Contrastingly, Lee, et al. (2016) presented a different viewpoint, stating that education was not significantly linked to satisfaction ratings. Instead, their study suggested that health literacy, rather than educational attainment, plays a more pivotal role in explaining variations in the care experiences of racial/ethnic minorities. Hench, current research was carried out to assess the potential connection between the educational level of bereaved caregivers and their satisfaction with the end-of-life care received.

2.2.2.3 RELIGION AND RELIGIOSITY

According to the 2020 census, Malaysia's population is predominantly Muslim (63.5%), followed by Buddhists (18.7%), Christians (9.1%), Hindus (6.1%), atheists (1.8) (US Embassy Malaysia, 2023). The concept of a "good death" varies across religions, with each tradition having its own rituals and practices. According to Choudry, Latif and Warburton (2018), families tend to feel more satisfied with end-of-life care when it respects and incorporates these religious practices, ensuring that their loved ones' final moments align with their spiritual beliefs.

In Islam, a "good death" is viewed as dying with faith and dignity. Muslims believe in the importance of reciting the Shahadah (declaration of faith) and having loved ones present to recite verses from the Quran. Dying in a state of prayer, facing Mecca during Ramadan or on a Friday are considered spiritually advantageous (Hammad, et al., 2020; Choudry, Latif and Warburton, 2018).

In Hinduism, death is viewed as a transition and emphasizes a "good death" that is timely, conscious, and prepared. The belief in reincarnation and karma influences their approach, where dying with dignity and acceptance is paramount. Hindus may refuse medications to maintain clarity of mind and view pain as a purifying process for sins (Sharma, et al., 2013; Chen, 2008; Choudry, Latif and Warburton, 2018).

Similarly, Buddhism teaches that a "good death" involves dying with a clear and peaceful mind. Buddhists may avoid mind-altering medications near death to maintain mental clarity, as they believe it affects the consciousness during the transition to the next life. Compassion and non-harming are central to Buddhist end-of-life care practices, emphasizing easing suffering without hastening death (Sharma, et al., 2013; Chen, 2008).

Christian beliefs emphasize the significance of a "good death" achieved through spiritual preparation and adherence to religious rituals. A good death often involves confession, communion, and anointing of the sick, providing spiritual comfort and preparing the soul for its journey. Christianity also allows for the use of palliative care to alleviate suffering while respecting the sanctity of life (Choudry, Latif and Warburton, 2018; Biancalani, at al., 2022).

According to Higgins, Garrido, and Prigerson (2015), religion and spirituality carry significance for many caregivers by giving them a sense of community with God and fellow believers when approaching a loved one's death (Higgins, Garrido, and Prigerson, 2015). Diverse preferences in end-of-life care highlight the crucial role of HCPs in providing culturally sensitive care. Recognizing and respecting the varied preferences of patients and families from different religious backgrounds is essential for ensuring satisfaction with end-of-life care (Shanmugasundaram, et al., 2014).

Aligning with the discourse, a study reported lower satisfaction among religion minority bereaved caregivers where spiritual care was insufficient (Nayfeh, et al., 2021). These findings encourage the exploration of association between one’s religion and religiosity and their overall satisfaction with the end-of-life care received.

2.3 CONCEPTUAL FRAMEWORK

The conceptual framework is adapted from the work of Teno (2000), underwent modifications to align more effectively with the research objectives and questions of this study. The framework encompasses 2 independent variables: the bereaved caregivers' sociodemographic characteristics and the aspects of end-of-life care; and 1 dependent variable: the overall satisfaction level towards the care received. These adaptations included the incorporation of a new branch to investigate the relationship between sociodemographic characteristics and overall satisfaction level to answer to the specific objective 4. The left-right arrow between the 4 aspects of end-of-life care and sociodemographic characteristics leading to overall satisfaction level illustrate the potential statistically significant association between these variables to answer to the specific objectives 3. The aspect of care encompasses 4 key domains: physical comfort and emotional support, inform and shared decision-making, focus on individual, attend to emotional and spiritual needs of family. Sociodemographic characteristics include the patient's ethnicity, education level, religion and religiosity. The conceptual framework adapted as shown in **Diagram 2.2** serve as a roadmap for conducting the research, offering guidance on how to explore and navigate the intricacies of the study's inquiry

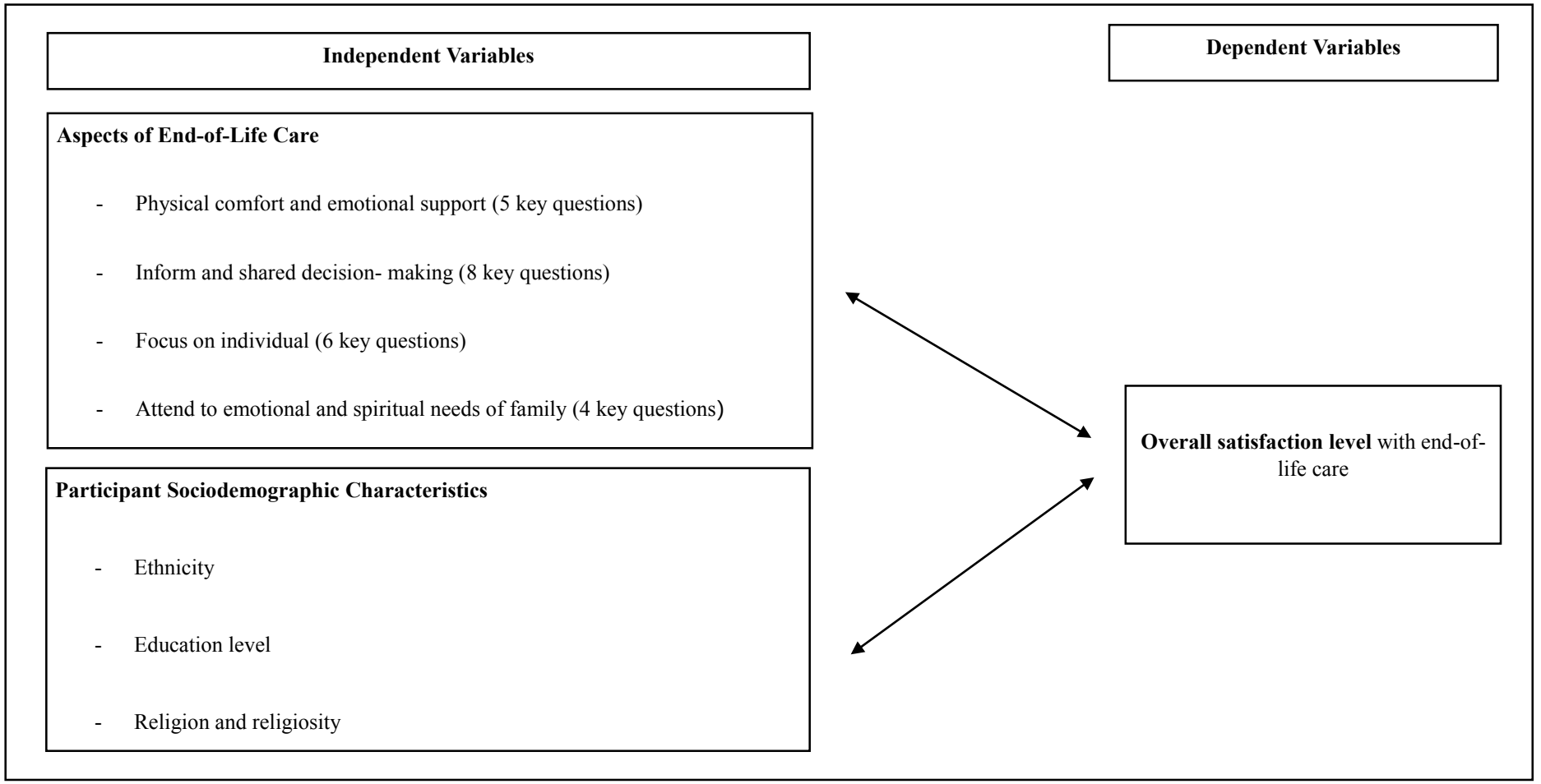

Diagram 2.2: Conceptual framework of the satisfaction level of bereaved caregivers with the care received during the end-of-life, a private university in Kajang.

2.4 SUMMARY

In conclusion, while there has been notable improvement in overall satisfaction with end-of-life care in hospitals, persistent challenges remain. Research highlights that satisfaction tends to be higher when care involves effective communication, respectful treatment, and alignment with cultural or religious expectations. Furthermore, studies suggest that sociodemographic factors such as ethnicity, education level, religion, and religiosity play a significant role in shaping overall satisfaction with end-of-life care. Although these connections have been well-documented internationally, there is a lack of comprehensive research within the Malaysian context to identify specific gaps in care. Therefore, it is crucial to explore this issue from the perspective of bereaved caregivers, as their insights can provide valuable data to inform future care improvements and policy development.

CHAPTER 3

METHODOLOGY

CHAPTER 3: METHODOLOGY

3.0 CHAPTER OVERVIEW

This chapter furnishes comprehensive insights into the research design, study settings, variables, and the applied sampling techniques, size, and criteria for this study. It further elaborates on the research instruments, content validity and reliability, pilot study, ethical considerations, and the obtained consents. Furthermore, the chapter delves into the details of data collection procedures and outlines the framework for data analysis.

3.1 RESEARCH DESIGN

This study adopted a quantitative, cross-sectional survey design as its research methodology to assess the prevalence of satisfaction with end-of-life care and its associations with various aspects of end-of-life care. Given that the particular bereavement experience is a one-time event, this design was chosen for its efficiency, as data collection occurs at a single point in time (Polit and Beck, 2017). Its cost-effectiveness, time efficiency, and simplicity further support its selection as a suitable research design for this study (Polit and Beck, 2017). The decision to employ a cross-sectional survey with a quantitative approach was rooted in its alignment with practical considerations, such as time constraints and the researcher's knowledge level. This design was deemed the most appropriate for evaluating the satisfaction levels of bereaved caregivers with the care provided during the end-of-life.

3.2 SETTING OF THE STUDY

This study was conducted at a private university situated in Kajang, Selangor Darul Ehsan, Malaysia. The chosen campus, established in 2005, experienced significant expansion through the merger of Petaling Jaya and Setapak campuses in 2015. With a commitment to providing affordable and high-quality education, the university plays a pivotal role in serving close to 9,000 active students in the selected branch. The institution was also rated Tier 5 (Excellent) in the most recent SETARA ranking exercise.

The campus is home to four Faculties, three Institutes, and two Centres of Studies, offering a diverse array of academic programs. These encompass 34 Bachelor's degrees, a Postgraduate Diploma, 21 Master's degrees, and seven PhD programs, underscoring the university's dedication to providing a comprehensive range of educational opportunities across various disciplines. Notably, the university boasted an impressive graduate employability rate, with approximately 95-97% of graduates securing employment within nine months of graduation as of March 2022 (UTAR, 2023).

3.3 POPULATION

3.3.1 TARGET POPULATION

The target population for this study was the staff members and students in Kajang who had lost a family member, close friend or relative.

3.3.2 ACCESSIBLE POPULATION

The accessible population was the staff members and students in the selected private university in Kajang who had lost a family member, close friend or relative within the last 5 years.

3.3.3 SAMPLE

The sample for this study was determined using a sample size calculation, with 107 staff members and students meeting the inclusion and exclusion criteria. All participants provided informed consent to participate in the study.

3.4 SAMPLING

3.4.1 SAMPLING METHOD

This study employed a non-probability technique, specifically opting for purposive sampling, wherein participants were intentionally selected based on predetermined criteria (Polit and Beck, 2017). In this study, individuals possessing prior bereavement experience who meet all specified inclusion criteria were deliberately chosen as participants. The decision to use purposive

sampling was motivated by its efficiency in terms of time and cost. This method ensured that only the most relevant and suitable candidates were included in the study, thereby enhancing the quality of responses. Additionally, purposive sampling ensured a better alignment of the sample with the aims and objectives of the research, thus, enhancing the validity and reliability of the study's data and results (Campbell, et al., 2020).

3.4.2 SAMPLE SIZE

The sample size was calculated using the Kish (1965) formula as followed:

$$N = \frac{p(1-p)Z^2}{d^2}$$

N = Estimated sample size

Z^2 = Confidence interval of 1.96

p = Prevalence from previous study = 0.87 (O'Sullivan, et al., 2018)

d = Degree of accuracy = 5% = 0.05

By applying the Kish (1965) formula,

$$N = \frac{(0.87)\ (1 - 0.87)\ 1.96}{(0.05)^2}$$

$= 89$

$S = 89 + 0.2\ (89) = 107$

O'Sullivan, et al. (2018) reported that 87% of bereaved caregivers expressed high satisfaction with the hospital care provided at the end of life. The initial

estimation of the sample size was 89. To account for potential dropout, an attrition rate of 20% was incorporated. Consequently, the final total sample size was calculated to be 107, considering a 20% attrition rate.

3.5 SAMPLING CRITERIA

3.5.1 INCLUSION CRITERIA

- Currently a staff member or student aged 18 and above in the selected private university.
- A family member or friend of a decedent aged 12 and above at the time of passing.
- A family member or friend of a decedent who passed away within the last 5 years.
- Decedent must have admission to the hospital for more than 48 hours within the last 3 months of life.

3.5.2 EXCLUSION CRITERIA

- A family member or friend of a decedent who passed away as a result of trauma (e.g., homicide, motor vehicle crashes)
- A family member or friend of a decedent aged 12 and below at the time of passing.
- Not a staff or student in the selected private university.
- People with depression.

3.6 VARIABLES

3.6.1 INDEPENDENT VARIABLES

The independent variable of specific objective 3 is the aspects of patient focused, family centred care. The aspects or domain of care are physical comfort and emotional support, inform and promote shared decision-making, focus on individual and attend to the emotional and spiritual needs of the family.

The independent variable for specific objective 4 is the sociodemographic characteristics including the patient's ethnicity, education level, religion and religiosity.

3.6.2 DEPENDENT VARIABLES

The dependent variable of specific objective 3 and 4 is the overall satisfaction level of bereaved caregivers with the care received during the end-of-life.

3.7 RESEARCH INSTRUMENT

The instrument used in this study was adapted from the After-Death Bereaved Family Interview by Teno (2000) as shown in **Appendix B**. The instrument comprises 5 sections: Section A- Screening, Section B- Sociodemographic Characteristics, Section C- Checking the Facts, Section D- Domain Questions and Section E- Overall Satisfaction Scale.

3.7.1 SECTION A: SCREENING

This section included two questions aimed at preliminarily assessing the suitability of participants. Only those who asserted they have the most knowledge about the patient's condition in the last few weeks of life were eligible to proceed with the questionnaire.

3.7.2 SECTION B: SOCIODEMOGRAPHIC CHARACTERISTICS

This segment consisted of two subsections. The initial subsection comprised five closed-ended questions gathering sociodemographic data about the deceased, covering aspects such as age, ethnicity, education level, religion, and religiosity. The subsequent subsection contained seven closed-ended questions, focusing on collecting sociodemographic data from the participants.

3.7.3 SECTION C: CHECKING THE FACTS

This section encompassed 6 closed-ended questions aimed at gathering data concerning the circumstances surrounding the death.

3.7.4 SECTION D: DOMAIN QUESTIONS

This section contained 33 questions with 23 of them being key questions that will contribute to the problem score for 3 domains of end-of-life care provided in hospital. Physical comfort and emotional support comprised 5 key questions (D12a, D15, D15a, D16b, D17b), inform and shared decision-making comprised 8 key questions (C1a, C1b, C1c, D19, D26a, D27a, D28a, E1), focus on

individual comprised 6 key questions (D21, D22, D23, D24, D25, E2), attend to emotional and spiritual needs of family comprised 4 key questions (E4/E5, E6, E7a/E7b, E8).

The sequence of the questions in this section appeared out of sequence as this questionnaire was based on a longer instrument and has been tailored by the author to reflect hospital services. To maintain consistency across versions, the authors have retained the numbering from the original instrument. The types of questions asked in this section included closed-ended Yes/No questions, ordinal responses ("Less than was needed", "Just the right amount" and "More than was needed") that rated the amount of care provided, as well as 4- point Likert scale questions ("Always", "Usually", "Sometimes" and "Never") that rated the frequency of care provided. For the purpose of data analysis, the responses were dichotomized. For instance, responses like ("Less than was needed", "Just the right amount" and "More than was needed") were dichotomized to "the right amount" vs "less/more than was needed", 4-point Likert scale questions were dichotomized to "Always" vs "other".

This process was done according to the scoring guide provided by the original author of the instrument. The problem score was the sum of the mean score of each key questions in a specific domain. A higher problem score suggested more issues and opportunities for enhancement. The domain score was derived by dividing the problem score by the number of key questions in the domain, with

a score >0.2 indicating a significant opportunity for improvement (Teno, et al., 2001).

3.7.5 SECTION E: OVERALL SATISFACTION SCALE

This section contains 1 single rating item question that employed a 5- point Likert Scale to assess the overall satisfaction level of bereaved caregivers with the care received. An all point-defined scale of [1- not at all satisfied, 2- not very satisfied, 3- somewhat satisfied, 4- very satisfied, 5- completely satisfied] is used. The ratings were further dichotomized into SATISFIED (“very satisfied” or “completely satisfied”) and NOT SATISFIED (“not at all satisfied”, “not very satisfied” or “somewhat satisfied”).

3.8 VALIDITY AND RELIABILITY

3.8.1 CONTENT VALIDITY

Content validation of the instrument was done by a nursing lecturer and a certified counsellor who had relevant experience in the field to determine the appropriateness of content and identify any potential misunderstandings or omissions in the instrument (Tanner, 2018). Amendments were made to the wording, grammar, and instructions for participants according to the suggestions to improve the clarity.

3.8.2 RELIABILITY

A reliability test in research ensures that the instrument consistently produces the same results under the same conditions (Taherdoost, 2016). However, in this study, reliability test was not conducted as the responses in current study were reduced to dichotomized variables. Dichotomized variables are less suitable for reliability testing with Cronbach's alpha because the alpha coefficient is based on continuous or ordinal data where the underlying scale reflects gradations in response (Cairns, 2019; Sijtsma, 2009). Dichotomized data, by nature, tend to reduce variability and limit the information that continuous variables can provide. This reduction in variability leads to a lower inter-item correlation, which in turn can artificially deflate the Cronbach's alpha coefficient, suggesting higher or lower reliability than may actually exist (Cairns, 2019; Sijtsma, 2009). Nevertheless, in a validation study by Teno, et al. (2004), the instrument demonstrated good internal consistency with Cronbach Alpha values greater than 0.7 for domains containing more than 4 items.

3.9 PILOT STUDY

Pilot study was conducted from 4th July to 12th July 2024 after ethical approval was granted by the UTAR Ethical Board. Pilot study was conducted prior to the main study to anticipate and address potential issues that may arise (Polit and Beck, 2017). Data collection process for the pilot study was conducted in the same manner as the main study. Responses were gathered from 11 participants, constituting 10% of the total sample size, and those involved in the pilot study were excluded from the actual study.

3.9.1 LESSONS LEARNED FROM PILOT STUDY

Based on the observations from the pilot study, several adjustments were made to enhance the instrument's comprehensiveness and delivery. Minor revisions included looking into the grammar and rephrasing one of the items. These changes aimed to provide a more thorough understanding of the participants' experiences and promote better focus of the respondents' attention and minimize confusion.

3.10 DATA COLLECTION PROCEDURE

The data collection process was conducted from 22nd July to 20th August 2024 after the pilot study was completed. The questionnaire and consent form were distributed to the participants through face-to-face interactions as well as online form. Prior to engaging with the self-administered questionnaire, participants were provided with a concise overview of the research title and study objectives. Special emphasis was placed on ensuring the privacy and confidentiality of their responses, and explicit informed consent was diligently sought to ensure participants' thorough understanding and voluntary participation.

Participants were informed that completing the questionnaire takes approximately 10-15 minutes. Throughout the data collection process, the researcher was present to prevent data contamination and addressed any queries participants had about the questionnaire. Following the submission of the questionnaire, the researcher reviewed the completeness of the responses, ensuring that all relevant questions had been adequately addressed.

3.11 ETHICAL CONSIDERATION

3.11.1 UNIVERSITY ETHICAL BOARD AND COMMITTEE

Application letter for approval to conduct research was submitted to the university's ethical board before commencing the pilot study. Approval was granted on 3rd July 2024, as attached in **Appendix E.**

3.11.2 PERMISSION TO USE INSTRUMENT

Permission to use the instruments from Teno, et al. (2000) was obtained via email on 30th November 2023. (**Appendix D**).

3.11.3 CONSENT INFORMATION

Prior to completing the questionnaire, participants received a detailed briefing covering their rights, the study's purpose, procedures, potential risks and benefits, and the researcher's contact information. Participants were informed of their right to withdraw from the study at any point in time and they were reassured that the data and information collected will be treated with utmost privacy and confidentiality, adhering to the clause mentioned in the Personal Data Protection Statement **(Appendix F)**. Additionally, participants consent was also obtained by signing a consent form **(Appendix A)**, confirming their agreement to participate in the study. Data collected will be retained for 5 to 7 years before disposal, with the soft copy being encrypted and the hard copy securely stored in a locked drawer.

3.12 GANTT CHART

A Gantt chart visually depicted tasks and durations, facilitating progress tracking and efficient project coordination in this study. The Gantt Chart can be referenced in **Appendix H**.

3.13 SUMMARY

A cross-sectional study utilizing purposive sampling was conducted at a private university in Kajang. Before data collection, a pilot study was conducted. The data were collected through a face-to-face and online approach using a self-administered questionnaire. The collected data were analysed using IBM SPSS version 29.0.

CHAPTER 4

DATA ANALYSIS AND RESULT

CHAPTER 4: DATA ANALYSIS AND RESULT

4.0 CHAPTER OVERVIEW

The previous chapter outlined the research methodology, whereby the measuring instrument were discussed and indication on the methods used for statistical analysis for this chapter was given. This chapter presents the study's results. Data collected were entered into IBM SPSS Statistics 29 and analysed using methods suited to the research questions. Results were tabulated, with detailed analysis of sociodemographic data, responses from each end-of-life care domain, and overall satisfaction level. Additionally, associations between variables were examined in accordance with the research questions.

4.1 DESCRIPTIVE AND INFERENTIAL ANALYSIS

In this study, the data collected were analysed using descriptive and inferential analysis based on the research questions.

4.1.1 DESCRIPTIVE ANALYSIS

The first two specific objectives of the study were to determine the overall satisfaction level and the opportunity to improve in each domain of end-of-life care. The overall satisfaction was presented in mean score ($\bar{x}$) and standard deviation (SD) while the dichotomized overall satisfaction level was presented in frequency (f) and percentage (%). The key questions of each domain were analysed using mean ($\bar{x}$) and standard deviation (SD). The sociodemographic characteristics (relationship, patient’s age at the time of passing, participant’s age at the time of patient’s passing, participant’s ethnicity, education level, religion,

religiosity and types of hospital patient last admitted to) were presented in frequency (f) and percentage (%).

4.1.2 INFERENTIAL ANALYSIS

The third and fourth specific objectives of the study were to determine the association and correlation between the variables. Pearson's Correlation test was used for specific objective 3 'to determine the correlation between the aspects of end-of-life care and the overall satisfaction level' as both the variables were continuous data (Laerd Statistics, 2018; Kremelberg, 2014). Normality test was done, and it shows 0.27 for Skewness and 1.43 for Kurtosis for inform and promote shared decision-making; 1.40 for Skewness and -1.79 for Kurtosis for focus on individual and -1.95 for Skewness and -1.75 for Kurtosis for attend to the emotional and spiritual needs of the family. The readings for all the domains were within the range of -2 to +2 for Skewness and -4 to +4 for Kurtosis, indicating the data were normally distributed and fit for Pearson's Correlation test (Laerd Statistics, 2018). The results were presented as mean, standard deviation, correlation coefficient and p-value.

Specific objective 4 was answered using Chi-square test to determine the association between the sociodemographic characteristics and the overall satisfaction level as both the variables were categorical (Kremelberg, 2014). Results were reported as statistically significant if the significance value (p-value) is less than the tabulated value at 95% confidence level (Laerd Statistics, 2018). The results were presented in across-tabulation as frequency, percentage, chi-

square value for when ≤20% of expected cell counts are less than 5 and Fisher's exact test for when ≥20% of expected cell counts are less than 5, degree of freedom and p-value.

4.2 STATISTICAL DATA PROCESSING AND ANALYSIS

After data collection, the responses were coded and entered into an Excel sheet to prevent double entry and facilitate the retrieval of errors or missing data before being imported into IBM SPSS Statistics 29. A total of 107 participants (100%) were initially recruited via a self-administered questionnaire. However, after data cleaning, only 92 responses (86%) were deemed valid. 15 (14%) of the participants were rejected due to invalid responses. 6 (5.6%), had missing data, 7 (6.5%), participants had insufficient knowledge of their loved ones' end-of-life experiences, and 2 (1.9%), refused participation, citing the emotional difficulty of revisiting their experiences. Due to time constraints, the researcher was unable to verify forms upon submission, which contributed to the missing data. Consequently, 92 valid responses were analysed in this study.

4.3 RESULTS

4.3.1 SOCIODEMOGRAPHIC CHARACTERISTICS

The sociodemographic characteristics explored were the participants' ethnicity, education level, religion and religiosity. The data were tabulated in frequency and percentages as shown in **Table 4.1**.

Table 4.1 Frequency and percentage of patients' and participants' sociodemographic characteristics (n=92)

Sociodemographic Characteristics	Frequency (f)	Percentage (%)
Participants' Ethnicity		
Malay	24	26.1
Chinese	52	56.5
Indian	14	15.2
Others	2	2.2
Participants' Education Level		
Less than high school	0	0.0
High school graduate	11	12.0
Technical school/diploma	16	17.4
Bachelor's degree	20	21.7
Master/PhD	45	48.9
Don't know	0	0.0
Participants' Religion		
Islam	25	27.2
Buddhism	37	40.2
Christianity	12	13.0
Hinduism	11	12.0
None/Atheist	5	5.4
Others	2	2.2
Don't know	0	0.0
Participants' Religiosity		
Religious	74	80.4
Non-religious	11	12.0
Not applicable	6	6.5
Don't know	1	1.1

Table 4.1 shows that more than half of the participants, 52 (56.5%), were Chinese. One fourth of them, 24 (26.1%), were Malay. Almost one fifth, 14 (15.2%), were Indian, and 2 (2.2%), identified as 'others'. Besides, almost half, 45 (48.9%), participants hold a Master's or PhD, nearly one fourth, 20 (21.7%), held a bachelor's degree, about one fifth, 16 (17.4%), completed technical school

or a diploma, and 11 (12.0%), were high school graduates currently furthering their education in the selected private university.

Religious affiliation showed approximately half of the participants, 37 (40.2%), were Buddhists, one fourth, 25 (27.2%), were Muslims, one eighth, 12 (13.0%), Hindus, 5 (5.4%) atheists, and 2 (2.2%), as “others.” Most participants, 74 (80.4%), identified as religious, one eighth, 11 (12.0%), as non-religious, 6 (6.5%), marked "not applicable,".

4.3.2 THE OVERALL SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE

Participant’s overall satisfaction level with the care received at their loved ones’ end-of-life were assessed using a 5-point Likert scale. The score was dichotomized into “Satisfied” and “Not satisfied”, then tabulated into frequency and percentage. The mean score and standard deviation were also obtained as shown in **Table 4.2**.

Table 4.2: Frequency, percentage, mean and standard deviation of participants’ responses on overall satisfaction level (n=92)

Overall Satisfaction Level	Frequency (f)	Percentage (%)	Mean ($\bar{x}$)	Standard Deviation (SD)
Satisfied	38	41.3	3.24	0.92
Not Satisfied	54	58.7		

Table 4.2 shows participants' overall satisfaction with the end-of-life care received by them and their loved ones. Out of the 92 participants, more than half, 54 (58.7%), rated their experience as 'not satisfied,' while 38 (41.3%), rated it as 'satisfied' when using a dichotomized 5-point Likert scale. However, the mean score for overall satisfaction was 3.24 (SD ±0.92) out of 5, indicating a moderate level of satisfaction with the care provided.

4.3.3 THE OPPORTUNITY TO IMPROVE IN THE PERCEIVED ASPECTS OF END-OF-LIFE CARE FROM THE CAREGIVER'S PERSPECTIVE

There were 4 domains of end-of-life care assessed in this study including physical comfort and emotional support, informed and promote shared decision-making, focus on individual and attend to the emotional and spiritual needs of the family. The data were tabulated in mean and standard deviation for each key questions and the sum mean score, which is the problem score, were obtained for each domain of end-of-life care, except for Physical Comfort and Emotional Support, as the psychometric testing shows that the key questions from this domain do not "hang together" (Teno, et al., 2001). Hence, the problem score and domain score were not calculated for that domain. The domain score is derived by dividing the problem score by the number of key questions in the domain, with a score >0.2 indicating a significant opportunity for improvement (Teno, et al., 2001).

4.3.3.1 PHYSICAL COMFORT AND EMOTIONAL SUPPORT

Table 4.3: Mean and standard deviation of participants' responses on physical comfort and emotional support (n=92)

	Items	Mean ($\bar{x}$)	Standard Deviation (SD)
D12a	While under care of the hospital, did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?	0.15	0.36
D15	While under care of the hospital, did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?	0.16	0.37
D15a	While under care of the hospital, was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?	0.32	0.47
D16b	How much help in dealing with (his/her) breathing did [PATIENT] receive – less than was needed, or about the right amount?	0.04	0.21
D17b	How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?	0.24	0.43

Table 4.3 showed the mean score and standard deviation for the domain of physical comfort and emotional support, comprising 5 key questions. The question regarding instances when a doctor or nurse provided conflicting information about pain treatment showed the greatest opportunity for improvement, with the highest mean score of 0.32 (SD ±0.47). This was followed by the question on the extent of help the patient received in managing sadness and anxiety, with a mean score of 0.24 (SD ±0.43). Questions related to clear explanations of pain treatment and the amount of pain medication administered showed similar mean scores of 0.15 (SD ±0.36) and 0.16 (SD ±0.37), respectively. The question concerning assistance with breathing difficulty had the lowest mean score of 0.04 (SD ±0.43), indicating fewer concerns in this area.

4.3.3.2 INFORM AND PROMOTE SHARED DECISION-MAKING

Table 4.4: Mean and standard deviation of participants' responses on inform and promote shared decision-making (n=92)

	Items	Mean ($\bar{x}$)	Standard Deviation (SD)
C1a	While under care of the hospital, was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?	0.22	0.42
C1b	While under care of the hospital, did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?	0.07	0.25
C1c	While under care of the hospital, how much information did the doctors provide you about [PATIENT'S] medical condition?	0.18	0.39
D19	While under care of the hospital, was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?	0.29	0.46
D26a	Would you have wanted (some/more) information about what to expect while (he/she) was dying?	0.75	0.44
D27a	Would you have wanted (some/more) information about what to do at the time of (his/her) death?	0.71	0.46
D28a	Would you have wanted (some/more) information about the medicines for symptoms control?	0.75	0.44
E1	While [PATIENT] was under care of the hospital, how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?	0.58	0.50
	Sum Mean Score- Problem Score	3.54	1.79
	Domain Score	0.44	0.22

Domain score=problem score/number of questions

Table 4.4 demonstrated the mean scores and standard deviations for the domain of informing and promoting shared decision-making, covering 8 key questions. While half of the family members reported that they were kept informed about the patient's condition with a mean score of 0.58 (SD ±0.50), most of them desire for more information. This was reflected on the greatest opportunity for improvement for this domain, where the participants reported would like more information about what to expect while the patient was dying and on medicines for symptom control, both with a mean score of 0.75 (SD ±0.44). The next most significant area was participants' desire for more information on what to do at

the time of their loved one's death, with a mean score of 0.71 (SD ±0.46). Questions about decisions made without family input and problem understanding doctors' explanations about treatment expectations scored lower, with means of 0.29 (SD ±0.46) and 0.22 (SD ±0.42), respectively. The adequacy of information provided by the doctor had a mean of 0.18 (SD ±.39), and the least concern was whether the doctor listened to participants' concerns, with a mean score of 0.07 (SD ±0.25).

The total mean score (problem score) for this domain is 3.54 (SD±1.79), and the domain score is 0.44 (SD±0.22), highlighting a significant opportunity for improvement.

4.3.3.3 FOCUS ON INDIVIDUAL

Table 4.5: Mean and standard deviation of participants' responses on focus on individual (n=92)

	Items	Mean ($\bar{x}$)	Standard Deviation (SD)
D21	While under care of the hospital, how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been?	0.59	0.50
D22	While under care of the hospital, how often was (he/she) treated with respect by those who were taking care of (him/her)?	0.50	0.50
D23	While under care of the hospital, how often was [PATIENT] treated with kindness by those who were taking care of (him/her)?	0.53	0.50
D24	While under care of the hospital), was there enough help available to meet (his/her) personal care needs, like bathing, feeding, and going to the bathroom?	0.15	0.36
D25	While under care of the hospital, was there enough help with medications and getting dressings changed?	0.14	0.35
E2	While [PATIENT] was under care of the hospital, how often did you have to worry about [PATIENT'S] personal care needs being met?	0.89	0.31
	Sum Mean Score- Problem Score	2.80	1.71
	Domain Score	0.47	0.29

Domain score=problem score/number of questions

Table 4.5 presented the mean score and standard deviation for the domain of focus on individual, consisting of 6 questions. The question about the frequency with which participants worried about patients' personal care needs had the highest mean score of 0.89 (SD ±0.31), making it the area with the greatest opportunity for improvement across all domains. Following this, questions regarding the frequency of patients' personal care needs being addressed, and patients being treated with kindness and respect, received similar mean scores of 0.59 (SD ±0.50), 0.53 (SD ±0.50), and 0.50 (SD ±0.50), respectively. The questions about the adequacy of help for meeting patients' personal care needs and help with medications and dressing changes had lower mean scores of 0.15 (SD ±0.36) and 0.14 (SD ±0.36), respectively, indicating lesser concerns in these areas.

The total mean score for this domain is 2.80 (SD ±1.71), with a domain score of 0.47 (SD ±0.29), highlighting a significant opportunity for improvement.

4.3.3.4 ATTEND TO EMOTIONAL AND SPIRITUAL NEEDS OF THE FAMILY

Table 4.6: Mean and standard deviation of participants' responses on attend to the emotional and spiritual needs of the family (n=92)

	Items	Mean ($\bar{x}$)	Standard Deviation (SD)
E4/ E5	While [PATIENT] was under care of the hospital, did someone talk with you about your religious or spiritual beliefs? Was this done in a sensitive manner? Did you have as much contact of that kind as you while [PATIENT] was under care of the hospital?	0.86	0.35
E6	While [PATIENT] was under care of the hospital, how much support in dealing with your feelings about [PATIENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide you?	0.42	0.50
E7a/ E7b	While [PATIENT] was under care of the hospital, did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death? Was it done in a sensitive manner? Would you have wanted them to?	0.47	0.50
E8	While [PATIENT] was under care of the hospital, did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?	0.73	0.45
	Sum Mean Score- Problem Score	2.48	1.05
	Domain Score	0.62	0.26

Domain score=problem score/number of questions

Table 4.6 displays the mean and standard deviation for the domain of attend to the emotional and spiritual needs of the family, which consists of 4 questions. The question about participants receiving sensitive discussions on religion or spiritual beliefs showed the greatest opportunity for improvement, with a mean score of 0.86 (SD ±0.35). This was followed by the question on participants receiving suggestions for support during stress, with a mean score of 0.73 (SD ±0.45). The questions about staff sensitivity in discussing feelings after the patient's death and staff providing support for dealing with feelings about death received lower mean scores of 0.47 (SD ±0.50) and 0.42 (SD ±0.50), respectively.

The total mean score for this domain is 2.48 (SD ±1.05), with a domain score of 0.62 (SD ±0.26), highlighting a significant opportunity for improvement.

In summary, all 3 domains (inform and promote shared decision-making, focus on individual and attend to the emotional and spiritual needs of the family) reflected significant opportunity for improvement with domain score >0.2. The highest was for the domain of attend to the emotional and spiritual needs of the family, 0.62 (SD ±0.26), followed by focus on individual, 0.47 (SD ±0.29), and inform and promote shared decision-making, 0.44 (SD ±0.22).

4.3.4 THE ASSOCIATION BETWEEN THE ASPECTS OF END-OF-LIFE CARE AND THE OVERALL SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE

The correlation between the three aspects of end-of-life care (excluding Physical comfort and emotional support) and the overall satisfaction level were determined using Pearson's correlation test as the Skewness and Kurtosis test suggested the data were normally distributed. The sum of the mean score and standard deviation of each domain, as well as the correlation coefficient (r) and p-value were presented in **Table 4.7.**

Table 4.7: Association between aspects of end-of-life care and overall satisfaction level (n=92)

Aspects of End-of-Life Care	Pearson's Correlation coefficient (r)	r^2	p-value
Inform and promote shared decision-making	-0.334	0.112	0.001*
Focus on individual	-0.424	0.180	<0.001*
Attend to the emotional and spiritual needs of the family	-0.290	0.084	0.005*

***Pearson's Correlation significant at the 0.05 level (2-tailed)**

Table 4.7 demonstrated the correlation between the aspects of end-of-life care and overall satisfaction. All 3 domain of end-of-life care were negatively correlated with overall satisfaction as the correlation coefficient, r, were in negative value. The strength of correlation with overall satisfaction was fair in focus on individual (r= -0.424) and inform and promote shared decision-making (r= -0.334), and poor in attend to the emotional and spiritual needs of the family (r= -0.290). The correlations were statistically significant since p- value were smaller than the tabulated value, 0.05, for all 3 domains. Therefore, the $H_0$1 was rejected. There was a significant poor to fair negative association between inform and promote shared decision-making [r (90)= -0.334, p=0.001], focus on individual [r (90)= -0.424; p<0.001], attend to the emotional and spiritual needs of the family [r (90)= -0.290, p=0.005] and the overall satisfaction. The results suggested that the higher problem score for each domain, the lower the overall satisfaction level. Besides, focus on individual (r^2= 0.180), inform and promote shared decision-making (r^2= 0.112), and attend to the emotional and spiritual needs of the family (r^2= 0.084) could explain 18%, 11% and 8.4% of the overall satisfaction level, respectively, while the other 82%, 89% and 91.6% of satisfactory level could be explained by other factors.

4.3.5 THE ASSOCIATION BETWEEN SOCIODEMOGRAPHIC CHARACTERISTICS AND THE OVERALL SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE

The association between the sociodemographic characteristics and the overall satisfaction level were determined using Chi-square test. The overall satisfaction level according to each sociodemographic characteristics was presented in frequency and percentage, with chi-square value (χ^2), Fisher's exact test and p-value to determine the statistical significance as shown in **Table 4.8.**

Table 4.8: Association between sociodemographic characteristics and overall satisfaction level (n=92)

Sociodemographic characteristics	Overall satisfaction level Frequency, f Percentage, (%)		Chi-square, χ^2	df	Fisher's Exact Test	P-value
	Satisfied	Not Satisfied				
Participants' Ethnicity						
Malay	13 (54.2%)	11 (45.8%)				
Chinese	19 (36.5%)	33 (63.5%)			3.183	0.357
Indian	6 (42.9%)	8 (57.1%)				
Others	0 (0.0%)	2 (100.0%)				
Participants' Education Level						
Less than high school	0 (0.0%)	0 (0.0%)				
High school graduate	3 (27.3%)	8 (72.7%)				
Technical school/ diploma	8 (50.0%)	8 (50.0%)	1.422	3		0.700
Bachelor's degree	8 (40.0%)	12 (60.0%)				
Master/PhD	19 (42.2%)	26 (57.8%)				
Don't know	0 (0.0%)	0 (0.0%)				
Participants' Religion						
Islam	13 (52.0%)	12 (48.0%)				
Buddhism	12 (32.4%)	25 (67.6%)				
Christianity	5 (41.7%)	7 (58.3%)				
Hinduism	5 (45.5%)	6 (54.5%)			4.363	0.512
None/Atheist	3 (60.0%)	2 (40.0%)				
Others	0 (0.0%)	2 (100.0%)				
Don't know	0 (0.0%)	0 (0.0%)				
Participants' Religiosity						
Religious	32 (43.2%)	42 (56.8%)				
Non-religious	3 (27.3%)	8 (72.7%)			1.870	0.702
Not applicable	3 (50.0%)	3 (50.0%)				
Don't know	0 (0.0%)	1 (100.0%)				

***Chi-square test significant at the 0.05 level (2-tailed); df= degree of freedom**

Table 4.8 illustrated the association between the sociodemographic characteristics and overall satisfaction level towards the end-of-life care received. Participants who identified as 'others' reported the highest prevalence of dissatisfaction, 2 (100%), followed by Chinese, 33 (63.5%), Indian, 8 (57.1%), and Malay, 11 (45.8%). However, these differences in prevalence were not statistically significant, as the results of the Fisher's exact test (p= 3.183) was greater than the tabulated value.

The highest prevalence of dissatisfaction was reported among participants who were high school graduates, 8 (72.7%), while the lowest was among those with technical school or diploma qualifications, 8 (50.0%). Nonetheless, there was statistically significant association between the participants' education level and overall satisfaction level as p-value was greater than the tabulated value [χ^2 (3, n=92)= 1.422, p=0.700].

The highest prevalence of dissatisfaction was reported among participants who identified as 'others', 2 (100%), followed by Buddhists, 25 (67.6%), Christians, 7 (58.3%), Hindus, 6 (54.5%), Muslims, 12 (48%), and Atheists, 2 (40.0%). The test showed no statistically significant association between participants' religion and overall satisfaction as the Fisher's test result was (p=4.363).

Participants who identified as non-religious revealed higher prevalence for dissatisfaction, 8 (72.7%), compared to being religious, 42 (56.8%). Nevertheless, there is no statistically significant association between the participant's religiosity and overall satisfaction level as (p=1.870) was greater than the tabulated value.

In conclusion, the sociodemographic characteristics had no statistically significant association with the overall satisfaction level. Hence, null hypothesis two 'there will be no statistically significant association between the sociodemographic characteristics and the overall satisfaction level' failed to be rejected.

4.4 Summary

In conclusion, 92 valid responses (86%) were analysed in this study. Most participants were Chinese, Buddhist, and religious. Many participants have a Master's or PhD. Over half of the participants expressed dissatisfaction with the overall care received, with moderate dissatisfaction reflected in the mean score. The three domains (inform and promote shared decision-making, focus on the individual, attend to emotional and spiritual needs of the family) showed significant opportunities for improvement with domain scores >0.2. Pearson's correlation test revealed a statistically significant poor to fair negative correlation between the domains of end-of-life care and overall satisfaction, while the Chi-square test showed no significant association between sociodemographic characteristics and overall satisfaction levels.

CHAPTER 5

DISCUSSION

CHAPTER 5: DISCUSSION

5.0 CHAPTER OVERVIEW

This chapter discusses the findings based on each specific objective and research question. These results will be interpreted and discussed in relation to existing studies, allowing for comparison and insight into how the current research aligns with or diverges from previous work.

5.1 DISCUSSION OF MAJOR FINDINGS

5.1.1 THE OVERALL SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE

The current study found that 38 (41.3%) participants were satisfied with the overall end-of-life care, while 54 (58.7%) were dissatisfied.

Similar findings were reported in a Canadian study of 1153 bereaved caregivers, where only 37% - 48% rated hospital care as "excellent" or "very good" across key support areas such as pain relief and emotional support (Bainbridge and Seow, 2017). Another study in U.S. that involved 391 relatives of decedents who received home hospice care found a moderate level of satisfaction with the care provided. The study revealed lower satisfaction was associated with hospitalization (Phongtankuel, et al., 2020). The relatively low satisfaction levels among patients and families can be attributed to inadequate personal care assistance and insufficient spiritual support (Bainbridge and Seow, 2017;

Phongtankuel, et al., 2020). The absence of these essential provisions can significantly undermine a patient's sense of dignity and may lead to heightened feelings of anxiety (Martins, et al., 2024; Kurtgöz and Edis, 2023; Holmberg and Godskesen, 2022). This decline in overall well-being not only impacts the patients themselves but also contributes to lower satisfaction ratings among families regarding the quality of care provided.

Conversely, U.S. (Carey, et al., 2019) and Swedish (O'Sullivan, et al., 2018) studies reported higher satisfaction than current study, where respectful and dignified care, open communication, and strong symptom management were key contributors. Both studies highlighted that treating patient with respect and dignity correlates with higher satisfaction in end-of-life care. This approach fosters open communication, emotional support, and an environment where patients feel valued, helping to prevent misunderstandings and medical errors (Kennedy, 2016).

Interestingly, several studies have found that the type of diagnosis significantly influences overall care satisfaction, with cancer patients typically enjoying better access to palliative care compared to those with non-cancer diagnoses (O'Sullivan, et al., 2018; Wachterman, et al., 2016; Suzuki, et al., 2024). Although the differences in satisfaction were not statistically significant, current study revealed that 63% of bereaved caregivers of non-cancer patients expressed dissatisfaction, compared to 37% for those in oncology or palliative care. This

discrepancy may reflect the more robust availability of specialized palliative care services for cancer patients in Malaysia (Perak Palliative Care Society, n.d.; Yip, et al., 2023). A Malaysian study indicated that 86.7% of the 4,346 patients referred to palliative care had cancer diagnoses, highlighting a potential bias in service provision (Yip, et al., 2023).

Additionally, the shorter referral-to-death times for non-cancer patients suggest access inequities in community palliative care (Yip, et al., 2023). While palliative care is crucial for various life-limiting conditions, limited resources often lead to a focus on cancer care, which typically has more predictable disease trajectories (PPCS, n.d.; Singapore Hospice Council, 2023; Wachterman, et al., 2016). This prioritization may result in more timely referrals and greater emotional and practical support for cancer patients and their families, ultimately contributing to higher satisfaction levels.

5.1.2 THE OPPORTUNITY TO IMPROVE IN THE PERCEIVED ASPECTS OF END-OF-LIFE CARE FROM THE CAREGIVER'S PERSPECTIVE

5.1.2.1 PHYSICAL COMFORT AND EMOTIONAL SUPPORT

In the current study, the highest need for improvement was identified in the item related to contradictory information regarding patients' pain treatment, with a mean score of 0.32 (SD ±0.47). A similar finding was reported in U.S., where 33% of respondents indicated that doctors sometimes provided contradictory or confusing information about medical treatment (Carey, et al., 2019). Conversely, a study in the UK found that less than 4% of respondents expressed concerns about conflicting clinical communication (Gallager and Krawczyk, 2013). Contradictory information from healthcare providers (HCPs) can often be caused by the lack of standardization in communication protocols across different healthcare systems. In countries like Malaysia, where healthcare systems are less integrated, inconsistencies among care organizations, lack of structured communication and collaboration among HCPs can result in conflicting information (Nalliah, Lim, and Rampal, 2021; Lau and Pickersgill, 2019; Hamdan, et al., 2023). Unclear communication can severely undermine the planning of care for patients, causing sufferings to patients and family dissatisfaction (Ibañez-Masero, et al., 2019). This highlights the critical need for accurate information and effective communication to enhance care delivery.

The item with the least concern in this domain, as well as across all other domains in the current study, was the adequacy of assistance in managing

breathing difficulties, which received a mean score of 0.04 (SD ±0.21). Similarly, a U.S. study indicated that most decedents experiencing pain and other symptoms were largely well-managed (Bainbridge and Seow, 2018; Carey, et al., 2019). This could be because symptom management is a fundamental and immediate aspect of end-of-life care that healthcare professionals, particularly in hospital settings, are well-trained to address (Eagar, Clapham and Allingham, 2020). In contrast, other aspects of care, such as emotional and psychological support, often require higher levels of emotional intelligence and may be harder to provide consistently due to time constraints or limited training (Hamdan, et al., 2023; Seng and Lee, 2022; Flugelman, 2021). According to Hamdan, et al. (2023), doctors had good knowledge of pain management, but their overall knowledge of palliative care was poor. This highlights gaps in areas beyond physical symptom control.

5.1.2.2 INFORM AND PROMOTE SHARED DECISION-MAKING

The item with the highest opportunity for improvement in this study was the participants' desire for more information about what to expect when the patient was dying, as well as the medications used for symptom control, both with a mean score of 0.75 (SD ±0.44). A similar finding was reported in UK, where 46% of the respondents desired more information regarding the dying process or the medications used for symptom relief (Gallagher and Krawczyk, 2013). Providing families with clear, sensitive communication about impending death ensures they are better prepared for the situation, thereby help them understand that their loved ones were receiving the best care possible. This communication

can promote acceptance, reduce feelings of guilt, and support healthier bereavement adaptation (Flugelman, 2021). Additionally, improving health literacy among Malaysians may explain the increasing demand from participants for high-quality information from HCPs (Chen, et al., 2018).

The lowest mean score, 0.07 (SD ±0.25) was reported for the item that highlighted that the doctors listened to the participants' concerns. A study in U.S. is in line with current study, with 87% respondents reporting that the doctors listened to their concerns (Carey, et al., 2019). According to Flugelman (2021), learning to become a good listener and observer is fundamental to being a good physician. The findings of the current study suggest that healthcare professionals in Malaysian hospitals are practicing these fundamentals considerably well.

Furthermore, compared to findings from the UK, the current study revealed that a higher number of decisions were made without sufficient input from the family (Gallagher and Krawczyk, 2013). This may be due to HCPs and patients in Malaysia have lesser knowledge about shared decision-making (Lee and Ng, 2021). Lee and Ng (2021) highlighted that the paternalistic attitude among doctors, patients' passivity in decision-making and excessive trust in HCPs hinders the implementation of shared decision-making in Malaysia. This highlights the need for improvements in involving both patients and their family members in the decision-making process to ensure that care is individualized and aligns with the wishes and needs of both patients and their families.

5.1.2.3 FOCUS ON INDIVIDUAL

The least concern in this domain was related to adequate help with nursing care such as medications and dressings with mean score 0.14 (SD ±0.35). Besides, 78 (84.8%) participants reported sufficient assistance with personal care needs such as bathing, feeding and grooming. Despite sufficient personal care, participants still expressed heightened worry about whether the patient's personal care needs were adequately addressed, with a mean score of 0.89. (SD ±0.31). Similarly, a UK study found that 63% of respondents expressed concerns about patients' personal care needs (Gallagher and Krawczyk, 2013). Providing adequate personal care is a vital aspect of end-of-life care, as it upholds the patient's dignity (Holmberg and Godskesen, 2022). However, long waiting times, lack of integrity in care, and deteriorating routines can compromise this dignity when fulfilling personal care needs (Holmberg and Godskesen, 2022). Despite the hospital setting, where a higher standard of care is expected, healthcare professionals often prioritize medical tasks such as medication management, while giving less attention to personal care needs like hygiene and feeding, largely due to time constraints and task overload (Nishiya, et al., 2023). For family members, the emotional burden of ensuring that their loved ones' basic personal care needs are met can lead to heightened worry when these needs are overlooked (Nishiya, et al., 2023). This highlights the possible gaps in personal care during end-of-life care.

5.1.2.4 ATTEND TO EMOTIONAL AND SPIRITUAL NEEDS OF THE FAMILY

Although more than half of the participants reported sufficient support provided by the HCPs in dealing with difficult feelings about the patient's death with a mean score of 0.42 (SD ±0.50), a significant majority, 79 (85.9%), indicated that staff either did not discuss with them on their religious and spiritual beliefs or, if they did, it was not done in a sensitive manner. This finding aligns with a UK study, where 70% of respondents received adequate support for difficult emotions, but 72% reported insufficient attention to their spiritual or religious needs (Gallagher and Krawczyk, 2013). This gap in spiritual care could be attributed to the multiethnic and multicultural nature of both Malaysia and the UK, wherein HCPs may struggle with how to navigate sensitive discussions involving religious and spiritual beliefs, particularly when patients' families practice religions different from their own (Siau, et al., 2021; Abdulla, Hossain and Barla, 2019; Glyn-Blanco, Lucchetti and Badanta, 2023; Laranjeira, et al., 2023). Additionally, there is generally a lack of formal training and standard guidelines in spiritual care as part of the formal healthcare education in Malaysia (Siau, et al., 2021; Abdulla, Hossain and Barla, 2019; Laranjeira, et al., 2023). Without adequate training, healthcare professionals may feel uncomfortable initiating spiritual conversations, leading them to either avoid these discussions or very reluctantly engaged in the conversation (Siau, et al., 2021; Abdulla, Hossain and Barla, 2019; Seng and Lee, 2022; Glyn-Blanco, Lucchetti and Badanta, 2023). The lack in spiritual care can result in higher levels of denial, anxiety, depression, difficulty in coping, and poor life quality among caregivers

(Martins, et al., 2024; Kurtgöz and Edis, 2023). This underscores the importance of providing spiritual care to the patients' families.

Moreover, 72.8% of participants in the current study reported not being directed to someone they could turn to when feeling stressed. This may be attributed to the lack of dedicated bereavement services in most healthcare facilities in Malaysia, as well as insufficient professional training for HCPs in offering grief support. Without structured bereavement services or guidance on coping mechanisms, families are often left without adequate emotional support during their time of loss, which can lead to prolonged and complicated grieving (Lai, et al., 2023; Seng and Lee, 2022). This highlights the need of advancement in the bereavement support provision in Malaysian Healthcare system.

In summary, the current study identified opportunities for improvement across all three domains of care, with domain scores exceeding 0.2. The domain attend to the emotional and spiritual needs of families had the highest score of 0.62 (SD ±0.26), followed by focus on individual, 0.47 (SD ±0.29), and inform and promote shared decision-making, 0.44 (SD ±0.22), which is consistent with the findings in a UK study (Gallagher and Krawczyk, 2013). The results emphasize the inadequacies in providing emotional and spiritual support to not only patients but also their families, the importance of attending to personal care needs and integrating families into the decision-making process, which are crucial components of comprehensive end-of-life care.

5.1.3 THE ASSOCIATION BETWEEN THE ASPECTS OF END-OF-LIFE CARE AND THE OVERALL SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE

The current study reveals a statistically significant poor to fair negative correlation [r (90)= -0.3 to -0.4, $p<0.05$] between various aspects of end-of-life care and overall satisfaction. This aligns with Teno, et al. (2004), who reported a slightly stronger correlation of (r (154)= 0.4 to 0.6, $p<0.5$) between different care domains and overall satisfaction with the care received during the end-of-life.

Multiple studies support the idea that caregiver satisfaction with overall care is intricately linked to specific factors (Frey, et al., 2020; Carey, et al., 2019; Sadler, et al., 2014; Gallagher and Krawczyk, 2013; Bainbridge and Seow, 2018). Key elements that enhance satisfaction include treating patients with respect and dignity, providing adequate support for symptom management, and emotional support to ensure the patient's quality of life (Frey, et al., 2020; Carey, et al., 2019; Sadler, et al., 2014; Gallagher and Krawczyk, 2013; Bainbridge and Seow, 2018). According to Phongtankuel, et al. (2020), patient's quality of life positively impacts the families' satisfaction with care. Additionally, regular communication about the patient's condition fosters shared decision-making, which enhances family satisfaction by making them feel involved in their loved one's care (Frey, et al., 2020; Carey, et al., 2019; Sadler et al., 2014; Gallagher and Krawczyk, 2013; Bainbridge and Seow, 2018). Moreover, spiritual and

emotional support for family members is increasingly recognized as a key factor contributing to higher satisfaction (Nayfeh, et al., 2021). A holistic approach to end-of-life care that addresses diverse care aspects can improve bereaved caregivers' satisfaction, subsequently enhancing their post-loss quality of life (Morishita-Kawahara, et al., 2021). This underscores the importance of delivering high-quality care to enhance family satisfaction.

While the correlations observed in this study are modest, this outcome was anticipated. End-of-life care is multifaceted, with various factors influencing satisfaction. Thus, achieving high-quality care requires a holistic approach that addresses the diverse needs of patients and their families rather than putting the focus on only any single aspect of care (Teno, et al., 2004; Verreault, et al., 2018).

5.1.4 THE ASSOCIATION BETWEEN SOCIODEMOGRAPHIC CHARACTERISTICS AND THE OVERALL SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE

5.1.4.1 ETHNICITY

The current study found no statistically significant association between participants' ethnicity and overall satisfaction with end-of-life care (p= 0.357). This aligns with a U.S. study that compared satisfaction levels between 275 Caucasian and non-Caucasian respondents, which also reported no significant correlation between ethnicity and satisfaction with end-of-life care (Sadler, et al., 2014).

Conversely, a study in UK indicated that South Asian respondents expressed lower satisfaction compared to their European counterparts (Gallagher and Krawczyk, 2013). Several studies suggested that ethnic minority patients often rate the quality of dying lower, attributed to increased life support measures at the end of life, as advance directives are less commonly utilized among these groups (Lee, et al., 2016; Chan, 2019). In Malaysia, a multi-ethnocultural country, linguistic diversity and cultural factors can impact patients' and families' access to care, leading to different preferences during the end-of-life (Lim, Ng and Lee, 2023). According to Cain, et al. (2018), variations in cultural values and communication needs may impact families' overall satisfaction with end-of-life care. When care does not align with specific cultural expectations, it can lead

to lower satisfaction levels. Although these findings suggest a potential link between ethnicity and overall satisfaction, the current study did not establish this connection, possibly due to a variation in the ethnic distribution within the sample. According to Sadler, et al. (2014), a study with a more culturally diverse participant population might reveal stronger relationships between ethno-cultural factors and overall satisfaction with care.

5.1.4.2 EDUCATION LEVEL

The findings of the current study indicate no statistically significant association between participants' education level and overall satisfaction with care, [χ^2 (3, n=92)= 1.422, p=0.700]. In contrast, Swedish (O'Sullivan, et al., 2018) and U.S. (Phongtankuel, et al., 2020) studies reported family members with higher educational attainment had lower satisfaction. It could be that family members with higher educational attainment generally have better access to resources and information, allowing them to have better knowledge with end-of-life care (Ibrahim, et al., 2024; Lakin and Kane, 2022). With better awareness, one would have elevated expectations regarding care, leading to their lower satisfaction levels.

Moreover, several studies suggested that higher educational attainment leads to better health literacy, which can influence how well individuals understand and engage with healthcare services (Jansen, et al., 2018; Jaafar, et al., 2021; Raghupathi and Raghupathi, 2020). However, a Canadian study reported an

unconventional finding in which individuals with high education, but low health literacy had lower satisfaction (Shahid, et al., 2022). This suggests that education alone is not a definitive predictor of positive healthcare outcomes. Rather, health literacy emerges as a more pivotal factor in fostering end-of-life discussions (Ladin, et al., 2018). By enhancing health literacy, families are better prepared to engage in shared decision-making and advance planning, which can prevent unwanted treatments, improve patients' quality of life, and ultimately enhance caregiver satisfaction (Ladin, et al., 2018). Thus, health literacy, regardless of educational background, could be key to improving caregiver satisfaction. The lack of association in the current study may be caused by the limited variation in participants' educational backgrounds. It is possible that by involving participants with more diverse educational level might yield greater significance between the variables.

5.1.4.3 RELIGION AND RELIGIOSITY

The current study found no statistically significant association between participants' religion ($p= 0.512$) or religiosity ($p= 0.702$) and their overall satisfaction with end-of-life care. These findings are consistent with a Canadian study, which similarly reported no significant relationship between religion, religiosity, and family satisfaction with care (Sadler, et al., 2014).

However, another Canadian study revealed that satisfaction with care was lower among family members of religion minority patients compared to their counterparts (RR 0.46, 95% CI 0.21-1.02, p=0.056) (Nayfeh, et al., 2021). This could be that families from less common religious backgrounds may have limited access to spiritual care, leading to lower satisfaction (Swihart, et al., 2023). In Malaysia, some faith-based NGOs that provide community-based palliative care also offer religious counselling to families. However, spiritual care in general remains fragmented and lacks standardization (Lau and Pickersgill, 2019). Several studies suggest that caregivers who seek spiritual support, such as consulting chaplains, having an environment conducive to performing religious rituals, and being allowed to share their experiences, tend to cope better with bereavement (Kennedy, et al., 2016; Superdock, et al., 2024; Kurtgoz and Edis, 2023; Lai, et al., 2023). Better adaptation to bereavement lead to higher satisfaction ratings with the overall care received (Akiyama, Numata and Mikami, 2010).

Nevertheless, this was not observed in current study. The discrepancies in findings may be due to the lack of religious diversity in the current study sample. Instead, families may prioritize their loved ones' physical comfort and pain management over religious aspects when evaluating overall satisfaction (Bainbridge and Seow, 2018).

5.2 SUMMARY

Overall, there is limited opportunity for direct comparison between the findings of the present study and local research, as, to the best of the researcher's knowledge, no prior studies have explored the perspectives of bereaved caregivers on end-of-life care in Malaysia. However, comparisons with studies conducted in other Asian and Western countries reveal both similarities and differences. These findings highlight the need for further local research to better understand the unique cultural, social, and healthcare contexts that shape the experiences of bereaved caregivers in Malaysia. This could ultimately contribute to the improvement of end-of-life care and support services tailored to the Malaysian population.

CHAPTER 6

CONCLUSION

AND

RECOMMENDATION

CHAPTER 6: CONCLUSION AND RECOMMENDATION

6.0 CHAPTER OVERVIEW

This chapter outlines the strengths and limitations of the study, as well as its implications for nursing practice. It will also provide recommendations for improving clinical practice and guide future research efforts in the field of end-of-life care. Finally, the chapter will conclude by summarizing the key findings and overall contributions of the study.

6.1 STRENGTH AND LIMITATION OF THE STUDY

6.1.1 STRENGTHS OF THE STUDY

The current study reported satisfactory response rate, 92 (86%), aligning with the calculated sample size to ensure the representativeness of the research findings within the study population. According to Goodwin et al. (2020), a satisfactory response rate enhances the validity and reliability if the findings and this can reduce the like hood if nonresponse bias. Thus, the current study is more representative and generalisable.

Besides, the sample size was achievable within the constricted time frame and to the best abilities of the researcher. An achievable sample size is a significant strength in research as it contributes to the credibility and robustness of the study findings (Andrade, 2020). Hence, the present study findings are generalisable due to the credibility associated with the achievable sample size.

Utilizing purposive sampling techniques, whereby the most suitable participants are recruited for the study, enhances the quality of the responses (Polit and Beck, 2017). Furthermore, according to Campbell et al. (2020), using purposive sampling will strengthen a research study, as the collected data is meaningful and directly addresses the research questions, thereby enhancing the study's validity and relevance. Thus, by using purposive sampling to recruit bereaved caregivers, this study was able to collect data regarding their satisfaction levels with care they received, further enhancing the present study's validity and relevance.

As the first research of its kind in Malaysia, this study holds significant strength by filling a critical gap in understanding the bereaved caregivers' perspectives on end-of-life care. This area has not been previously explored in the Malaysian context, and the findings provide culturally relevant insights. Such insights are particularly valuable for setting a foundation for future research in a multi-ethnic, multi-religious society like Malaysia, where local social, cultural, and healthcare dynamics can differ significantly from other regions.

6.1.2 LIMITATIONS OF THE STUDY

However, as a retrospective study, the findings might be subjected to recall bias as the participants might have forgotten some details of their experiences (Nayfeh, et al., 2021; Morishita-Kawahara, et al., 2021). To address this limitation, the researcher set a recall period of 5 years from the year of incident to the period of current study.

As the sample size was not vast and only conducted among population from one private university, the findings of current study lack generalizability. Besides, the study used the family caregivers' assessment as a proxy for the assessment of the quality of care. It is possible that family caregivers will inappropriately assess the care received by their family members. However, surveys of the patients themselves have numerous challenges and limitations. Surveys of terminally ill patients are likely to be unrepresentative and/or biased because many patients are too physically ill and/or mentally incapable of participation (Silva, Ribeiro and Moreira-Almeida, 2024; Miyashita, et al., 2015; Choi, et al., 2013). A review of studies on the reliability of information provided by proxies revealed that they were more reliable with regard to the reporting of observable symptoms and quality of services than were the patients themselves (Silva, Ribeiro and Moreira-Almeida, 2024; Choi, et al., 2013).

6.2 IMPLICATIONS OF THE STUDY

This study provides valuable insights into the bereaved caregivers' perspectives on end-of-life care in Malaysian hospitals. By empowering caregivers to voice their experiences, the study gives them a platform to express their challenges and emotional journeys, which are often overlooked. This feedback is invaluable for revealing gaps in care, such as communication barriers, inadequate support, or unmet emotional and spiritual needs.

The findings could serve as a reference for future studies, providing baseline data that informs healthcare policies and reforms. Such data can be pivotal in crafting evidence-based interventions that enhance support systems for patients and families, ensuring their needs are met in a more personalized and compassionate manner. Ultimately, the insights gained from caregivers' experiences could guide the development of improved end-of-life care practices, creating a more patient- and family-centered approach in hospitals across Malaysia.

6.3 RECOMMENDATIONS

6.3.1RECOMMENDATION FOR FUTURE PRACTICE

Integrating palliative care education into health science curricula and providing ongoing training for healthcare staff are crucial steps in addressing the gaps in end-of-life care in Malaysian hospitals. By preparing students through lectures, simulation programs and attachment programs, future healthcare professionals can develop both emotional intelligence and practical knowledge to offer compassionate care (Yoong, et al., 2023; Lau and Pickersgill, 2019). Workshops and seminars on communication regarding end-of-life, bereavement support, and symptom management for current staff will equip them with the skills needed to provide comprehensive and dignified care during the challenging end-of-life period (Hamdan, et al., 2023; Lau and Pickersgill, 2019). These efforts are essential for improving the overall quality of end-of-life care.

6.3.2 RECOMMENDATION FOR FUTURE RESEARCH

Moving on, future studies can focus on experimental interventions to determine whether implementing specific aspects of care improves patient and caregiver satisfaction. These interventions could include structured communication strategies, enhanced symptom control, or family support programs, providing data on which approaches lead to the most significant improvements in end-of-life care experiences.

Furthermore, given Malaysia's multicultural society, future research should aim for more diverse participant recruitment from different ethno-cultural backgrounds. By including participants from varied ethnic and religious backgrounds, researchers can identify cultural nuances in end-of-life care needs and preferences, improving the inclusivity and cultural sensitivity of care delivery. In addition to recruiting participants from various universities, studies could be extended to include individuals from the general public. These would enhance the representativeness and generalizability of findings and provide a more comprehensive understanding of end-of-life care experiences across different segments of the population.

Lastly, translating research instruments into Malaysia's major languages—Bahasa Malaysia, Chinese, and Tamil—will minimize language barriers and increase participation from communities with different linguistic proficiencies. This step will allow researchers to gather more accurate data from a broader demographic, ensuring that the voices of all groups are represented in future studies.

6.4 CONCLUSION

In conclusion, end-of-life care is a crucial aspect in healthcare that remains undermined in Malaysia. This study was set out to understand the bereaved family members' perspectives on the end-of-life care received in Malaysian hospitals. The bereaved caregiver's satisfaction with care, the needs for

improvements in the aspects of care and their associations were explored among bereaved caregivers from a private university in Kajang.

Overall, the study revealed that more than half of the participants, 54 (58.7%), expressed low satisfaction with the end-of-life care their loved ones received in Malaysian hospitals. A poor to fair negative correlation was observed between aspects of care and overall satisfaction, indicating that unmet care needs directly impacted caregivers' perceptions. However, no statistically significant association was found between sociodemographic characteristics (participant's ethnicity, education level, religion and religiosity) and satisfaction levels, suggesting that dissatisfaction spans across various demographic groups.

The findings of the study emphasize the need for Malaysian hospitals to improve the quality of end-of-life care, with particular focus on decision-making, addressing patients' personal care needs, providing respectful and compassionate care, and attending to the emotional and spiritual needs of family members. Additionally, empowering caregivers by giving them opportunities to share their experiences is crucial for continuous improvement. Further training for future and current healthcare providers is essential to enhance their competence in delivering holistic, patient- and family-centered end-of-life care.

(10958 words)

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APPENDICES

APPENDIX A: CONSENT DECLARATION FORM

PARTICIPANT CONSENT FORM

Research Title: The Satisfaction Level of Bereaved Caregivers with the Care Received during the End-Of-Life, A Private University in Kajang.

- I confirm that I have read and understand the information and cover letter of recruitment explaining the above research.
- I confirm that the purpose of the research, risks and benefits have been explained to me.
- I understand my participation is strictly voluntary and I am free to withdraw at any time without consequence.
- I understand my identity will be maintained anonymous and my responses will be kept private and confidential.
- I understand I am entitled to ask questions and to receive information and feedback for educational purpose after the study.
- I agree the data collected from me will be used in future research.
- I permit members of the research team to access my responses.
- I hereby give my consent to participate in the above research.

_____	_____	_____
Name of Participant	Date	Signature

I hereby believe the participant agree to participate in the research.

WONG JIA YAN	_____	_____
Name of Researcher	Date	Signature

APPENDIX B: RESEARCH INSTRUMENT

SECTION A- SCREENING

These questions below are to understand how well you know regarding [PATIENT] last few weeks of life/while under care of the hospital. You are required to answer ALL the following questions.

Please put (√) to the answer.

1. How were you related to [PATIENT]? You are [PATIENT'S] _____?

   [ ] SPOUSE
   [ ] PARTNER
   [ ] CHILD
   [ ] DAUGHTER-IN-LAW/SON-IN-LAW
   [ ] PARENT
   [ ] SIBLING
   [ ] GRANDCHILDREN
   [ ] OTHER RELATIVE
   [ ] FRIEND
   [ ] OTHERS (SPECIFY: _____)

2. Would you say you are one of the people who knows the most about how [PATIENT] was doing during (his/her) last few weeks of life/while under care of the hospital?

   [ ] YES
   [ ] NO (THE QUESTIONNAIRE ENDS HERE)

SECTION B- SOCIAL BACKGROUND

PATIENT DEMOGRAPHIC CHARACTERISTICS

These questions below are to collect sociodemographic data of the late patient. You are required to answer ALL the following questions.

Please put (√) to the answer.

1. How old was the [PATIENT] when (he/she) passed away?

   _____ YEARS OLD

2. What was the highest level of schooling [PATIENT] completed?

   [ ] LESS THAN HIGH SCHOOL
   [ ] HIGH SCHOOL GRADUATE
   [ ] TECHNICAL SCHOOL OR DIPLOMA
   [ ] BACHELOR DEGREE
   [ ] MASTER OR PHD
   [ ] DON'T KNOW

3. What was [PATIENT'S] religious preference?

   [ ] ISLAM
   [ ] BUDDHISM
   [ ] CHRISTIANITY
   [ ] HINDUISM
   [ ] NONE/ATHEIST
   [ ] OTHERS (SPECIFY: _____)
   [ ] DON'T KNOW

4. In your opinion, would you describe the [PATIENT] as:

   [ ] RELIGIOUS
   [ ] NON- RELIGIOUS
   [ ] NOT APPLICABLE
   [ ] DON'T KNOW

5. What was [PATIENT] ethnicity?

   [ ] MALAY
   [ ] CHINESE
   [ ] INDIAN
   [ ] OTHERS (SPECIFY: _____)

6.What was [PATIENT] gender?

[ ] MALE
[ ] FEMALE

RESPONDENT DEMOGRAPHIC CHARACTERISTICS

These questions below are to collect sociodemographic data of you as the respondent to this questionnaire. You are required to answer ALL the following questions.

Please put (√) to the answer.

7.Are you a (student/staff) of UTAR, Sg Long Campus?

[ ] STUDENT
[ ] STAFF

8.How old were you when the [PATIENT] passed away?

_____ YEARS OLD

9.What is your gender?

[ ] MALE
[ ] FEMALE

10.What is the highest level of schooling you have completed?

[ ] LESS THAN HIGH SCHOOL
[ ] HIGH SCHOOL GRADUATE
[ ] TECHNICAL SCHOOL OR DIPLOMA
[ ] BACHELOR DEGREE
[ ] MASTER OR PHD
[ ] DON'T KNOW

11.What was your religious preference?

[ ] ISLAM
[ ] BUDDHISM
[ ] CHRISTIANITY
[ ] HINDUISM
[ ] NONE/ATHEIST
[ ] OTHERS (SPECIFY: _____)
[ ] DON'T KNOW

12.In your opinion, would you describe yourself as:

[ ] RELIGIOUS
[ ] NON- RELIGIOUS
[ ] NOT APPLICABLE
[ ] DON'T KNOW

13.What is your ethnicity?

[ ] MALAY
[ ] CHINESE
[ ] INDIAN
[ ] OTHERS (SPECIFY: _____)

14.How would you rate your overall health? Would you say excellent, very good, good, fair, or poor?

[ ] EXCELLENT
[ ] VERY GOOD
[ ] GOOD
[ ] FAIR
[ ] POOR

SECTION C- CHECKING THE FACTS

These questions below are to understand more details regarding the late patient's last week/while under care of the hospital. You are required to answer ALL the following questions.

Please put (√) to the answer.

1. Where did the [PATIENT'S] death take place?

   [ ] AT HOME
   [ ] AT HOME WITH HOSPICE OR HOME NURSING SERVICES (e.g. Homage Malaysia, Hospis Malaysia)
   [ ] IN A PRIVATE HOSPITAL
   [ ] IN A GOVERNMENT HOSPITAL
   [ ] NURSING HOME OR OTHER LONG-TERM CARE FACILITY
   [ ] SOMEWHERE ELSE (SPECIFY: _____)

2. In which year the [PATIENT] passed away?

   _____

3. What is the primary diagnosis that have led to the end-of-life condition for the [PATIENT]?

   [ ] TRAUMA (e.g. MOTOR VEHICLE ACCIDENTS)
   [ ] CANCER
   [ ] RESPIRATORY DISEASES (e.g. ASTHMA, COPD, CYSTIC FIBROSIS)
   [ ] CARDIOVASCULAR DISEASES (e.g. HEART ATTACK, STROKE)
   [ ] OTHERS (SPECIFY: _____)

4. Were you in contact with the [PATIENT] in the last 7 days of their life?

   [ ] YES
   [ ] NO

For the following questions, provide your answer based on the last time [PATIENT] was admitted to the hospital if death did not occur in hospital.

5. Where did the [PATIENT'S] last hospital admission take place?

   [ ] IN A PRIVATE HOSPITAL
   [ ] IN A GOVERNMENT HOSPITAL
   [ ] OTHERS (SPECIFY: _____)

6. How long was [PATIENT] hospitalized before passing away/discharge?

   [ ] 1-6 DAYS
   [ ] 7- 17 DAYS

SECTION D- DOMAIN QUESTIONS

These questions below are about **[PATIENT'S]** experience during (his/her) (last week/while under care of the hospital). You are required to answer all the questions that applies.

Please put (√) to the answer.

C1. While [PATIENT] was under care of the hospital, did you talk with any of [PATIENT'S] doctors yourself?

[ ] YES
[ ] NO (SKIP TO A8)
[ ] NO, BUT THE DOCTORS TALKED TO MY OTHER FAMILIES (SKIP TO A8)

C1a. While under care of the hospital, was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

[ ] YES
[ ] NO

C1b. While under care of the hospital, did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

[ ] YES
[ ] NO
[ ] HAD NO CONCERNS

C1c. While under care of the hospital, how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

[ ] LESS THAN WAS NEEDED
[ ] JUST THE RIGHT AMOUNT
[ ] MORE THAN WAS NEEDED

Following are some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of the hospital.

A8. About how many days or weeks before (he/she) died did [PATIENT] lose consciousness?

_____ DAYS OR _____ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

D12. While under care of the hospital, was [PATIENT] on medicines to treat (his/her) pain?

[ ] YES
[ ] NO (SKIP TO D15)
[ ] DON'T KNOW (SKIP TO D15)

D12a. While under care of the hospital, did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

[ ] YES
[ ] NO

D15. While under care of the hospital, did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT

D15a. While under care of the hospital, was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

[ ] YES
[ ] NO

D16. While under care of the hospital, did (he/she) have trouble breathing?

[ ] YES
[ ] NO (SKIP TO D17)
[ ] DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive – less than was needed, or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D17. While under care of the hospital, did (he/she) have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO D19)
[ ] DON'T KNOW (SKIP TO D19)

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D19. While under care of the hospital, was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

D21. While under care of the hospital, how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D22. While under care of the hospital, how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D23. While under care of the hospital, how often was [PATIENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D24. (In that last week/ While under care of the hospital), was there enough help available to meet (his/her) personal care needs, like bathing, feeding, and going to the bathroom?

[ ] YES
[ ] NO

D25. While under care of the hospital, was there enough help with medications and getting dressings changed?

[ ] YES
[ ] NO

D26. At any time while [PATIENT] was under care of the hospital did you or your family receive any information about what to expect while (he/she) was dying?

[ ] YES
[ ] NO

D26a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D27. At any time while [PATIENT] was under care of the hospital did you or your family receive any information about what to do at the time of (his/her) death?

[ ] YES
[ ] NO

D27a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D28. At any time while [PATIENT] was under care of the hospital did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO

D28a. Would you have wanted (some/more) information about the medicines?

[ ] YES
[ ] NO

These next questions are about **your** experience while [PATIENT] was under care of the hospital.

E1. While [PATIENT] was under care of the hospital, how often were you or other family members kept informed about [PATIENT'S] condition – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E2. While [PATIENT] was under care of the hospital, how often did you have to **worry** about [PATIENT'S] personal care needs being met?

(such as bathing, dressing, and changing bedding)

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E4. While [PATIENT] was under care of the hospital, did someone talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO E6)

E4a. Was this done in a sensitive manner?

[ ] YES
[ ] NO

E4b. Did you have as much contact of that kind as you while [PATIENT] was under care of the hospital?

[ ] YES
[ ] NO

E6. While [PATIENT] was under care of the hospital, how much support in dealing with your feelings about [PATIENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

E7. While [PATIENT] was under care of the hospital, did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

[ ] YES	E7a. Was it done in a sensitive manner? [ ] YES [ ] NO
[ ] NO	E7b. Would you have wanted them to? [ ] YES [ ] NO

E8. While [PATIENT] was under care of the hospital, did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone <u>you</u> could turn to for help if you were feeling stressed?

[ ] YES
[ ] NO

SECTION E- OVERALL SATISFACTION

Overall, were you satisfied with the care given to you, [PATIENT] and other family and friends in [PATIENT'S] last week of life/ while [PATIENT] was under care of the hospital)?

Please put (√) to the answer.

1 NOT AT ALL SATISFIED	2 NOT VERY SATISFIED	3 SOMEWHAT SATISFIED	4 VERY SATISFIED	5 COMPLETELY SATISFIED

THE QUESTIONNAIRE ENDS HERE
********** THANK YOU FOR YOUR PARTICIPATION **********

"A great soul serves everyone all the time. A great soul never dies. It brings us together again and again."

— Maya Angelou

APPENDIX C: COVER LETTER OF RECRUITMENT

THE SATISFACTION LEVEL OF BEREAVED CAREGIVERS WITH THE CARE RECEIVED DURING THE END-OF-LIFE, A PRIVATE UNIVERSITY IN KAJANG

Dear Participant,

My name is Wong Jia Yan, a fourth-year nursing student from Universiti Tunku Abdul Rahman, Sungai Long Campus. The objective of this research is to assess the aspects of care and the overall satisfaction level of the bereaved caregivers with the care received during the end-of-life.

You are invited to fill out this questionnaire if you are:

- Currently a staff member or student of UTAR, Sungai Long Campus aged 18 and above.
- A family member or friend of a decedent aged 12 and above at the time of passing.
- A family member or friend of a decedent who passed away within the last 5 years.
- Decedent must have admission to the hospital for more than 48 hours within the last 3 months of life.

There are a total of 5 sections in this questionnaire and expected to take about 10-15 minutes of your time. There is no identified risks or compensation for participating in this research. Your response will be anonymous and intended for research purposes only. Your participation is entirely voluntary. If at any point during the answering of the questionnaire that makes you not feel comfortable, you may withdraw at any time without consequences. If you have decided to participate in this survey, kindly answer all questions as honestly as possible.

Thank you for taking your time to assist me in the research. The data collected will provide useful information for future research related to end-of-life care and how can we improve the care for patients and their family. Feedback and information will be provided to all research participants for educational purpose after the study. Your participation is greatly appreciated.

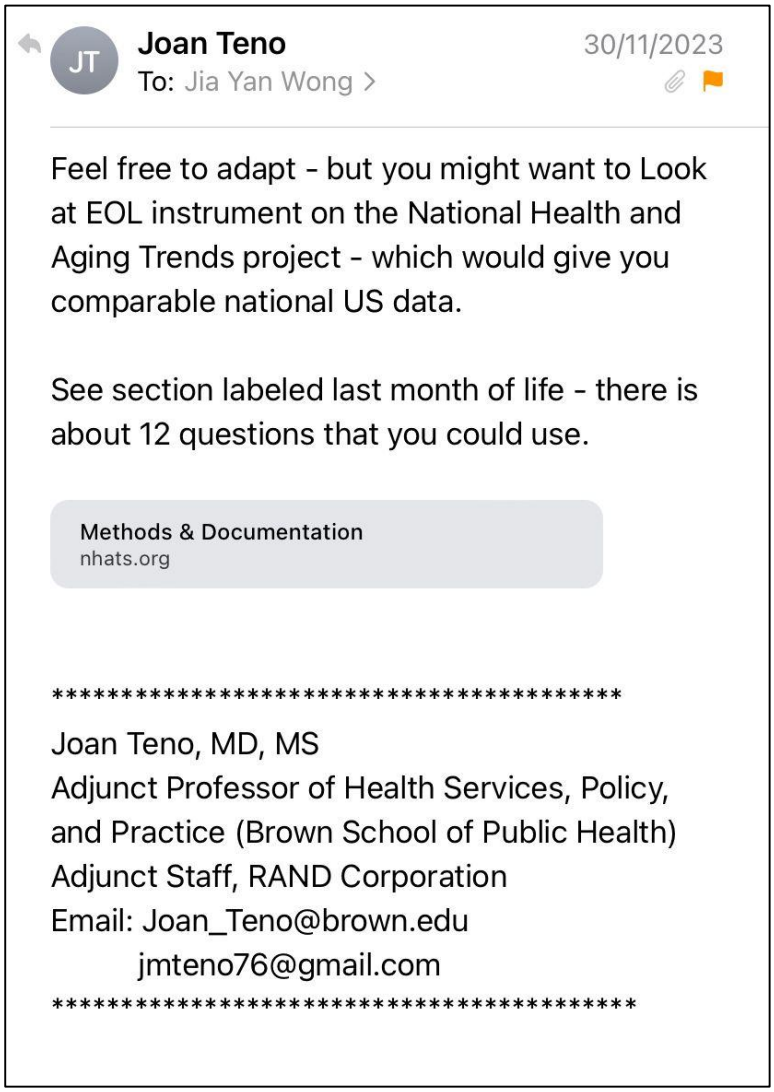
Yours sincerely,

JI A

(WONG JIA YAN)

(wongjiayan@1utar.my)

APPENDIX D: PERMISSION TO USE INSTRUMENT



JT

Joan Teno 30/11/2023

To: Jia Yan Wong >

Feel free to adapt - but you might want to Look at EOL instrument on the National Health and Aging Trends project - which would give you comparable national US data.

See section labeled last month of life - there is about 12 questions that you could use.

Methods & Documentation
nhats.org

****

Joan Teno, MD, MS
Adjunct Professor of Health Services, Policy, and Practice (Brown School of Public Health)
Adjunct Staff, RAND Corporation
Email: Joan_Teno@brown.edu
jmteno76@gmail.com

****

APPENDIX E: ETHICAL BOARD APPROVAL LETTER

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Re: U/SERC/78-316/2024

3 July 2024

Ms Liew Siew Fun
Head, Department of Nursing
M. Kandiah Faculty of Medicine and Health Sciences
Universiti Tunku Abdul Rahman
Jalan Sungai Long
Bandar Sungai Long
43000 Kajang, Selangor

Dear Ms Liew,

Ethical Approval For Research Project/Protocol

We refer to your application for ethical approval for your students' research project from Bachelor of Nursing (Honours) programme enrolled in course UMNE4024. We are pleased to inform you that the application has been approved under Expedited Review.

The details of the research projects are as follows:

No	Research Title	Student's Name	Supervisor's Name	Approval Validity
1.	Knowledge and Attitude Towards Diabetes Mellitus (DM) Among Non-Diabetic Academic Staff in A University in Sungai Long, Selangor, Malaysia	Low Huan Le	Ms Jagjit Kaur a/p Najar Singh	3 July 2024 – 2 July 2025
2.	Examining Gen Z's Willingness on Family Presence During Resuscitation (FPDR): in A Private University in Selangor, Malaysia	Jocelyn Low Zi Yeng	Prof Dr Hamidah Binti Hassan	
3.	A Study on the Influences of Social Media Use on Appearance Anxiety Among Undergraduate Students in one of the Private Universities in Kajang	Camie Man Xian Chyi	Prof Dr Hamidah Binti Hassan	
4.	A Study on Knowledge and Attitudes Towards Organ Donation Willingness Among Undergraduate Students in A Private University in Sungai Long	Chai Pei Zi	Ms Choo Peak Yean	
5.	A Study on Knowledge and Attitudes in Menstrual Cup Usage Among Female Undergraduate Students in A Private University in Sungai Long	Lim Jia Hui	Ms Thalasy a/p Perumal	
6.	A Study on the Knowledge and Use of E-cigarettes Among Female Undergraduate Students in A Private University in Kajang	Choh Yong Sheng	Dr Thavamalar a/p Paramasivam	
7.	The Satisfaction Level of Bereaved Caregivers With the Care Received During The End-Of-Life, A Private University in Kajang	Wong Jia Yan		
8.	A Study on Knowledge, Attitude and Preventive Measures Towards Sexually Transmitted Infections Among Undergraduate Students in A Private University in Kajang	Leow Guo An	Ms Liew Siew Fun	

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The conduct of this research is subject to the following:

(1) The participants' informed consent be obtained prior to the commencement of the research;

(2) Confidentiality of participants' personal data must be maintained; and

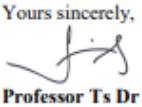
(3) Compliance with procedures set out in related policies of UTAR such as the UTAR Research Ethics and Code of Conduct, Code of Practice for Research Involving Humans and other related policies/guidelines.

(4) Written consent be obtained from the institution(s)/company(ies) in which the physical or/and online survey will be carried out, prior to the commencement of the research.

Should the students collect personal data of participants in their studies, please have the participants sign the attached Personal Data Protection Statement for records.

Thank you.

Yours sincerely,



Professor Ts Dr Faidz bin Abd Rahman
Chairman
UTAR Scientific and Ethical Review Committee

c.c Dean, M. Kandiah Faculty of Medicine and Health Sciences
Director, Institute of Postgraduate Studies and Research

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APPENDIX F: PERSONAL DATA PROTECTION STATEMENT

PERSONAL DATA PROTECTION NOTICE

Please be informed that in accordance with Personal Data Protection Act 2010 ("PDPA") which came into force on 15 November 2013, Universiti Tunku Abdul Rahman ("UTAR") is hereby bound to make notice and require consent in relation to collection, recording, storage, usage and retention of personal information.

1. Personal data refers to any information which may directly or indirectly identify a person which could include sensitive personal data and expression of opinion. Among others it includes:

   a) Name
   b) Identity card
   c) Place of Birth
   d) Address
   e) Education History
   f) Employment History
   g) Medical History
   h) Blood type
   i) Race
   j) Religion
   k) Photo
   l) Personal Information and Associated Research Data

2. The purposes for which your personal data may be used are inclusive but not limited to:

   a) For assessment of any application to UTAR
   b) For processing any benefits and services
   c) For communication purposes
   d) For advertorial and news
   e) For general administration and record purposes
   f) For enhancing the value of education
   g) For educational and related purposes consequential to UTAR
   h) For replying any responds to complaints and enquiries
   i) For the purpose of our corporate governance
   j) For the purposes of conducting research/ collaboration

3. Your personal data may be transferred and/or disclosed to third party and/or UTAR collaborative partners including but not limited to the respective and appointed outsourcing agents for purpose of fulfilling our obligations to you in respect of the purposes and all such other purposes that are related to the purposes and also in providing integrated services, maintaining and storing records. Your data may be shared when required by laws and when disclosure is necessary to comply with applicable laws.

4. Any personal information retained by UTAR shall be destroyed and/or deleted in accordance with our retention policy applicable for us in the event such information is no longer required.

5. UTAR is committed in ensuring the confidentiality, protection, security and accuracy of your personal information made available to us and it has been our ongoing strict policy to ensure that your personal information is accurate, complete, not misleading and updated. UTAR would also ensure that your personal data shall not be used for political and commercial purposes.

Consent:

6. By submitting or providing your personal data to UTAR, you had consented and agreed for your personal data to be used in accordance to the terms and conditions in the Notice and our relevant policy.

7. If you do not consent or subsequently withdraw your consent to the processing and disclosure of your personal data, UTAR will not be able to fulfill our obligations or to contact you or to assist you in respect of the purposes and/or for any other purposes related to the purpose.

8. You may access and update your personal data by writing to us at_____.

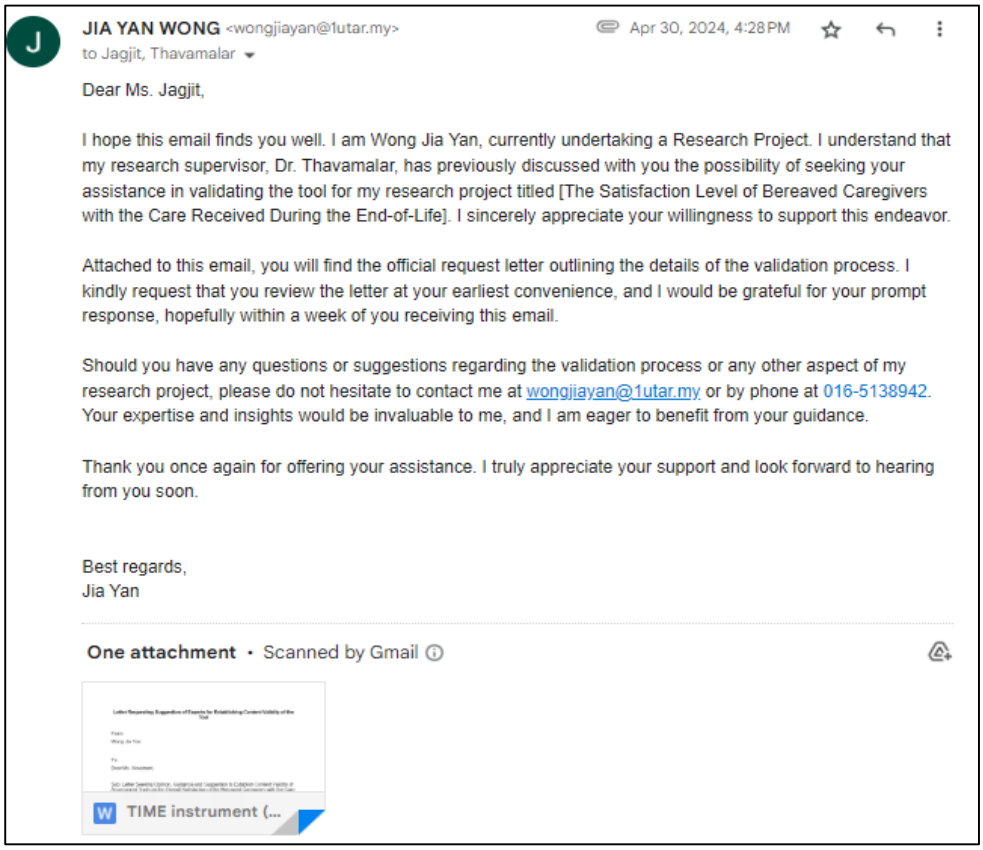
Acknowledgment of Notice

[ ] I have been notified and that I hereby understood, consented and agreed per UTAR above notice.

[ ] I disagree, my personal data will not be processed.

.....
Name:
Date:

APPENDIX G: RESEARCH INSTRUMENT CONTENT VALIDATION



JIA YAN WONG <wongjiayan@1utar.my> Apr 30, 2024, 4:28 PM
to Jagjit, Thavamalar

Dear Ms. Jagjit,

I hope this email finds you well. I am Wong Jia Yan, currently undertaking a Research Project. I understand that my research supervisor, Dr. Thavamalar, has previously discussed with you the possibility of seeking your assistance in validating the tool for my research project titled [The Satisfaction Level of Bereaved Caregivers with the Care Received During the End-of-Life]. I sincerely appreciate your willingness to support this endeavor.

Attached to this email, you will find the official request letter outlining the details of the validation process. I kindly request that you review the letter at your earliest convenience, and I would be grateful for your prompt response, hopefully within a week of you receiving this email.

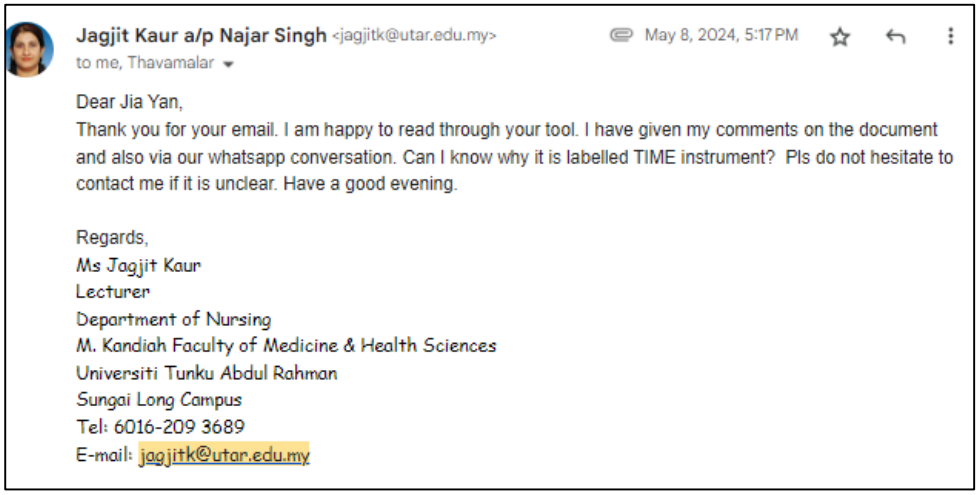
Should you have any questions or suggestions regarding the validation process or any other aspect of my research project, please do not hesitate to contact me at wongjiayan@1utar.my or by phone at 016-5138942. Your expertise and insights would be invaluable to me, and I am eager to benefit from your guidance.

Thank you once again for offering your assistance. I truly appreciate your support and look forward to hearing from you soon.

Best regards,
Jia Yan

One attachment • Scanned by Gmail

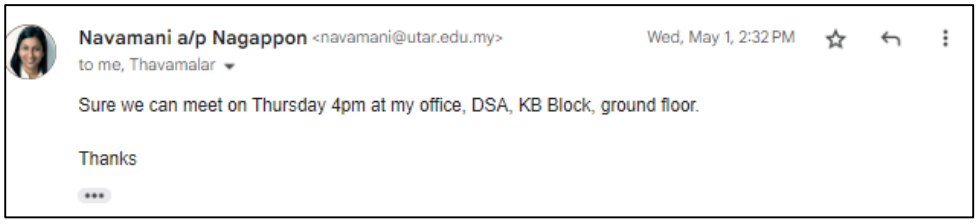
TIME instrument (...



Jagjit Kaur a/p Najar Singh <jagjitk@utar.edu.my> May 8, 2024, 5:17 PM
to me, Thavamalar

Dear Jia Yan,
Thank you for your email. I am happy to read through your tool. I have given my comments on the document and also via our whatsapp conversation. Can I know why it is labelled TIME instrument? Pls do not hesitate to contact me if it is unclear. Have a good evening.

Regards,
Ms Jagjit Kaur
Lecturer
Department of Nursing
M. Kandiah Faculty of Medicine & Health Sciences
Universiti Tunku Abdul Rahman
Sungai Long Campus
Tel: 6016-209 3689
E-mail: jagjitk@utar.edu.my

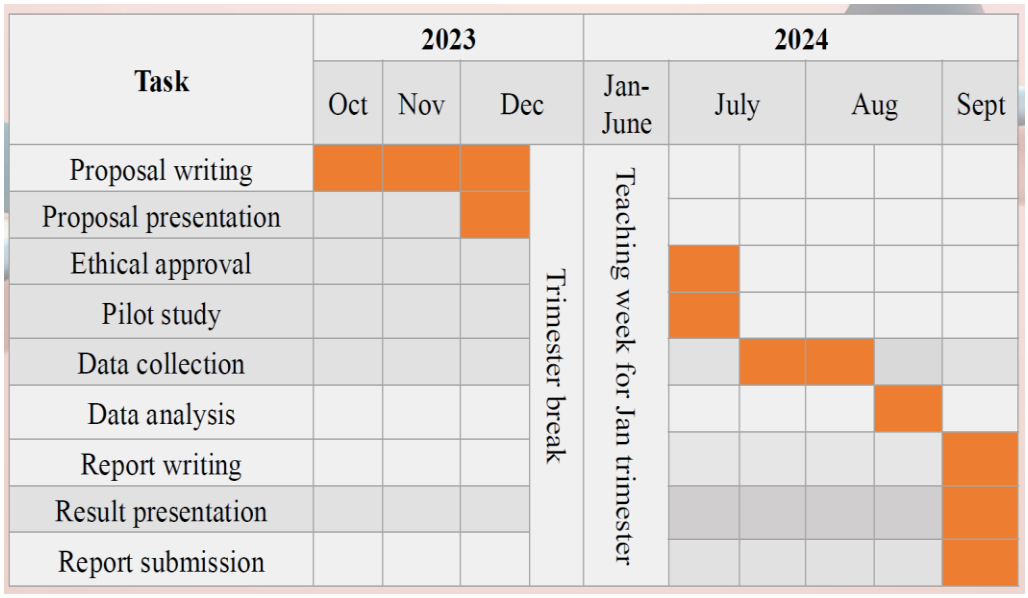


Navamani a/p Nagappon <navamani@utar.edu.my> Wed, May 1, 2:32 PM
to me, Thavamalar

Sure we can meet on Thursday 4pm at my office, DSA, KB Block, ground floor.

Thanks

APPENDIX H: GANTT CHART



APPENDIX I: TURNINIT ORIGINALITY REPORT

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ORIGINALITY REPORT

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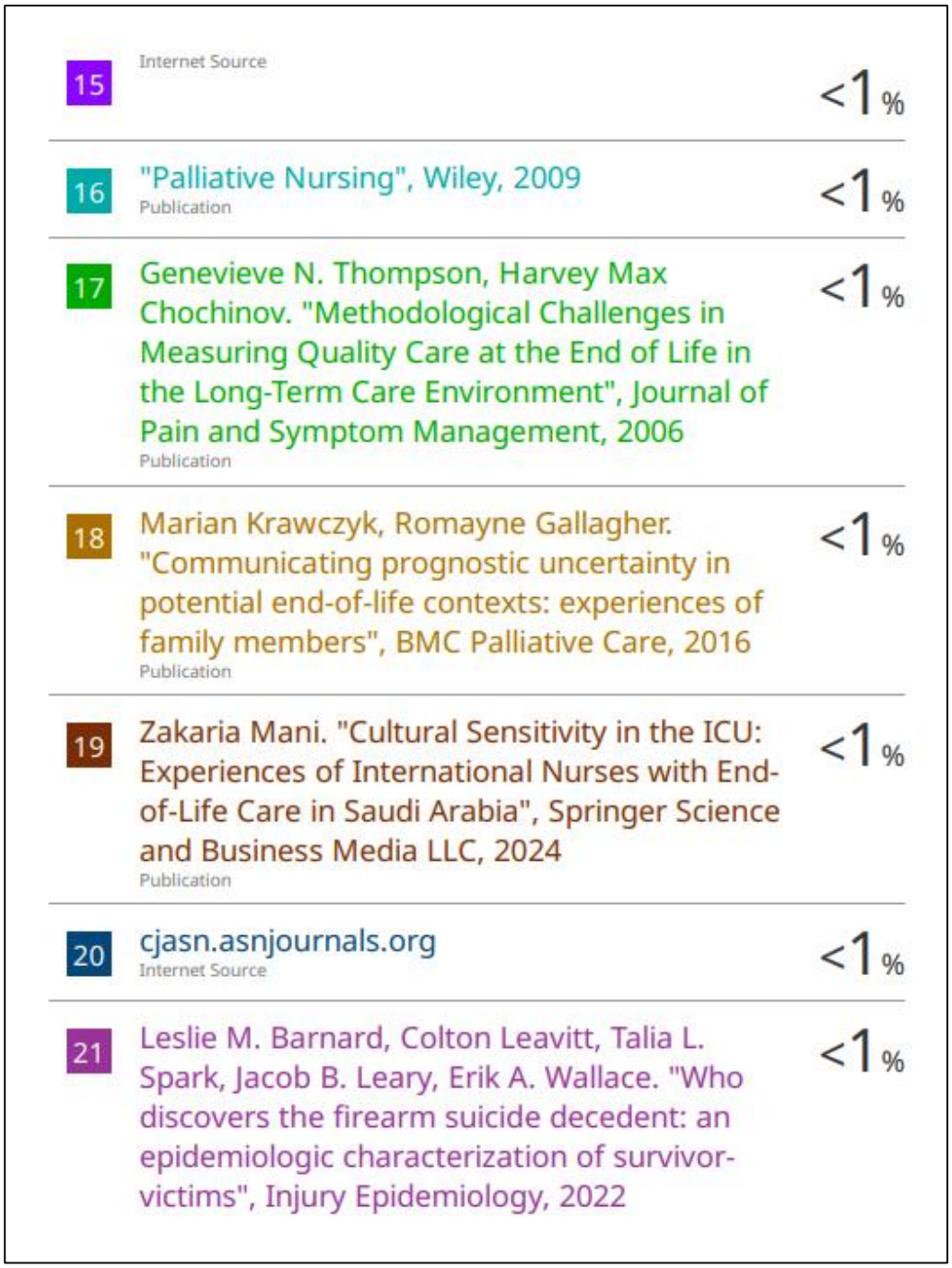
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25	Fred Burge, Beverley Lawson, Grace Johnston, Yukiko Asada, Paul F McIntyre, Eva Grunfeld, Gordon Flowerdew. "Bereaved family member perceptions of patient-focused family-centred care during the last 30days of life using a mortality follow-back survey: does location matter?", BMC Palliative Care, 2014 Publication	<1 %
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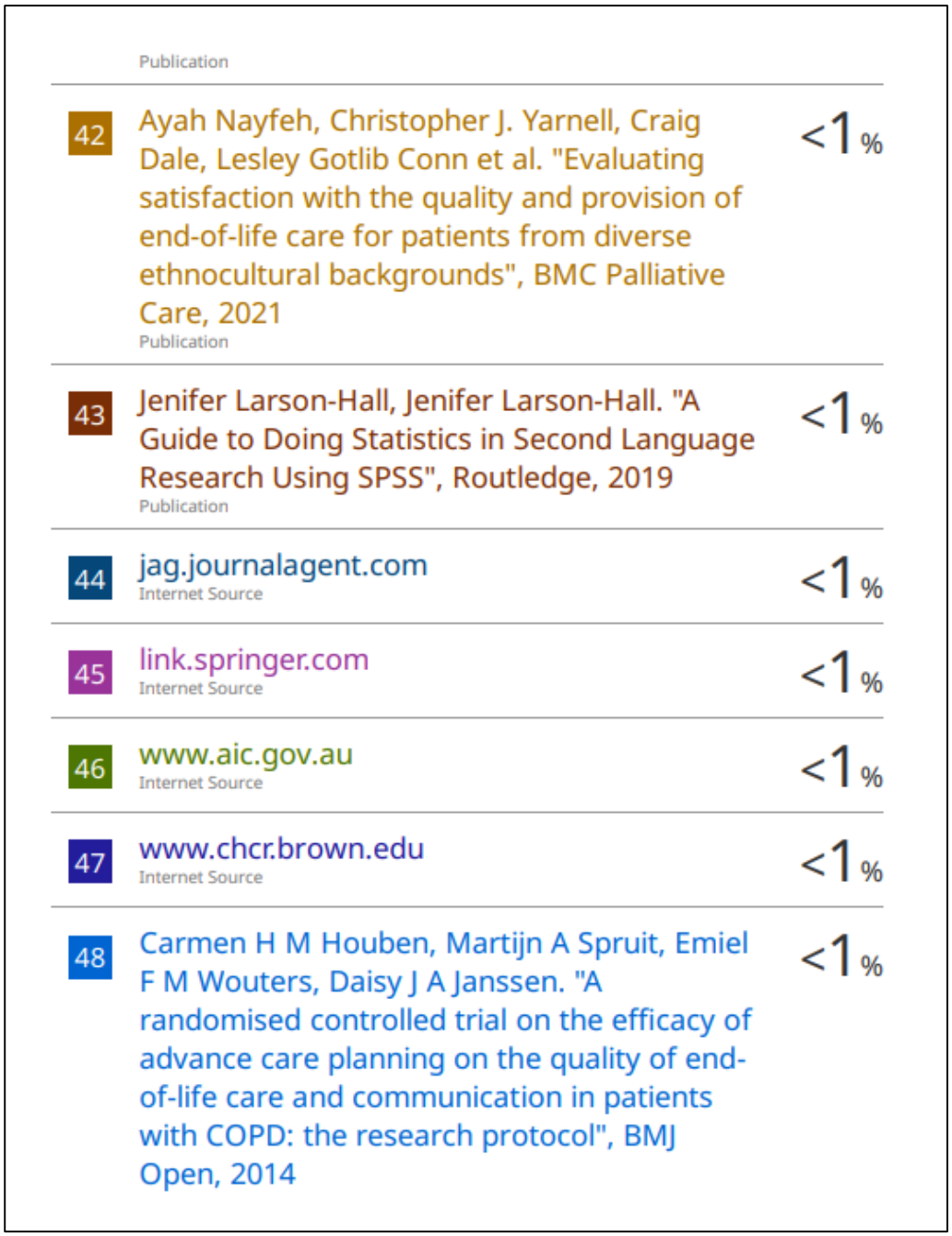

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