AN EXPLORATION OF PALLIATIVE CARE SERVICES IN TWO PALLIATIVE CARE FACILITIES IN INDONESIA: AN ETHNOGRAPHIC STUDY

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Abstract

Background

Patients at end of life and their families have complex needs that require comprehensive care. Along with pain and physical symptoms, psychological, social and spiritual needs have been identified in the literature. Historically palliative care services have been developed for some time in well-resourced countries, the development of these services particularly in low resource countries has been more recent and as result may be less developed. In Indonesia, formal palliative care services have been established since the 1990s to provide care for patients and families mainly with cancer. As models of palliative care were first developed in well-resourced western countries there is a need to explore if the ongoing growth of palliative care in the developing countries, such as in Indonesia, is culturally appropriate.

This study sought to explore the current provision of palliative care for cancer patients to describe, understand, provide insight and explore the implications for provision of culturally appropriate palliative care services. The central research question guiding this study was ‘What is the current practice of palliative care services in two facilities in Indonesia?’

Methodology and methods

Contemporary ethnography based on interpretive and post-positive paradigm was adopted to undertake this study incorporating multiple methods of data collection and analysis. Observations was conducted in the hospital-based palliative care; interviews and collection of relevant documents were undertaken in both facilities; a survey questionnaire explored the perceptions and satisfaction of patient’s relatives.

Findings and discussions

Multiple methods of data collection with palliative care staff, palliative care patients and their relatives gave in-depth insight into the phenomena under investigation. The culture of palliative care provision was described as having many challenges relating to the patient’s complex needs while maintaining his/her dignity. Some of interventions offered or employed by the palliative care team may be viewed as being unnecessary or even aggressive care for patients at end of life. The patients were primarily being cared for in their own home. As a result the family played significant role in providing care for the patients. The cultural context also suggested that local community support was an additional important feature in the palliative care provision.

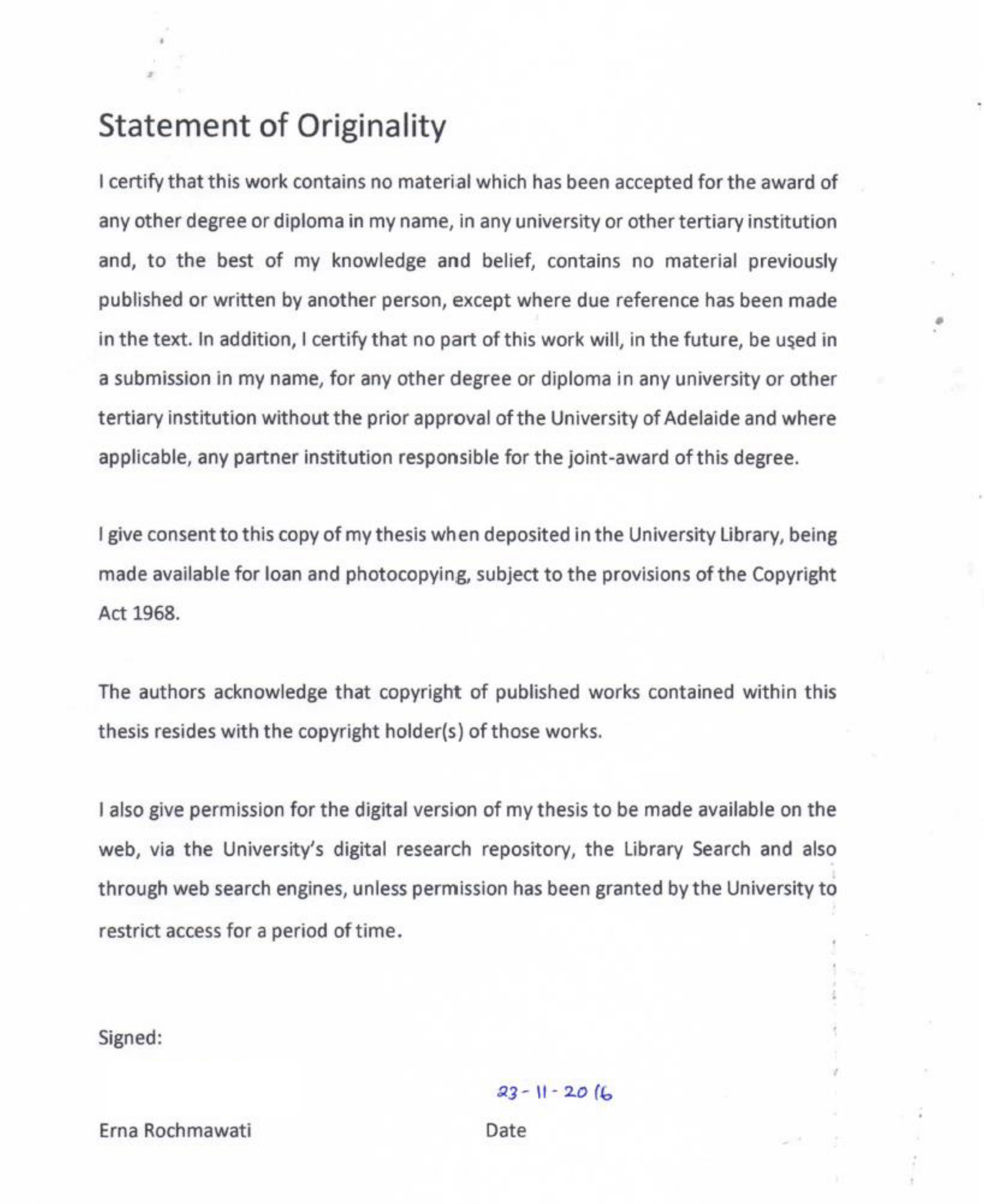
Spirituality/religiosity was identified as central to daily life for the patients, the family and the palliative care staff in this study and became a significant element in the palliative care provision. This study showed that all the cultural actors (the palliative care team, the patients and the relatives) were affiliated to particular religions and performed their religious practices in their daily life. It was also observed that the patient’s relatives in this study commonly acknowledged and addressed the patient’s needs for spiritual care. The palliative care staff provided support for spiritual care of the patients (e.g. religious/spiritual discussion, conducting prayers together). In return the patients and relatives supported the health professionals to perform worship in their home.

A particular cultural issue emerged in this study around discussions about end of life. Discussions between the palliative care team and the patient’s relatives were overt and frank. However, discussions about impending death between the palliative care team and the patients, where often oblique at best or even not discussed.

Conclusion

This study has provided a more comprehensive understanding of the cultural aspects of palliative care provision in two facilities in Indonesia. Challenges identified in the care provision included late referral, interventions employed by the palliative care team that might be perceived as unnecessary care and the complexity of care. Supporting factors included family and community involvement and spirituality has a significant role in the provision of palliative care.

Statement of Originality



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Dissemination of findings has been undertaken throughout the course of my PhD journey and will be continuing in the future. One paper has been published in a peer-reviewed journal and several conferences and seminar were presented:

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Conferences:

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Chapter 1: Introduction and Thesis Overview

Background

Cancer is a major global health issue and the leading cause of death in the world. The International Agency for Research on Cancer (IARC) (2012) reports there were approximately 14 million new cases of cancer worldwide in 2012. Cancer is also prevalent in Indonesia where there were 299,700 new cases of cancer in Indonesia, with 194,500 deaths in 2012 (International Agency on Research on Cancer 2012). Most cancer patients present to health care providers at the late stage of the disease (Soebadi & Tejawinata 1996). This was supported by one study conducted at several Primary Health Care Centers in one Indonesian province that found 80% of newly diagnosed cancer patients presented in advanced stages (Fles et al. 2010).

Various studies have reported impacts of advanced cancer on the individual, including the high prevalence of pain (van den Beuken-van Everdingen et al. 2007; Yamagishi et al. 2012), fatigue, weakness, and appetite loss (Abu-Saad Huijer & Abboud 2012; Halawi et al. 2012; Teunissen et al. 2007a). In addition, patients with advanced cancer experience depression and anxiety (Hotopf et al. 2002; Solano, Gomes & Higginson 2006; Wilson et al. 2007), and loss of faith and despair (Byrne 2002). Given the broad negative impacts on the patients' lives from cancer, palliative care was first introduced intending to improve the quality of life for these patients (Clark 2007). The global increasing number of cancer and other life-limiting illnesses have increased the demand for palliative care services worldwide. Using the prevalence of pain as an indicator of palliative care need at end-of-life, the World Hospice and Palliative Care Alliance (WHPCA) (2014) estimated that over 19 million of adults were in need of end-of-life palliative care worldwide, with 34% of them being cancer patients. Furthermore, the WHPCA (2014) report that 78% of these adults in need of palliative care lived in low- and middle-income countries. In Southeast Asian countries, including Indonesia, the need for palliative care among adults was 234 - 353 per 100,000 population, with 69 - 145 per 100,000 population being adults with cancer (World Hospice and Palliative Care Alliance 2014). With these large numbers of patients needing support it is imperative that palliative care services are developed within health care systems. The development and provision of palliative care services can be problematic, however, because of the varied availability of resources, and the complexity and breadth of patients' and family's needs.

An early model of palliative care service was first started in a hospice in England in the late 1960s, providing end-of-life care for patients with advanced malignancies (Clark 2007; Coyle 2010). Since then, palliative care services have been developed in other countries worldwide and extended to other life-limiting illness, although the services have often been closely related to oncology (Clark 2007). Palliative care services have developed in many settings and include models that are hospital-based, home-based care, and those operating in community settings and nursing homes. Such development has mostly occurred in developed countries. Given that palliative care has been developed primarily within well-resourced countries, there is a need to explore if the ongoing growth of palliative care in developing countries is culturally appropriate.

The provision of palliative care service in developing countries began during the 1980s-1990s (Downing, Powell & Mwangi-Powell 2010; Komurcu 2011; Soebadi & Tejawinata 1996). Several studies of the development of palliative care in developing countries have been conducted in Malaysia, India, Indonesia, South Africa, Uganda, Pakistan and Turkey. There has been considerable variability shown in terms of the level of palliative care development in these countries. For example, in Malaysia, South Africa and Uganda, palliative care activities have been developed in a wide range of locations with a variety of palliative care providers and types of services. In contrast, in countries such as Indonesia, Pakistan and Turkey, the services were still localised or only available in few locations, and had limited numbers of available palliative care services (Lynch, Connor & Clark 2013).

In Indonesia, the development of formal palliative care commenced in the 1990s as part of the National Cancer Control program (Al-Shahri 2002). During its development, the provision of palliative care has been extended to other life-limiting illness, but most available palliative care facilities are designated for patients with cancer (Ernawati 2012; Saleh, Danantosa & Kusumawardhani 2008; Soebadi & Tejawinata 1996). Thus, this study focused on formal palliative care provision for cancer patients.

Although palliative care first commenced in Indonesia over three decades ago, it was not until 2007 that the specific national regulation on palliative care '*Keputusan Menteri Kesehatan tentang Kebiijakan Perawatan Paliatif* no 812/Menkes/SK/VII/ (Ministry of Health Regulation on Palliative Care no 812/Menkes/SK/VII)' was issued (Ministry of Health 2007). The regulation was issued in recognition of the growing incidence of cancer and other terminal diseases, the burden of symptoms experienced by the patients, limited availability of palliative care facilities and limited palliative care trained physicians. The regulation aimed to encourage the development of palliative care and to improve the quantity and quality of palliative care services. Following the issued regulation, in 2013 a technical guideline for palliative care for cancer was developed (Ministry of Health 2013). Over the last two decades, however, the development of palliative care has been rather slow. Findings from data collected in 2011 show that the indicative ratio of palliative care service to population in Indonesia was 1:22,996,000; only ten palliative care organisations and service providers were available across Indonesia (Lynch, Connor & Clark 2013). These palliative care organisations and service providers are subsequently referred to as formal palliative care in this study.

Since most palliative care models and services were first developed in well-resourced countries, it is important to explore the practice and identify elements and cultural aspects which influence the provision of palliative care in developing countries. This is essential for further development of palliative care services in these countries. There have been a number of studies that have identified issues related to facilitators and barriers in the development and provision of palliative care. Most of these studies have reported issues from the health professionals' perspectives, and have focused mainly on barriers. Internal factors such as problems with communication and insufficient education are recognised as barriers in the provision of palliative care (Ahmed et al. 2004; Dalgaard, Thorsell & Delmar 2010; Goepp et al. 2008; Groot et al. 2005b; Johnson et al. 2011; Lynch et al. 2010; Miyashita et al. 2007). While most studies reported challenges within Western countries, there have been a small number of studies from Eastern/Asian countries, including from China (Li, Davis & Gamier 2011), Malaysia (Devi, Tang & Corbex 2008), India (Shanmugasundaram, Chapman & O'Connor 2006), and Indonesia (Effendy et al. 2015; Soebadi & Tejawinata 1996; Witjaksono, Sutandiyo & Suardi 2014). These studies identified that lack of trained staff, limited availability and access to opioids, limited availability of palliative care service, lack of resources, financial problems and limited government support are challenging factors for palliative care development in developing countries. In most developing countries, there is also limited availability of staff trained in palliative care due to inadequate education and lack of integration of palliative care into medical and health sciences curriculum (Shad, Ashraf & Hafeez 2011; Witjaksono, Sutandiyo & Suardi 2014). The availability of opioids, particularly morphine, also remains a problem in resource-poor countries. A number of studies have identified this limited access to and supply of morphine and presence of opioidphobia or reluctance to use opioids (Komurcu 2011; Shad, Ashraf & Hafeez 2011; Witjaksono, Sutandiyo & Suardi 2014).

A review by Rochmawati, Wiechula and Cameron (2016) identified a number of studies regarding palliative care in Indonesia. Most studies focused on describing the development of palliative care, but none explored the provision of palliative care services or cultural aspects associated with palliative care provision. As such, a gap exists in Indonesian literature. In consideration of this deficit, this study aimed to describe and understand the palliative care provision in Indonesia by exploring the current practice and cultural aspects in provision of care. In addition, due to the high incidence of cancer in Indonesia, the number of adults with palliative care needs, the limited availability of formal palliative care service providers and most of the service provision relates to cancer care, this study focused on the provision of palliative care for cancer patients.

Purpose of the study

This study aimed to understand and describe the current provision of formal palliative care for cancer patients in Indonesia. It explored how care is provided within the specific settings of palliative care services. The perspectives of health care professionals, patients and their relatives in care provision were investigated to describe and understand the provision of care. Moreover, cultural aspects that influence the care provision were also explored. An understanding of palliative care provision and its cultural elements in the specific context may provide insights of the provision to palliative care that are culturally appropriate.

The overall research question was: What is the current practice of palliative care services in two facilities in Indonesia?

To address this overall research question, a set of research objectives were formulated:

1. To explore palliative care practice and delivery for cancer patients in two palliative care services.
2. To explore views and experiences of patients and their families about the provision of formal palliative care.
3. To identify cultural elements that influence the provision of formal palliative care in Indonesia.

Research approach

The previous section has described that palliative care service was first developed in well-resourced countries. From these beginnings the model of care delivery then developed and expanded, mostly throughout other well-resourced and high-income countries. Considering this, it was important to therefore explore the ongoing growth of palliative care in the developing world and gain understanding of the role of culture in the provision of care, to see if such models of care are culturally appropriate. To gain this understanding, it was appropriate to employ an ethnographic approach to examine this phenomenon. In recent years, ethnography has been adapted and reinterpreted to meet research needs that are different in term of aims, scope, resources and time. This development has been described as contemporary ethnography (de Laine 1997; Picken 2009; Speziale & Carpenter 2007).

Contemporary ethnography was typically conducted in small elements of society, where it was used to capture a specific topic, in relatively shorter-term field visits (Knoblauch 2005). The ability of contemporary ethnography to capture data on specific topics of importance to researchers makes this genre suitable for health research (Cruz & Higginbottom 2013; Higginbottom, Pillay & Boadu 2013). The shorter period in the cultural setting is possible because researchers can have prior knowledge of the culture, such as the language and etiquette of groups. In addition, the shorter period in the cultural sites is typically compensated for by the intensive use of audiovisual technologies of data collection and data analysis (Knoblauch 2005). Contemporary ethnographic approaches allow the researcher to use both qualitative and quantitative methods to establish validity and provide rich understanding about the cultural groups being examined (Bernard 2006; Fetterman 2010; Savage 2006).

This study adopted contemporary ethnography due to its the ability to capture specific issues within a given context; in this study it was the provision of care and cultural elements that influence palliative care services in two facilities in Indonesia. Based on the tenets of contemporary ethnography, this study involved field observations, questionnaires, informal discussions, interviews and collection of relevant documents to enable understanding of the studied cultural groups. It should be noted that ethnographic study aims to provide descriptions and interpretations of a cultural or social group. When using this approach an ethnographer should observe, understand and report rather than judge behaviours, values and interactions of cultural groups studied.

Significance of the study

This ethnographic study is the first to explore the provision of formal palliative care for cancer patients in Indonesian palliative care facilities, and to identify cultural elements that impact on the provision of such care. Accordingly, it will contribute to knowledge in a number of ways, primarily by providing insights that can inform the palliative care practices. Finally, this study will provide a sound basis for conducting further research into care in Indonesian palliative care facilities. It is hoped that the provision of palliative care service in Indonesia will be advanced as a result of this study.

Definition of terms

Palliative care

The World Health Organization (2010, p. 1) has defined palliative care as:

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

In this study, due to the high incidence of cancer in Indonesia and because most of available formal palliative care services are closely related to cancer patients, this study focused on the provision of formal palliative care for cancer patients and their families. This study also focused on the care that was provided by health care professionals with expertise in palliative care.

Hospice

According to the National Hospice and Palliative Care Organization (*Hospice Care* 2016), hospice care is a program which focus on caring for patients with life-limiting illness that can be provided at the patient's home, nursing homes, and other long term care facilities.

Community based palliative care

Community based palliative care is a model of care designed to meet the needs of seriously ill individuals and their families outside the hospital setting (Meyer, Kerr & Cassel 2014). Community based palliative care is a suggested model for the provision of palliative care service in the limited resource countries (World Health Organization 2014).

Hospital based palliative care

The concept of hospital based palliative care is palliative care services which are provided in the hospital setting to improve physical, psychological and spiritual sufferings of patients and families with life-limiting illness. The service may include palliative care consultation service, dedicated palliative care unit or wards and primary palliative care service (Meier & McCormick 2016).

Spirituality/religion

Religion is a system of practices and beliefs that are designed to facilitate closeness to the sacred being (i.e. God, higher power) (Candy et al. 2012). Spirituality refers to a connection with a larger reality that gives one's life meaning, and is experienced through a religious practices or other paths (Peteet & Balboni 2013). Although, there has been growing separation of the concepts of spirituality and religion (Edwards et al. 2010), they are, however, often interrelated and used interchangeably. Spirituality/religion in this study can be defined as practices and rituals to facilitate closeness to the transcendent, which can be in the form of religious-based practices or other paths (e.g. meditation).

Family caregiving

Family caregiving is a crucial element in palliative care. Family caregivers are defined as family members, friends and other people who have significant relationships with a patient and provide care for her/him during the illness period and at end-of-life (Woodman, Baillie & Sivell 2015).

Culture

The concept of culture in this study refers to a set of behaviours, attitudes, knowledge, beliefs and ideas that people use to shape their ways of living or actions they choose to make (de Laine 1997; Schensul & LeCompte 2013; Spradley

1980). In a cultural group, however, there may be people who do not believe in the same things or act in the same way as other members. This is because people’s beliefs, attitudes and behaviours vary depending on ethnicity, gender, educational levels and age.

Structure of the thesis

The following describes the chapters within this thesis. It should be noted that this is an ethnographic study and therefore, there are no conventional results and discussion chapters presented. These elements will be addressed in three chapters (chapters 6-8). Chapter 6 provides descriptions of actors and the space of the cultural group. The descriptions of applying a cultural lens to palliative care services using vignettes to explore a range of cultural themes are provided in Chapter 7. Chapter 8 provides interpretations of these cultural themes to give meanings of the participants’ experiences during the final phase of life’s journey.

Chapter One: **Introduction and Thesis Overview.** This chapter introduces the research and provides the background, purpose, research questions, and significance of this study. This chapter also provides an overview of the thesis.

Chapter Two: **Literature Review**. This chapter presents the literature review, which begins with discussion about palliative care, its past and current global development. Discussions on a holistic approach on symptoms control, models of palliative care delivery and elements in palliative care service are also provided in this chapter. This will provide a broad perspective on the understanding of palliative care services and aspects of the service in general.

Chapter Three: **Current Progress of Palliative Care in Indonesia – An Integrative Review**. This chapter will present findings from an integrative review of palliative care in Indonesia that includes the history of palliative care development, and facilitators and challenges in palliative care provision. This integrative review implied the need to explore cultural factors that influence the provision of palliative care. The integrated review provides understanding of current progress of palliative care development in Indonesia which will then be the basis for justification of this research.

Chapter Four: **Methodology.** This chapter describes the study methodology. The chapter begins with the research framework and philosophical principles underpinning this study. The chapter then focuses on ethnography, where similarities and differences between classical and contemporary ethnography are highlighted. In this chapter, a discussion of issues in translation and language is provided because all types of data (including observations, interviews and survey) were collected and transcribed in Bahasa Indonesia (the national language) but the analysis was conducted in English. This chapter will also consider strategies to promote the rigour and trustworthiness of the research methodology.

Chapter Five: **Research Methods**. This chapter concentrates on the study design, including the settings and participant selections. A recruitment process and difficulties in gaining access, particularly with patients, will be discussed. The main data collection techniques such as field observations, survey, interviews and analysis of related documents are elaborated. Following this, the process of translation of transcripts and the questionnaire are scrutinised. Detailed description of data analysis, which incorporated approaches from Spradley (1980) and LeCompte and Schensul (2013) are be provided in this chapter.

Chapter Six: **The Place and the People.** This chapter presents the findings of the study. Detailed descriptions of the actors and the space in which they lived within the two study settings are provided.

Chapter Seven: **The Practice**. This chapter takes the cultural lenses to the palliative care service using vignettes to explore a range of cultural themes. Identified cultural domains are: '*the provision of care: meeting many challenges*', '*building* *relationships', 'family caregiving', 'spirituality/religious care',* and *'dealing with dying and death'*.

Chapter Eight: **Interpretation**. This chapter provides interpretations of the findings. The cultural themes were interpreted to give meaning to the experiences of the participants during the final phase of life's journey. The chapter also focuses on discussions of palliative care as a journey, which was divided into the three major sections: '*stepping into the journey', 'in the middle of the journey' and 'nearing the end points'*.

Chapter Nine: **Implications and Conclusions**. This last chapter summarises the major findings of the study and their significance. This is followed by identification of the strengths and limitations of the study. This chapter also provides implications for future practice, education and research.

Summary

Palliative care service was first established in England in the late 1960s to provide end-of-life care for patients with advanced malignancies. The services have been developed mostly in well-resourced countries and have been closely related to care for those suffering from cancer (Clark 2007). In Indonesia, formal palliative care services have been established since the 1990s to provide care for patients and families with cancer. As palliative care was first developed in well-resourced countries there is a need to explore if the ongoing growth of palliative care in the developing countries, such as in Indonesia, is culturally appropriate. This study seeks to explore the current provision of palliative care for cancer patients to understand, describe, provide insight and explore the implications for provisions of culturally appropriate palliative care. In the next two chapters, a critical review of the literature, including a conventional literature review and an integrative review is undertaken to compare the findings from previous studies. In Chapter 2, a conventional literature review of palliative care service in general is presented.

Chapter 3 provides an integrative review of palliative care in Indonesia to provide understandings and to identify gaps in the knowledge pertinent to formal palliative care services in Indonesia.

Chapter 2: Literature Review

Introduction

In this chapter, an overview of palliative care service and its elements will be evaluated and elaborated. A comprehensive discussion of palliative care is provided by reviewing available international literature. The chapter begins with an overview of palliative care service and is described in the following sections by moving from a broad to specific perspective. Palliative care service is first broadly presented including the need and the development of palliative care. Secondly, the needs of palliative care are outlined, and lastly models of palliative care delivery are presented. The second part of the chapter describes specific cultural domains in palliative care including family caregiving, communication, spirituality/religion and dying and death.

Development of palliative care services

Historically, the development of palliative care services was embodied within the modern hospice movement, where palliative care services were first offered to dying people in the hospice (Buckley 2009). Dame Cicely Saunders is recognised for her important contributions to the early development of palliative care services. She was involved in the hospice movement in providing pain relief, spiritual care, and psychosocial needs to dying patients (Buckley 2009).

The modern hospice movement that started in 1967 in England began as an early model of palliative care delivery (Coyle 2010). Since then, services have developed and expanded over the years to include other settings such as hospitals, home-based care, community settings and nursing homes. Moreover, in 1987 palliative care was recognised as an area of medical specialty (Milligan & Potts 2009).

The increasing number of new cancer cases has raised the global awareness of palliative care (Coyle 2010). This is reflected in the growing number of palliative care services over 40 years, not only in the United Kingdom but also in other parts of the world. In a recent review to measure palliative care development in all countries of the world, Lynch, Connor and Clark (2013) use six categories – four main categories and two additional sub categories – to designate different levels of palliative care development. The categories are: level 1 – no known hospice or palliative care activity, level 2 – capacity building, level 3a – isolated provision, level 3b – generalised provision, level 4a – preliminary integration, and level 4b – advanced integration.

Using these categories, Lynch, Connor and Clark (2013) identified that 136 of 234 countries have one or more hospice or palliative care services, which was an increase from 21 countries in 2008 as reported by Wright et al. (2008b). In addition, the number of countries in which palliative care was not known also reduced from 78 countries in 2008 (Wright et al. 2008b) to 75 countries in 2013 (Lynch, Connor & Clark 2013). The unavailability of palliative care services and lack of integration into main health care systems, particularly in resource-poor countries has been due to several barriers. A number of studies have identified these barriers, to include; lack of multidisciplinary teams, lack of champions, lack of resources, financial problems, no government support, few hospices and trained nurses, increasing numbers of patients, no specialised care teams and poor access to opioids (Callaway et al. 2007; Coyle 2010; Edens, Harvey & Gilden 2008).

The current need for palliative care

Palliative care is a global issue as the need for this service is growing due to an increase in cancer and other non-communicable diseases, and the world's ageing population. Globally, there were approximately 54.6 million deaths in 2011, and 66% of these are due to non-communicable diseases (Department of Health Statistics and Information Systems 2014). While not all death requires palliative care, a report from the World Hospice and Palliative Care Alliance (2014) indicates that the estimated number of people requiring palliative care at their end of life worldwide was 20.4 million. The majority were adults (94%) and there was a slight predominance of males (World Hospice and Palliative Care Alliance 2014). In addition, most palliation needs were due to cardiovascular, cancer and chronic respiratory disease. In addition, this report identified that the majority (78%) of adults in need of palliative care at the end of life lived in low and middle-income countries.

Models of palliative care delivery

It is now appropriate to review models of palliative care delivery. Palliative care services are developed and delivered variably throughout all regions in the world due to different cultural, social and political contexts. Among the various models are hospital-based, community-based and home-based approaches for care. The following section provides discussions on these models.

Hospital-based palliative care

The ever-increasing number of patients with cancer and other life-limiting illness has led to an escalating demand for palliative care services in hospitals. Towns et al. (2012) argue although patients with palliation needs prefer to be cared for and die at home, the demand for hospital-based palliative care remains high. Such increases are likely due to unstable symptoms, lack of ability of family members to provide care, or deteriorating conditions (Champion, Medigovich & Morrison 2015).

A number of studies have identified services that offer hospital-based palliative care including consultation services with regard to pain and symptom management, palliation procedures (i.e. palliative radiation), home care support and the use of life-sustaining treatment (Babcock & Robinson 2011; Glass & Burgess 2011; Weissman & Meier 2011). The provision of palliative care in hospital has generally improved the patients' conditions. Previous studies have indicated that hospital-based palliative care can improve a patient's physical symptoms (i.e. fatigue, dry mouth, edema), and also provide psychological and social support (Chi-Yin et al. 2014; Groot et al. 2005a). Groot et al. (2005a) reported that hospital-based palliative care teams can be helpful in managing cancer patients' physical discomfort and provide psychological and social support.

Conversely, hospital-based palliative care has several limitations and barriers with many studies conducted in Western countries reporting this concern. For instance, Kamal et al. (2011) used a survey approach with 4980 patients in North Carolina, United States, and reported that hospital-based palliative care was often poorly structured to support patients' complex needs and severe symptoms. Another study conducted by Hall et al. (2014) in hospitals in New York, used key informants' interviews and found similar results. Another barrier associated with hospital-based care is a lack of knowledge of palliative care among health care professionals, patients and families (Gibbs et al. 2015; Glass & Burgess 2011; Hall et al. 2014). Lack of palliative care knowledge among physicians may lead them to focus on curative treatment and, as a result, a more aggressive treatment being provided to the palliative care patients (Miller, Lima & Thompson 2015).

Community-based and home-based palliative care

The number of patients who prefer to be cared for at home during their end of life is increasing (Arnaert & Wainwright 2009; Storey, O'Donnell & Howard 2002). The development of community-based and home-based palliative care can be initiated through improving knowledge and skills among health care professionals and training volunteers from the community (Storey, O'Donnell & Howard 2002). Building on this knowledge, activities such as simplifying referral, facilitating access to medication, and more broadly providing political support and funds, and increasing public awareness can be implemented (Devi, Tang & Corbex 2008).

A number of studies have identified several factors that influence the delivery of quality palliative care in the community and at home. These factors include health professionals' competence, experiences and skills and multidisciplinary involvement (Allen et al. 2012; Groot et al. 2005c; Kamal et al. 2011). Community-based and home-based palliative care models have advantages when compared to the hospital-based model. Bosanquet (2002) reviewed existing palliative care literature from Western countries to find the most cost-effective model of palliative care service delivery. The findings indicated that home-based care cost less, and was associated with the increase of family's satisfaction. A study in India indicated that all patients receiving specialist home care showed improvements in physical symptoms and the majority of family caregivers had good bereavement outcomes (Dhiliwal & Muckaden 2015).

The World Health Organization (2014) has suggested that community and home-based care is a success factor in the palliative care service provided in limited-resource countries. Several developing countries have implemented these models, for example, in the Indian district of Kerala a community-based palliative care service has been successfully implemented (Clark & Graham 2011; Sallnow, Kumar & Numpeli 2010). The home care services are linked to outpatient treatment and provided free of charge to patients in need (Shanmugasundaram, Chapman & O'Connor 2006). In addition, the services collaborated with trained volunteers to assist family members in the delivery of care that was sustainable and continuous (Sallnow, Kumar & Numpeli 2010; Shanmugasundaram, Chapman & O'Connor 2006). Clark and Graham (2011) argue that these models were both sustainable and affordable and had potential for replication in other developing countries.

Care needs of patients with life-limiting illness

Palliative care aims to provide holistic care for patients with life-limiting illness, including cancer. Palliative care patients invariably have complex needs that encompass physical, psychosocial, and spiritual needs. Detailed discussions of these needs and their management are provided in the following sections.

Control of physical symptoms

Several physical symptoms are commonly reported by palliative care patients including: pain, fatigue, lack of energy, weakness, nausea, and appetite loss (Abu-Saad Huijer & Abboud 2012; Halawi et al. 2012). Pain, appetite loss, and fatigue are experienced by more than half of patients with incurable cancer (Teunissen et al. 2007a). Pain and fatigue can be caused by the cancer itself or adverse reactions to its treatment. Approximately 60% of cancer patients experience pain, with 20 - 30% reporting moderate and severe levels of pain (van den Beuken-van Everdingen et al. 2007; Yamagishi et al. 2012).

The World Health Organization developed an analgesic ladder to treat cancer pain consisting of several steps, starting with the use of non-opioids, then from weak opioids to strong opioids (Vargas-Schaffer 2010). Despite the recommendations of this analgesic ladder, however, almost half of the patients with cancer who experience pain do not receive adequate pain treatment (Deandrea et al. 2008). It is also evident that inadequate pain management is a particular issue in low-resourced countries (Dehghan et al. 2010; Soebadi & Tejawinata 1996). Effendy et al.'s (2014a) study of five major hospitals in Indonesia supported this position as they found that more than of half patients had unmet pain needs. This situation was often the result of limited availability and use of morphine (Dehghan et al. 2010; Soebadi & Tejawinata 1996). Inadequate pain and fatigue management may negatively affect a patients' physical, psychological and social functioning (Hofman et al. 2007). Evidence shows that interventions such as education, counselling, and communication can have positive impacts on perceived fatigue and pain (Hofman et al. 2007; Reif et al. 2012; Tse et al. 2012).

Fatigue is another of the most common physical symptoms reported by patients with advanced cancer (Oechsle et al. 2013b; Peters et al. 2016; Ryan et al. 2013). It can be caused by the disease process, metabolic disturbances and also as a result of cancer treatments (Morgan 2010). It is important to manage fatigue because uncontrolled fatigue can adversely affect a patient's quality of life (Tsai et al. 2012). Several interventions that potentially can improve a patient's fatigue have been identified in the literature. Findings from a systematic review of pharmacological treatment for fatigue associated with palliative care showed that amantadine had shown benefit for patients with fatigue (Mücke et al. 2016). Furthermore, the researchers suggested further trials for other medicines such as dexamethasone, methylprednisolone and armodafinil. Kraft (2012) report that the use of complementary and alternative medicine (CAM) such as acupuncture and the use of natural products also had positive effects on fatigue. Other studies have reported that education on fatigue assessment and management (i.e. energy conservation) had beneficial outcomes for patient's fatigue (Borneman et al. 2011; Morgan 2010).

Other physical symptoms that are commonly reported by palliative care patients are appetite loss and nausea (Al-Shahri, Eldali & Al-Zahrani 2012; Gestsdottir et al. 2015; Halawi et al. 2012). Lack of control of these symptoms can lead to dehydration and electrolyte imbalance, poor oral intake and poor quality of life (Kelly & Ward 2013). Several studies have reported that non-pharmacological strategies and anti-emetics are the main therapeutic options for these symptoms. Non-pharmacological strategies such as acupuncture and modification of meal size and frequency have been associated with a reduced intensity of nausea (Nystrom, Ridderstrom & Leffler 2008; Timothy et al. 2014). The most common anti-emetics which are used in managing a patient's nausea are metoclopramide and haloperidol (Timothy et al. 2014). A systematic review of the use of haloperidol in palliative care settings found that haloperidol was effective in managing a patient's nausea (Murray-Brown & Dorman 2015).

As palliative care patients are closer to their end of life, their symptom burdens often increase. They often receive active symptom management at their end of life that aims to improve their symptoms (Teno et al. 2013). The level and nature of interventions at the end of life cancer care are demonstrated by the use of anti-cancer treatments and antibiotics, the use of ventilation and resuscitation, Intensive Care Unit admission, multiple rehospitalisation, and multiple Emergency Department visits in the final weeks of life (Chen, Chen & Tang 2013). Such interventions are identified as indicator of aggressive care. Studies have found that this type of active intervention or aggressive care has been linked with negative impacts, such as worsening quality of life for the patient, worse bereavement adjustment for their caregivers (Wright et al. 2008a) and lower levels of family satisfaction (Wright et al. 2016). Another disadvantage of aggressive care was the higher cost of treatments (Cheung et al. 2015). Despite these negative impacts, patients from minority backgrounds, living in rural regions and having lower economic status were more likely to be receiving aggressive care at their end of life (Chun-Ming et al. 2014; Ho et al. 2011; Johnson et al. 2013).

In contrast, several studies have suggested that palliative care services and increasing knowledge about dying phases were associated with less aggressive care at end of life. Veerbeek et al. (2008) indicate that recognising dying phases was also associated with an improvement in comfort care and a reduction of diagnostic tests (i.e. lab tests, radiology tests). A study conducted by Miller, Lima and Thompson (2015) identified that higher palliative care knowledge was associated with less use of feeding tubes, restraints, injections and end of life hospitalisation. Furthermore, Jang et al. (2015) found that palliative care consultation was associated with reduced opportunities to receive chemotherapy, Intensive Care Unit admission, multiple Emergency Department visits and multiple hospitalisation near death. While these studies were from developed countries, such studies from less-developed countries have not yet been identified.

Addressing psychosocial needs

In addition to physical needs, palliative care patients often have non-physical concerns such psychosocial needs that require support from health care professionals and families.

Depression and anxiety disorders are frequently experienced by patients with advanced cancer who are receiving palliative care (Wilson et al. 2007). A number of studies highlight that depression requires more attention by health care professionals in palliative care settings due to its prevalence (Hotopf et al. 2002), its impact on a patient’s quality of life, and physical and social functioning (Teunissen et al. 2007b). It should also be noted, however, that depression is often unrecognised, undertreated and therefore becomes an unmet need (Hallford et al. 2012; Irving & Lloyd-Williams 2010). This has been attributed to a lack of knowledge in identifying depression, and limited communication skills among health professionals caring for palliative care patients (Hallford et al. 2011; McCabe et al. 2012). To better manage depression, comprehensive guidelines were developed by European palliative care experts (Rayner et al. 2011) and the American College of Physicians (Qaseem et al. 2008). The clinical guidelines include using effective communication, screening and assessing depression severity, and providing psychological therapy and antidepressant medication.

Warmenhoven et al. (2012) explored family physicians' opinions in addressing depression in palliative care patients. They found that the family physicians more often used open communication rather than prescribing antidepressant in managing a patient's depression (Warmenhoven et al. 2012). Another intervention to manage depression is psychological therapy such as dignity therapy and discussion of life completion. A repertoire of approaches to conserve dignity of the patient with palliative care has been developed in Chochinov's (2006) dignity model that includes maintaining normalcy, resilience and providing spiritual comfort. Juliao et al. (2013) reported that dignity therapy (i.e. promoting a patient's sense of meaning and worth) was found to have beneficial effects for palliative care patients. Steinhauser et al. (2009) identified that discussion of life completion (i.e. values, accomplishment) could improve a patients' health outcomes at their end of life.

Anxiety is another common psychological symptom among palliative care patients and is experienced by approximately 3 - 79% of cancer patients (Solano, Gomes & Higginson 2006). Roth and Massie (2007) identified that anxiety can be caused by insufficient pain management, untreated symptoms and can be drug induced. Available effective anxiety management includes use of psychotherapy, behavioural therapy, pharmacological management and complementary therapy (Roth & Massie 2007). For example, Kraft (2012) reviewed complementary therapies for symptom management in palliative care and found that anxiety can be effectively managed by yoga, music therapy, acupuncture and aromatherapy.

All definitions of palliative care from several organisations have emphasised a need for comprehensive care including social supports for patients and their families (European Association for Palliative Care Research 2016; Palliative Care Australia 2005; World Health Organization 2010). Social support refers to any services being provided to patients and their family caregivers including information, emotional, financial, companionship, self-esteem support and assistance with tasks (Chida & Vedhara 2009; Stoltz, Uden & Willman 2004). Such support can also be provided by professionals (Cadell et al. 2010; Lundberg, Olsson & Fürst 2013), family and community (Sallnow, Kumar & Numpeli 2010). Studies have demonstrated that patients also considered social support was important for them (Borneman et al. 2015). It was reflected that social support is one of the education topics selected by most palliative care patients (Borneman et al. 2015). A number of studies have identified positive outcomes from social support that include having positive health perceptions, minimising hospital admission and improving family caregiver's resilience (Lundberg, Olsson & Furst 2013; Stoltz, Uden & Willman 2004; Zabalegui et al. 2013).

Addressing spiritual and religious needs

Another concern among palliative care patients is the need for religious/spiritual care. Spiritual wellbeing is an important aspect of a patient's quality of life with Kandasamy, Chaturvedi and Desai (2011) suggesting that a patient's religion/spirituality should be adequately and appropriately addressed in palliative care settings.

Spirituality, which is defined as a search for meaning in life can be affected during a crisis such as a palliative condition (Delgado-Guay et al. 2011). During the period of terminal illness, particularly at the final stages of the diseases, spiritual issues may arise. Previous studies have identified issues to include anger at God, feelings of isolation from God, community or others (Puchalski et al. 2009), loss of faith and despair (Byrne 2002), difficulties in accepting the disease and difficulties in being available for others (Effendy et al. 2014a). Furthermore, Gomez-Castillo et al. (2015) highlighted that spiritual distress led to a lower quality of life and higher rates of morbidity.

As a patient’s religion/spirituality is likely to be affected in palliative conditions, health care professionals should have an awareness of their patients’ religion/spiritual needs. This can be implemented by integrating spiritual assessment (Amoah 2011), maintaining relationships, and helping patients and families identify meaning (Penman, Oliver & Harrington 2009). Kang et al. (2012) report that addressing the spiritual needs of patients with terminal cancer led to better quality of life. One systematic review identified that meditation combined with massage was one of the spiritual and religious interventions that had beneficial effects for patients (Candy et al. 2012). Furthermore, Candy et al. (2012) identify that the involvement of chaplaincy was associated with feelings of being emotionally supported and spiritual wellbeing.

Patient-centred care

The provision of patient or person-centred care is encouraged in the current health care system, particularly in the United Kingdom (Dewing 2004). This is a challenging process, however, because the provision of patient-centred care requires specific knowledge and skills, an effective workplace environment, and substantial organisational support (Manley, Hills & Marriot 2011). These three factors relate closely to each other in providing patient-centred care. One previous study showed that the workplace environment was associated with the engagement of nursing staff and with patient-centred care behaviours (Abdelhadi & Drach-Zahavy 2012).

The main principles of patient-centred care include treating people as individuals, respecting patients’ rights and values, building mutual trust and understanding, empowering individuals, and encouraging autonomy (McCance, Slater & McCormack 2009; McCormack et al. 2010; Pope 2012). Marshall, Kitson and Zeitz (2012) added connectedness, attentiveness, and involvement as attributes that staff should ideally cultivate or possess in relation to patient-centred care.

It has been demonstrated that the ideals of patient-centred care – including holistic care, communication and collaboration, and an interdisciplinary/team approach – are closely aligned with the principles of palliative care (Hall et al. 2007; Rose & Yates 2013; Wittenberg-Lyles, Goldsmith & Platt 2014). A number of studies that have focused on the implementation of patient-centred care in the palliative care arena have identified several benefits of a patient-centred approach. Hall et al.'s (2007) case study demonstrated that the patient-centred approach improved efficiency, job satisfaction, and continuity of care. Job satisfaction among staff was also indicated in other studies (Moyle et al. 2011; Rose & Yates 2013). Other benefits of implementing this approach in palliative care include positive patient outcomes (Rose & Yates 2013), cost reductions (Sahlen, Boman & Brannstrom 2016), positive family perceptions (Brazil et al. 2012), and family satisfaction (Moyle et al. 2011).

Family caregiving in palliative care

In the health care systems throughout the world, family caregivers are considered to have a central role in health care delivery and form an essential component of palliative care (Guerriere, Zagorski & Coyte 2013; Stajduhar et al. 2010). In this context, family caregivers are individuals who provide support (physical, social, and psychological) and health-related assistance to a family member with a life-limiting illness (Hudson et al. 2009; Janze & Henriksson 2014). In the broadest sense, a family caregiver could be a relative, a friend or anyone who has a significant relationship with the patient but they are mostly the patient's spouse, child, or parent (Benton et al. 2015). Previous studies have also shown that most caregivers in palliative care are females (Benton et al. 2015; Williams et al. 2008; Williams, Zimmerman & Williams 2012).

Several studies have explored the decision-making process in becoming a family caregiver. Linderholm and Friedrichsen (2010) found that the motivation for becoming a family caregiver stemmed from a sense of duty in fulfilling the wishes of loved ones at the end of their life; there was also a genuine willingness to take on this role. Another study also reported similar reasons of becoming a family caregiver (Wallerstedt, Andershed & Benzein 2014). Cultural expectations were also identified as a reason for becoming a family caregiver (Shanmugasundaram, Chapman & O'Connor 2006).

The extent of caregiving is holistic and varies between individuals. Performing tasks related to personal care, meals, management of symptoms, and medication were the most common aspects of care provision (Given, Given & Sherwood 2012; Williams, Zimmerman & Williams 2012). In addition to physical care, these authors identified that family caregivers also assisted with social issues, addressing the patient’s emotional issues, communicating with professional caregivers and coordinating care.

Becoming a family caregiver of a person with a life-threatening illness often comprises new responsibilities and handling unknown situations, even if the responsibility is shared with professionals. Recent research has indicated that family caregivers are increasingly performing tasks that health care professionals typically undertake, such as tube-feeding, wound care, and administering medications. Most family caregivers undertake these tasks without preparation or training (Benton et al. 2015; Given, Given & Sherwood 2012). Furthermore, (Given, Given & Sherwood 2012) highlight family caregivers’ concerns about the quality of care they provided. The evidence shows that many family caregivers have mixed emotions about their role as a carer and highlight both its positive and negative aspects (Hudson, Aranda & Kristjanson 2004; Weibull, Olesen & Neergaard 2008). A number of studies have reported the positive consequences associated with end-of-life caregiving, such as feelings of reward, thankfulness, and personal growth (Andershed & Ternestedt 2001; Henriksson et al. 2012; Stajduhar 2003).

In contrast, there are numerous studies reporting that caregiving can also be burdensome for family members. Caregiving is often time-consuming and physically and psychologically demanding. Studies by Carlsson (2009) and Jo et al. (2007) found that fatigue was the most common physical burden experienced by family caregivers. Other studies have reported the psychological consequences of family caregiving, such as fear, exhaustion, anxiety, depression, social isolation, and psychological distress (Oechsle et al. 2013a; Osse et al. 2006). In addition to such consequences, a number of studies have reported that family caregivers often have other issues to face, such as difficulties with finances and with interpersonal relationships, particularly within the family (Oh & Kim 2014; Waldrop et al. 2005; Yoo, Lee & Chang 2008).

Family caregiving at the end of life, either in a private home or a health care facility, is a complex process affecting individual family members and the family as a whole. Thus, not only the patients, but also the caregivers, need attention. This is also reflected in the World Health Organization (2010) definition of palliative care, in which caring for family caregivers is mentioned as an essential part of palliative care, particularly in terms of preparing and supporting them in taking on the caregiving for their loved ones.

While most caregivers are unprepared and untrained, the existing evidence shows that preparedness for caregiving can influence the caring experience, as well as the ability to manage the caregiver role and to lessen the perceived caregiver burden. Family caregivers’ preparedness also facilitates the transition experience in the illness trajectory (i.e. knowing what to expect during the transition and the strategies that may be helpful in managing the issues that may arise) (Meleis et al. 2000). Potentially, family caregiving could lead to better patient outcomes as family competence in caregiving increases (Hudson et al. 2009; Weinberg et al. 2007). Preparedness has a practical as well as an emotional dimension in knowing not only what to do, but also in feeling ready to manage the demands of the caregiver role (Dev & Dev 2015). Learning through actively seeking information, trial and error, earlier experience, and guidance by others, are examples of ways in which family caregivers prepare to care for loved ones approaching the end of life (Stajduhar et al. 2010).

Another significant issue for the family caregiver is their need for support. Providing care at home is often labour-intensive and emotionally complex; therefore, it is vitally important to support family caregivers in their efforts (Epiphaniou et al. 2012; Guerriere, Zagorski & Coyte 2013). Preventing the adverse effects of caregiving and increasing the caregivers' sense of security and worth could be addressed by both informal and formal support (Grande et al. 2009; Wallerstedt, Andershed & Benzein 2014). Formal support refers to that provided by health care professionals and which ranges from providing information, psychosocial education and spiritual support, through to the provision of respite care (Hudson, Remedios & Thomas 2010; Payne et al. 2009; Wallerstedt, Andershed & Benzein 2014). Previous studies have shown that psychosocial education and spiritual support had beneficial effects for family caregivers (Hudson et al. 2009; Hudson, Remedios & Thomas 2010; Sherman et al. 2005). Informal support refers to assistance provided by non-health care professionals. Several studies have reported that trained volunteers, local community members, and other family members often helped with non-medical tasks and provided psychological support for family caregivers (Bollini, Venkateswaran & Sureshkumar 2004; Reinhard et al. 2008).

Connection, communication, and relationships in palliative care

Communication has been determined a critical part of the health professional - patient relationship; both the relationship and communication are fostered through the foundation of trust and personal attitudes and values brought in by the health care professionals (Lowey 2008). Similarly, in the context of palliative care, communication and relationship are also considered as the key elements for the provision of effective and quality palliative care and end-of-life care (Curtis et al. 2012; Lowey 2008; National Consensus Project 2009). In addition, from the nurses’ point of view, a study conducted by White and Hardy (2010) found that nurses perceived communication as the second most important competency in palliative care.

Given the importance of communication and relationship as discussed above, effective communication skills are requisite in palliative care (de Haes & Teunissen 2005). Such skills include effective sharing of information, active listening, determination of goals and preferences, assistance with medical decision-making, empathy, trust, continuity, and understanding (Curtis et al. 2012; Lowey 2008). In addition to these, a qualitative study conducted by Seccareccia et al. (2015) highlighted important elements in effective communication included building rapport, addressing expectations and providing safe space for prognosis and death discussions.

Health care professionals are responsible for maintaining open and effective communication with the patients and the families throughout the provision of palliative care (Seccareccia et al. 2015). Effective communication provides the foundation of a trusting relationship among the patients, family, and health care providers (Fawole et al. 2012). Relational coordination between family caregivers and health care professionals improves the family caregiver’s preparedness in caring and leads to better outcomes (Weinberg et al. 2007). In addition, broad positive outcomes that have been associated with effective health care professional–patient and health care professional–family communication include improved patient experience, improved quality of health care professionals - patient interaction, and effective and collaborative decision-making (Zoppi & Epstein 2002). Conversely, lack of communication has a negative impact and becomes one of the barriers in providing optimal end-of-life care (Back et al. 2008). A hermeneutic study involving family members in four primary health care settings in Sweden found that family caregivers often felt left out and powerless when they could not manage relationships with health professionals (Linderholm & Friedrichsen 2010).

Many nurses feel uncomfortable communicating with dying patients, and this may be due to their lack of training, lack of confidence to incorporate communication into their practice, and lack of mentoring in effective communication (Dahlin 2010). Existing evidence identifies that nurses with more years of experience, and better education and training in palliative care have increased comfort and competency, and feel better prepared for palliative care communication (Barth & Lannen 2011; Keall, Clayton & Butow 2014; Moir et al. 2015).

Spirituality/religion in palliative care

Spirituality/religion is a critical aspect in comprehensive palliative care, as palliative care is committed to holistic care that integrates physical, psychological and spiritual care of patients and families. The terms spirituality and religiosity have generally been differentiated in the recent literature (Edwards et al. 2010; Ginting et al. 2015), although in some literature these two terms are still being used interchangeably (Bauer-Wu, Barrett & Yeager 2007; Hill et al. 2000; Taylor & Brander 2013).

Experiencing life-threatening illness may impact on an individual's spirituality/religiosity. At such a time, spirituality/religion may help an individual to cope by renewing hope, finding meaning and purpose and adjusting to insoluble problems (Candy et al. 2012; Ferrell & Munevar 2012). Alternatively, it may cause negative spirituality/religion experiences including anger to God (Puchalski et al. 2009) and loss of belief (Byrne 2002).

A number of studies have suggested that individuals with life-threatening illness, especially during their final stage of life, often question issues around life and death, and increase their awareness about their spirituality. Chochinov and Cann (2005) concluded from several studies that the majority of patients with life-limiting illness were interested in having spiritual/religious discussions with their physicians. These authors add that the patients also expressed their need of spiritual supports, such as the needs to find hope and spiritual resources.

To be able to address a patient’s spiritual needs, two important strategies must be implemented by health care professionals: spiritual assessment and the provision of spiritual care. Health care professionals are required to have skills in conducting spiritual assessment (Ferrell & Munevar 2012), although they might face difficulties due to lack of training, time constraints and lack of vocabulary surrounding spiritual issues (Abbas & Dein 2011). Existing evidence shows that spiritual assessment in palliative care could be conducted by either using routine systematic questions (Ahmed et al. 2014) or using existing structured history-taking tools that have been widely used. Examples of such tool are the Faith Application Influence Talk Help (FAITH), Faith Importance/influence Community Address (FICA) and Sources of Hope Organised religion Personal spirituality Effects on medical care (HOPE) (Blaber, Jone & Willis 2015).

The provision of spiritual/religious care is a crucial component of comprehensive palliative care. It has been reported that spiritual/religious care practice is more advanced in palliative care settings than in acute settings (Ronaldson et al. 2012). In their study comparing spiritual care perception among palliative care registered nurse (RNs) and acute RNs in Sydney, Ronaldson et al. (2012) found that palliative care RNs had stronger perspectives of spiritual care and practices of spiritual care. The delivery of spiritual care may vary depending on some factors such as religious background and culture (Byrne 2002). For example, prayers, the use of chaplains or spiritual counsellors and worship facilitation is more common in the palliative care setting where there are strong religious beliefs (Balboni et al. 2011; Candy et al. 2012; Kwiatkowski, Arnold & Barnard 2011). Other forms of spiritual care practice include meditation, tai chi, and yoga (Taylor 2005). Evidence from several systematic review and meta analyses have shown benefits from spiritual care delivery to include a better quality of life, less aggressive care at end of life care (Balboni et al. 2010), better spiritual wellbeing and a decrease in depression and anxiety (Oh & Kim 2014).

Dying and death

This final section provides discussion related to dying and death including attitudes towards dying and death, and discussion related to death. This is followed by descriptions of activities conducted by either the patients and their families or the health care professionals.

Attitudes towards dying and death

Dying and death is an inevitable point in the palliative care service and could happen at any time during the care provision, however, dying and death is a complex and interactive process. This situation affects all individuals who are involved, including the palliative care patients and their family caregivers, as well as health care professionals. For health care professionals, attitudes towards death are influenced by the areas they have worked and their experience or length of working (Gama, Barbosa & Vieira 2012; Lange, Thom & Kline 2008; Leclerc et al. 2014). Previous studies have indicated that health care professionals working in long-term care and palliative care had positive attitudes towards dying and death (Leclerc et al. 2014). Nurses working in these areas had less fear of death compared to their colleagues who worked in medical and haematology areas (Gama, Barbosa & Vieira 2012). In addition, more working experience was also associated with a more positive attitude towards death (Gama, Barbosa & Vieira 2012; Lange, Thom & Kline 2008).

Dying and death events also affect patients and their family caregivers. A number of studies have shown that when considering the possibility of death, palliative care patients had different responses. While some of the patients felt ready to die (Strang 2014), others often had anxiety, worrying about their families and concerned about burdening others (Nedjat-Haiem et al. 2013; Tsai et al. 2005). Tsai et al. (2005) further indicated that death anxiety could lead the patients to experience fewer characteristics of good death (i.e. peace of body, mind and thought, awareness of death and peaceful death acceptance). Family caregivers' fear of patient death has been reported in many studies. When family caregivers were aware that their loved one would die soon, they were fearful of this situation (Bachner, O'Rourke & Carmel 2011; Gunnarsson & Öhlén 2006). This fear caused the caregivers to feel tense and that they stated that they never felt relaxed and were always giving full attention to the patient's condition (Janze & Henriksson 2014). Gunnarsson and Öhlén (2006) identify that the family caregivers often put their own feelings at a distance, which caused them suffering in silence. This suggests the need for support of the family caregivers to facilitate and enable them in adjusting and managing the situation adequately.

Knowing the patient's choice of a place to die is an important aspect in end of life care to facilitate this choice. Many studies have documented that the majority of patients with terminal illness would prefer to die at home (Evans & Hallett 2007; Gomes et al. 2013; Gomes, Calanzani & Higginson 2012). Hales et al. (2014) identified that home deaths were associated with better symptom control and death preparation. About half of the patients who died at home did so in their preferred location (Burge et al. 2015). Several factors have been associated with this congruence, including healthcare professionals' home visits, palliative care program involvement and family support (Bell, Somogyi-Zalud & Masaki 2010; Burge et al. 2015). Despite the patients' preferences some still died in hospitals and this was often due to caregivers' difficulties in providing capable end of life care, patients' unstable symptoms and deteriorating condition (Champion, Medigovich & Morrison 2015).

End of life discussions

Understanding and honouring patients' preference of treatment and wishes at their end of life is crucial for quality palliative and end of life care. This requires effective communication between patients/relatives and health care professionals (Trice & Prigerson 2009). Discussions about prognosis and end of life gave terminally ill patients opportunities to voice their feelings about death and their wishes at end of life (Harrison & Walling 2010). While such discussions are encouraged, a number of studies have shown that discussions about prognosis and death were often not conducted. This was associated with health care professionals' factors, patients' factors, caregivers' views and culture (Hancock et al. 2007). In their systematic review, Hancock et al. (2007) found that physicians felt stressed and lacked training in conducting open conversations with patients. In addition, the physicians were reluctant to disclose such information due to concerns about possible negative impacts on patients (Hancock et al. 2007). Walczak et al. (2015) found that many family caregivers preferred to discuss about clear treatment preferences rather than having a discussion on life expectancy and unknown treatment outcomes. Prognosis and end of life discussions between patient/relatives and health care professionals are influenced by culture. In Western countries such discussions are more often being conducted. However, in Asian cultures, patients or relatives are more reluctant to have such discussions (Cheng et al. 2015; Hsu, O'Connor & Lee 2009; Tang et al. 2014; Wen et al. 2013). This is because discussions about death are considered taboo in a number of cultures (Hsu, O'Connor & Lee 2009).

Practices at end of life

When recognising that patients are approaching their end of life, health care professionals need to provide appropriate and effective support. A number of studies have identified interventions that had beneficial outcomes for the patients, such as forgiveness therapy and discussions of life completion. Two experimental studies indicated that forgiveness therapy improved terminally ill patients' health outcomes at their end of life (Hansen et al. 2009; Steinhauser et al. 2009). Discussion of life completion which included discussion of patient's values and completions was associated with better patient's health outcomes at their end-of-life (Steinhauser et al. 2009).

Several other practices are also conducted by family caregivers. Existing evidence shows several activities and rituals associated with such events including inviting attendance by a clergy or a religious person (Cheng et al. 2015), asking for forgiveness (Baker 2005; Hansen et al. 2009; Steinhauser et al. 2009), and cremation among Hindus and immediate burial in Jews (Clements et al. 2003; Gupta 2011).

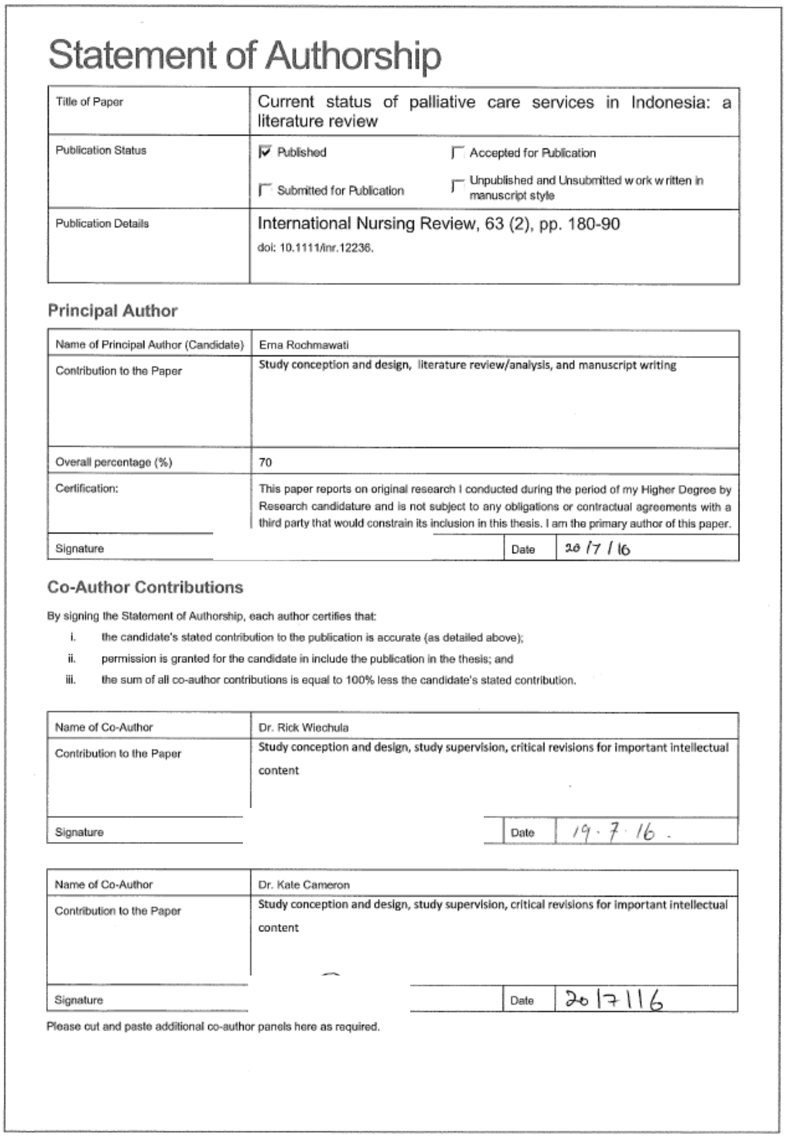
Summary

This chapter has provided discussion on the international literature and indicated that several gaps in current research have been identified. Palliative care is a relatively new field of health care that provides support for those with advanced life-limiting illnesses. Concerns of palliative care patients include those of the physical, psychological and spiritual domains, and support should also be included for the relatives during the care provision. Yet not all domains of personhood receive adequate attention, with psychological and spiritual care needs often overlooked. Causes for this oversight include lack of time, skills and confidence. This chapter has highlighted that there are important elements in the provision of palliative care, particularly in the home-based care, family caregiving and spirituality/religion.

The next chapter presents findings of an integrative review of palliative care services in Indonesia in the form of a published article. The integrative review was conducted to capture broad information and specifically addresses the provision of palliative care in Indonesia to identify gaps in the knowledge pertinent to formal palliative care services in Indonesia. This can then provide basis and justification for this study.

Chapter 3: Current status of palliative care services in Indonesia: a literature review

This chapter contains the integrative review titled “Current status of palliative care services in Indonesia: a literature review” published in *International Nursing Review*, vol. 63, no. 2, pp. 180-190. The presented paper is the last version prior to publication.



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Overall percentage (%)	70		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	20 /7 / 16

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By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

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Current status of palliative care services in Indonesia: a literature review

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ROCHMAWATI E., WIECHULA R. & CAMERON K. (2015) Current status of palliative care services in Indonesia: a literature review. *International Nursing Review* **00**, 00–00

Aim: To review healthcare literature in relation to the provision of palliative care in Indonesia and to identify factors that may impact on palliative care development.
Background: People living with life-limiting illness benefit from access to palliative care services to optimize quality of life. Palliative care services are being expanded in developing countries but in Indonesia such services are in their infancy with many patients with life-limiting illnesses having access to appropriate health care compromised.
Methods: Relevant healthcare databases including CINAHL, PubMed, Science Direct and Scopus were searched using the combinations of search terms: palliative care, terminal care, end-of-life care, Indonesia and nursing. A search of grey literature including Internet sites was also carried out.
Results: Nine articles were included in the review. Facilitating factors supporting the provision of palliative care included: a culture of strong familial support, government policy support, volunteering and support from regional organizations. Identified barriers to palliative care provision were a limited understanding of palliative care among healthcare professionals, the challenging geography of Indonesia and limited access to opioid medications.
Conclusions: There are facilitators and barriers that currently impact on the development of palliative care in Indonesia. Strategies that can be implemented to improve palliative care include training of nurses and doctors in the primary care sector, integrating palliative care in undergraduate medical and nursing curriculum and educating family and community about basic care. Nurses and doctors who work in primary care can potentially play a role in supporting and educating family members providing direct care to patients with palliative needs.

Keywords: Cancer Care, Developing Countries, End-of-Life Care, Indonesia, Life-Limiting Illness, Literature Review, Nursing, Palliative Care, Terminal Care

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No conflicts of interest have been declared by the authors.

Introduction

Cancer is a major global health issue and the leading cause of death in the world (International Agency on Research on Cancer (IARC) 2012). Palliative care has been shown to improve patients' well-being and symptoms (Gómez-Batiste et al. 2010) which subsequently improves their quality of life (Paiva et al. 2012). It is estimated that of all deaths resulting from a diagnosis of cancer, approximately 63% would benefit from palliative care, supporting the imperative for integrating palliative care within healthcare systems (Murtagh et al. 2014).

Palliative care services have been established in 136 of the world's 234 countries, although activities of these services in 75 less developed countries are not well known (Lynch et al. 2013). When palliative care services are introduced into countries often they operate as standalone services where patients come for terminal care separate from the rest of the healthcare system. As the services develop and mature they become more integrated with mainstream services. Palliative care service categories have been used by Lynch et al. (2013) to designate six different levels:

- level 1 – no known hospice-palliative care activity,
- level 2 – capacity building,
- level 3a – isolated provision,
- level 3b – generalized provision,
- level 4a – preliminary integration, and
- level 4b – advanced integration.

Indonesia faces a challenge regarding the growing incidence of non-communicable disease including cancer, diabetes and cardiovascular disease (World Health Organisation (WHO) 2010). Consequently, the number of patients who need palliative care is increasing. Generally, palliative services are provided to people in the late stage of disease (Utari 2008). In 2014, the estimated rate of adults who needed palliative care at their end of life in the South East Asia region which includes Indonesia was approximately 234–353 per 100,000 population (WHO 2014a). The greatest need was for progressive non-malignant disease, followed by cancer and HIV/AIDS. In Indonesia, palliative care services were initiated in 1990 through the establishment of pilot palliative services provided in existing health institutions (Al-Shahri 2002; Soebadi & Tejawinata1996). A global overview identified that Indonesian palliative care services are currently classified as level 3a, i.e. not fully integrated into mainstream healthcare services (Lynch et al. 2013).

This leads to the following questions: How is palliative care currently provided in Indonesia? What are the barriers and are there any facilitating factors in providing palliative care? What is the role of Indonesian healthcare professionals including nurses in palliative care? The purpose of this paper was to address these broad questions through the review of literature relating to palliative care services in Indonesia. Specifically, it aims to identify the provision of palliative care including barriers and facilitating factors. This will inform the understanding of where healthcare professionals, including nurses, can contribute to the improvement in the provision and quality of palliative care in Indonesia.

Background

Health care in Indonesia

Indonesia is an archipelago which is located between Asia and Australia. It consists of approximately 17,000 islands, 6000 of which are inhabited, with five major inhabited islands. Indonesia has a diverse culture with hundreds of ethnic groups dispersed over a wide area and is the fourth most populated country in the world after China, India and the United States (Tjindarbumi & Mangunkusumo 2002). According to the August 2010 census, the population of Indonesia had reached 237.6 million, with 50% living in rural areas (Central Bureau of Statistic (Badan Pusat Statistik/BPS) 2010). People in Indonesia generally have a relatively adequate level of health services with one public health centre for every 30,000 people on average, but those living in remote locations have comparatively poor access (WHO 2010).

Indonesia's health system has two sectors: public and private. The Government of Indonesia provides funds for public hospitals and *Puskesmas* (Primary Healthcare Units). The private health system is comprised of individual organizations, particularly faith-based Islamic and Christian organizations (Shields & Hartati 2006). Community-based health care is also provided by the Family Welfare Movement (Joint Committee on Reducing Maternal and Neonatal Mortality in Indonesia, National Research Council & Indonesian Academy of Sciences 2013). There are strong links between the Family Welfare Movement and the *Puskesmas'* programmes such as community nutrition, maternal and child health, health promotion and disease prevention. In addition, cancer screening programmes are regularly offered by non-profit organizations to people in the community at no cost (Indonesian Cancer Foundation (Yayasan Kanker Indonesia/YKI) 2012).

In January 2014, a new universal health coverage; the *Badan Penyelenggara Jaminan Sosial Kesehatan* or *BPJS Kesehatan* (Healthcare and Social Security Agency) which covers the cost of primary and referral care was implemented (BPJS Kesehatan 2014; Kwok 2014). The impact of the new policy is not yet known as its implementation is relatively new and there is no published evaluation at this time.

Methods

Aim

To review peer-reviewed publications and grey literature that provides information on the provision of palliative care in Indonesia.

Search strategy

Relevant literature was reviewed following searches of databases including CINAHL, PubMed, Science direct, Scopus and the Google Scholar search engine, using the following keywords: palliative care, terminal care, end-of-life care, Indonesia and nursing. Grey literature was searched from relevant websites.

Inclusion and exclusion criteria

This review aimed to provide an overview of palliative care provision in Indonesia. A comprehensive and thorough review was conducted and care was taken to search using a systematic approach including grey literature. The search period ran from 1990 to 2015. We included papers related to the early and more recent development of palliative care in Indonesia to enable a comprehensive description of the state of affairs of palliative care in the country. We limited the search to English and Indonesian language articles. Each article identified was read in full and assessed for the relevance to the review using the sole inclusion criterion that the article provides information about palliative care services in an Indonesian setting.

Result

This review identified nine articles that met the inclusion criteria. Most papers discussed the development of palliative care in Indonesia in its earlier stage; three papers discussed more recent developments. Only one paper was written in Bahasa Indonesia, while the other articles were written in English. With regard to disease type, eight of the articles discussed palliative care for cancer patients and one article focused on HIV/AIDS (see Table 1).

Of these nine articles, three were primary research reports written by Indonesian nurses ($n = 2$) and a British physician ($n = 1$). Two were descriptive surveys; one study examined the role of family, nurse and physician in dealing with palliative patients' symptoms and the other investigated learning needs of healthcare professionals in relation to palliative care. The third article was a qualitative study exploring the need for home-based palliative care for people living with HIV/AIDS. All three articles also included information on barriers and facilitating factors for palliative care in Indonesia.

Six of the articles were review articles written by leading Indonesian palliative experts ($n = 4$) or overseas physicians ($n = 2$). These authors utilized previous literature, reported data from their own practice to develop their publications. The search produced much information about the provision of palliative care in Indonesia. The broad issues were the current progress, facilitating factors and challenges in palliative care. Details of each issue are provided in the following sections.

Palliative care in Indonesia – major findings

Findings from this review identified that the slow development of palliative care in Indonesia is multifactorial. Healthcare professionals having limited knowledge of palliative care was the most reported barrier. Facilitating factors identified included strong family and community supports. These and other barriers and facilitating factors are discussed below.

Current progress

As previously noted the provision of palliative care in Indonesia commenced in the 1990s (Al-Shahri 2002; Lickiss 1993; Soebadi et al. 1996). The development of palliative care services in Indonesia has been slow and their availability is still limited (Effendy et al. 2015; Witjaksono et al. 2014); however, a national guideline for palliative care has been produced (Witjaksono et al. 2014). Recent publications indicate there are only 10 organizations designated as specifically providing palliative care services and all of them are located in seven cities on three of the major islands in Indonesia (Effendy et al. 2015; Witjaksono et al. 2014). These authors suggest that development of palliative care among cities and centres varies. In addition, although palliative care services are available in seven cities, the literature only describes in detail palliative care provision in Jakarta and Surabaya (Effendy et al. 2015; Saleh et al. 2008; Soebadi et al. 1996).

Palliative care in Indonesia is provided by hospitals and non-profit organizations. Palliative care services are delivered to people of all ages, with one particular non-profit organization focusing on the provision of paediatric palliative care services (Effendy et al. 2015). This non-profit organization provides symptom management, spiritual care and emotional support for patients and families in their hospice and home care programme. Models related to the provision of the service include hospital-based care, home-based care and community-based care. Witjaksono et al. (2014) reported that palliative care services are available in several hospitals where

Table 1 Summary of included articles informing palliative care services in Indonesia by year of publication

Author (year)	*Language*	*Source*	*Aim*	*Design and data collection methods*	*Findings*	*Implications for palliative care service in Indonesia*
Lickiss (1993)	English	Academic database	Describing the process of palliative care development	Discussion paper	Palliative care was initiated in 1990s. Three hospitals were appointed to be part of pilot project on the use of oral morphine	Leadership is an important factor in palliative care development
Soebadi & Tejawinata (1996)	English	Academic database	Providing discussion on cancer pain and its management, and early development of palliative care in Indonesia	Discussion paper	Most cancer patients came to hospital at the end stage of disease Incidence of cancer pain is high Limited use of opioids Palliative care in Indonesia was started in 1990s Limited knowledge by health workers is the major constraint of cancer pain management	A need to train nurses and other healthcare professionals in palliative care and cancer management
Al-Shahri (2002)	English	Academic database	Summarising the development of palliative care in Islamic countries where Indonesia is included	Review	Cancer patients in Islamic countries present to hospital with more advanced disease than in more developed countries Opioid use is still limited	Limited use of opioid for pain cancer is a barrier in palliative care development
Saleh et al. (2008)	Indonesian	Web site	To describe the provision of palliative care in a Primary Healthcare setting	Discussion paper	Palliative care team: comprises healthcare professionals and volunteers Holistic palliative care is provided by the healthcare professional in the *Puskesmas*	Volunteering has a positive impact in palliative care services
Amery (2012)	English	Academic data base	To summarize the development of Paediatric PC and educational needs	Descriptive quantitative: online Questionnaire	Participants are less confident when caring for dying children	Limited availability of palliative care experts in Indonesia

Ibrahim, Haroen & Pinxten (2011)	English	Academic database	To explore the care needs of patients living with HIV infection	Qualitative methods: observations, interviews and focus group	Home-based care is urgently needed by patients living with HIV infection particularly those who need palliative care	Family has an important role in caring for the patient A need to strengthen the role of family in delivering care Training and knowledge dissemination is needed for families to be able to take care of loved ones
Effendy et al. (2014)	English	Academic database	To describe patients' symptoms and prevailing issues. Investigate how family members, nurses and physicians deal with patients' symptoms and issues	Descriptive quantitative: questionnaire to patients	Financial difficulty is the most common issue for advanced cancer patients Families address financial, autonomy and psychological issues by themselves Family, nurses and physicians addressed physical symptoms and spiritual issues	Strong family ties in Indonesian culture have a positive impact for patients
Witjaksono et al. (2014)	English	Web site	To describe the current progress of PC in Indonesia including challenges and opportunities	Discussion paper	Challenges to PC provision: limited training, government policy on opioid use, limited understanding of PC among healthcare professionals, wide geographic area Opportunity: support from regional and community organizations	Regional and community organizations have positive impact in the development of palliative care provision in Indonesia. A need for further availability of palliative care module and trainings for healthcare professionals.
Effendy et al. (2015)	English	Academic data base	To provide an overview the current provision of palliative care in Indonesia	Discussion paper	Several palliative care services are available in Indonesia, however more efforts are required to increase the number of the services and the quality of palliative care	A need to seek the most appropriate model of palliative care delivery that consider Indonesian cultural traits A need to use quality indicators to develop standard of palliative care provision and to evaluate the existing palliative care services.

the facilities for cancer care are located. Soebadi et al. (1996) identified that palliative care services provided in the hospitals included pain and symptom management, support systems for patients and their families, palliative consultation, psychosocial and spiritual support. These authors reported that the palliative care services also extend to provision of home visits and community-based care collaborating with other organizations. Partners include the *Puskesmas,* the Family Welfare Promotion Movement and Indonesian Cancer Foundation (Soebadi et al. 1996; Saleh et al. 2008).

Home-based care was provided by both hospitals and non-profit organizations (Soebadi et al. 1996). Among the identified literature, only one study provided specific findings about a model of palliative care which was home based. Ibrahim et al. (2011) in their qualitative study with family caregivers, healthcare providers and community leaders found that home-based care was urgently needed by patients with HIV/AIDS, particularly those who needed palliative care. The study also revealed that specific types of care were needed to be incorporated into home-based care, such as symptom management and self-care, psychological and spiritual care, basic nursing care and care for death and dying. Although the study only focused on care for patients with HIV/AIDS, the findings might also reflect the needs of patients with other life-limiting illness requiring palliative care services.

The integration between existing palliative care facilities is still in its early stage. Effendy et al. (2015), however, in their review describe two palliative care facilities (a hospital and a hospice) that have started to integrate their services with a referral system being implemented, enabling patients from the hospital to obtain palliative care from the hospice.

Facilitating factors

This review identified several facilitating factors. These factors included support from regional authorities (Effendy et al. 2015; Witjaksono et al. 2014), individual families (Effendy et al. 2014; Soebadi et al. 1996) and the involvement of the community (Saleh et al. 2008; Soebadi et al. 1996). The government's support for palliative care was shown when the national policy on palliative care were enacted by the Ministry of Health in 2007 (Effendy et al. 2015; Witjaksono et al. 2014). Effendy et al. (2015) reported that this policy stated that palliative services should be available in the five main cities of Indonesia including Jakarta, Yogyakarta, Surabaya, Denpasar and Makasar. The policy should have a positive impact on palliative care services as it encourages all types of healthcare organizations to provide palliative care services. Witjaksono et al. (2014) and Effendy et al. (2015) however suggest the need for palliative care services is evident but the available palliative facilities are limited. Witjaksono et al. (2014) suggest that the national palliative care policy has not been applied in the healthcare system due to the absence of palliative care guidelines and standards, an appropriate referral system and lack of resources. Although there is criticism of government support at the national level, one publication highlighted support from local authorities through conducting basic palliative care training for healthcare professionals in hospitals and primary health centres (Witjaksono et al. 2014).

Family support and community involvement also have a potentially positive impact on the provision of palliative care in Indonesia. Effendy et al. (2014) in their survey of three general hospitals in Indonesia found that in Indonesian culture there are strong family ties with family members playing a key role in providing direct care for those who are ill or dying. Soebadi & Tejawinata (1996) in their review of early palliative care development in Indonesia added that in general families are eager to help and suggest that this can be an opportunity for health professionals to train relatives to assist with patient care.

The involvement of community, in the form of the Family Welfare Movement (*Pemberdayaan Kesejahteraan Keluarga* or PKK) is addressed by Saleh et al. (2008) in their paper discussing the delivery of palliative care in a primary health centre in Surabaya. They highlighted the involvement of volunteers from the Family Welfare Movement in home-based palliative care activities. The volunteers were provided with basic training prior to commencing their volunteer work. Saleh et al. (2008) stressed that basic training is important for the volunteers so that they can better support palliative patients and families. Similar activities may also exist in other cities as the Family Welfare Movement has partnerships with many primary healthcare providers, however this was not reported.

Challenges

Although there have been several facilitators to support the development of palliative care in Indonesia, many challenges still exist. The main challenges reported included limited use of opioids (Al-Shahri 2002; Soebadi et al. 1996; Witjaksono et al. 2014), lack of palliative care education and consequently the limited number of palliative trained health professionals (Amery 2012; Witjaksono et al. 2014), as well as geographical constraints (Soebadi et al. 1996; Witjaksono et al. 2014).

The limited use of opioids has been a significant challenge to the provision of palliative care. When palliative care services were first developed in Indonesia there was limited availability of oral morphine. Weak opioids were used in the early years of palliative care development until oral morphine became available in some referral hospitals (Al-Shahri 2002; Soebadi et al. 1996). Apparently this was related to concerns about the safety of using opioids in the home. The recent review conducted by Witjaksono et al. (2014) identified government policy on opioids as a reason on the limited use of this medication but did not elaborate on this. They did, however, state that opiophobia is still a concern in Indonesia today.

An enduring problem in Indonesia is the lack of palliative care education (Witjaksono et al. 2014) and subsequently the limited availability of palliative care specialist clinicians (Amery 2012). Witjaksono et al. (2014) further highlighted the absence of palliative care education modules in most medical schools in Indonesia. This then prevents early exposure to palliative care learning by medical students. The authors also indicate that few physicians are undertaking advanced training in palliative care. Those who are certified in palliative care are concentrated in the two major cities of Indonesia, Surabaya and Jakarta, creating further challenges to palliative care information dissemination to other existing healthcare professionals. In addition, in Jakarta, the capital city of Indonesia, fewer introductory courses in palliative care are offered in hospitals and *Puskesmas* than in Surabaya because there is less palliative care certified doctors available to provide this (Witjaksono et al. 2014). The literature did not address the availability of palliative care modules in nursing schools.

Geographical constraints are also a considerable challenge to palliative care delivery (Soebadi et al. 1996; Witjaksono et al. 2014). As previously discussed, Indonesia is an archipelago, spread over a wide area and transport for treatment is particularly difficult. All of the palliative care facilities are located in the larger cities while more than 50% of Indonesian people live in the rural areas.

Discussion

This review of the literature has outlined the past and recent provision of palliative care services including the type of care and the facilitators and barriers in relation to palliative care services in Indonesia. The current provision of palliative care is still in its infancy. According to the six levels of palliative care development described earlier, palliative care activity in Indonesia is at level 3a where the provision of services is isolated (Lynch et al. 2013). Although the Indonesian healthcare context may be different from developed nations, in both contexts the need for palliative care is growing (WHO, 2014a) However, in developed countries, palliative care services are generally well established and integrated within mainstream healthcare systems, while in Indonesia the scope of palliative care activity is still patchy (Lynch et al. 2013) and the referral system to the existing palliative care services has only recently commenced (Effendy et al. 2015). In low- and middle-income countries and particularly in Indonesia, the availability of palliative care services is still limited and in many parts of the country is simply not available. In this review, we found there were 10 hospice and palliative organizations and service providers as reported by Lynch et al. (2013). In considering the size of population and geographical location of services, clearly there are significant constraints in terms of the number of palliative care services available. Data collected in 2011 provides a telling comparison where the indicative ratio of palliative care service to the population in Indonesia was 1:22,996,000 and for Australia was 1:67,000 (Lynch et al. 2013). Consequently, the quality of life for those living with life-limiting illness whether in Indonesia or other developing nations remains relatively poor. This present review highlights that the progress of palliative care in Indonesia has been slow. It is not clear why palliative care has not been given a higher priority but clearly there is a great need.

There is a potential to provide care from hospitals where some expertise exists. Currently, palliative care is provided within a few hospitals and some of these organizations provide an outreach service in patients' homes. A small number of non-profit organizations also offer home care. The executive board of the World Health Organisation views home care as appropriate for the implementation of palliative care especially in countries like Indonesia that have limited resources (WHO 2014b). Some factors point to home care fitting the cultural needs of Indonesian society such as a tradition of family (Effendy et al. 2014) and community involvement (Saleh et al. 2008) in care. However, only one study conducted by Ibrahim et al. (2011) specifically investigated the potential of home care to be culturally appropriate for palliative care provision in Indonesia. Therefore, there is a clear need to conduct studies exploring the provision of palliative care.

In Indonesia, family and community support are viewed as having a significant role in providing care to the sick and dying. This reflects findings from other developing countries in Asia such as Malaysia (Namasivayam et al. 2011) and India (Shanmugasundaram et al. 2006) where providing care for the sick and dying is a moral obligation for family members. Indonesian culture stresses the important role that family members play in providing care for their loved ones (Effendy et al. 2014). This is also reflected in a study reporting on the assistance given by relatives to women post mastectomy with families providing physical and spiritual support (Anggraeni & Ekowati 2011). Although only one study identified addressed in detail community involvement in palliative care activities (Saleh et al. 2008), it has been recognized that community involvement has been a feature of the Indonesian healthcare system more generally (Joint Committee on Reducing Maternal and Neonatal Mortality in Indonesia, National Research Council & Indonesian Academy of Sciences 2013). Given the level of family and community support that currently exists for family caregiving in cancer care, research is required to determine how best to support families and community groups in the provision of palliative care in Indonesia.

The main barriers to provision of palliative care include limited access to opioids, limited knowledge of palliative care and geographical constraints. Other developing countries such as Turkey (Komurcu 2011) and Pakistan (Shad et al. 2011) also face similar constraints. Existing evidence states that access to opioids is limited (Al-Shahri 2002; Soebadi et al. 1996). A recently published report based on data from the International Narcotics Control Board, the International Agency for Research on Cancer's GLOBOCAN 2012 data set and the World Health Organisation indicated approximately 80% of cancer patients in Indonesia still die with moderate or severe pain (O'Brien 2014). One study stated that opioidphobia is still an issue (Witjaksono et al. 2014). To be able to get health professionals feeling comfortable with the use of opioids, education (e.g. the safe use at home, treating misconceptions on opioids) is required to overcome this issue.

Limited knowledge and understanding of palliative care can be attributed to a shortage of palliative care expertise (Amery 2012) and lack of palliative care education (Witjaksono et al. 2014). Education on palliative care can be conducted for doctors and nurses working in the community and can be integrated into the curriculum of health profession undergraduate and postgraduate programmes. In addition to this, educating family and community groups about palliative care, particularly on how to provide care at home, would improve the status of palliative care.

Another major constraint is Indonesia's geography. Half of Indonesian population live in rural areas (Central Bureau of Statistic (Badan Pusat Statistik/BPS) 2010) while only ten palliative care services are available in seven larger cities (Effendy et al. 2015; Witjaksono et al. 2014). This situation results in very limited access for Indonesian people living in rural areas to obtain palliative care. Australia also has difficulties in providing specialist health services in rural areas. Several strategies have been implemented to improve access to palliative care in rural areas including capacity building for non-specialist practitioners (Recoche et al. 2014), integrating palliative care to primary care services (Palliative Care Australia 2005) and increasing involvement of general practitioners in developing local palliative care services (Phillips et al. 2006). Some of these strategies could also be implemented to improve access to palliative care in Indonesia. For example, shifting the focus from educating specialists in palliative care to educating generalist nurses and doctors working in the community, in the form of continuing professional education, would have considerable potential. It is likely most specialists in palliative care would continue to be based in larger cities not in rural areas. Such education then needs to focus on building non-specialist doctors' and nurses' capabilities in palliative care. These doctors and nurses would then be able to directly implement better palliative care to their patients.

Acknowledgement of these constraints in Indonesia might be the first step towards better development of palliative care. In relation to palliative care knowledge acquisition, the World Health Organisation (WHO 2014b) recommends the mandatory integration of hospice and palliative care education in undergraduate medical and nursing programmes. Training programmes targeting existing health professionals would also be of benefit; the World Health Organisation (WHO 2014a) indicates that continuing professional education should include palliative care in its content. Consequently, skilled and qualified health professionals would be able to support the implementation of palliative care in Indonesia.

Limitations

This was a comprehensive review of the literature and may be considered limited in that no explicit critical appraisal was conducted of the material presented, as would occur with a systematic review. The decision not to conduct a systematic review was based on the nature of the question which was broad and explorative rather than seeking to answer a specific clinical question. In addition, it is acknowledged that palliative care services, particularly those provided in rural and remote settings, may be provided but not documented in published or other public sources.

Implications for nursing and midwifery policy, education and practice

Palliative care provision encourages an interdisciplinary approach in delivering the service. Among health professionals, however, nurses have the potential to play a more central role in the provision of palliative care. Nurses are more engaged with patients and their families particularly in the provision of care such as symptom management. This provides an opportunity to educate patient's families in how to provide basic care at home.

Primary care nurses without specialist palliative care education and experience will increasingly come in contact with patients diagnosed with a life-limiting illness. The limited understanding of palliative care among nurses can be improved by introducing palliative care education more broadly into nursing education programmes, and through professional development activities. This should be aimed at not only training specialist palliative care nurses but pragmatically all generalist nurses who may come in direct contact with patients who have palliative care needs.

Limited understanding by families of palliative care services, such as timing of referral, symptom management, and service availability can be associated with poor quality of life of palliative patients. A study conducted by Ibrahim et al. (2011) verified the need for informational support and capacity building for families to enable them to better provide care for patients. Nurses could contribute by educating patients, their families, and communities about palliative care services. This includes basic care for patients, symptom management, care for dying and death, and how to access palliative care services.

Informing the general public about palliative care is also important. A number of healthcare professionals are involved in the Indonesian Palliative Society. They are lifting the profile of palliative care by participating in events such as the World Hospice and Palliative Care Day in 2014; conducting press conferences and palliative care seminars (Bararah 2014; World Hospice and Palliative Care Day 2014). We propose that nurses should participate in these activities to raise families' and communities' understanding about palliative care and in particular how to provide basic care for patients. Consequently, this will help to improve the quality of life of people with life-limiting illness.

Implications for research

Given the limited palliative care research identified in the Indonesian setting in this review, nurses and other health professionals have an opportunity to undertake research to identify culturally appropriate strategies to improve the quality and reach of palliative care. Aspects of nursing practice which could be investigated in relation to improving provision of palliative care include the exploration of cultural factors that influence the provision of palliative care, comparison of the effectiveness of nursing interventions, identifying patient and family preferences and how these affect nursing care, developing or adapting tools to measure changes in health status, and patient satisfaction with palliative care provision.

Conclusion

Advancement of palliative care within the healthcare system in Indonesia is needed to ensure equity of access and improve the quality of life of patients with cancer and their families. The development of palliative care is progressing across the globe; however, the present review has highlighted a dearth of studies addressing palliative care in Indonesia. The literature that was identified also paints a picture of the relatively slow progress of palliative care development. However, there are a number of factors that are a cause for encouragement. Families in Indonesia are actively involved with the care of loved ones and the community also has had a history of involvement in health care. Regional and national government acknowledge the importance of this issue through the national policy statement that promotes palliative care service development and implementation of basic palliative care training for health professionals. The challenge is to provide sufficient resources for this to occur. Although this paper focuses on the Indonesian context which has certain unique features, our findings also have international relevance. Aspects such as slow progress in development, a culture of strong family involvement and geographical constraints are relevant to many other developing countries attempting to improve palliative care services.

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Author contributions

Study conception and design: ER, RW, KC.
Literature review/analysis: ER.
Manuscript draft writing: ER.
Study supervision: RW, KC.
Critical revisions for important intellectual content: RW, KC.

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Synthesis of chapter two and three

The discussion of international literature has been provided in Chapter two. This discussion has indicated that the development of palliative care has been largely in well-resourced countries. The integrative review in the Chapter three has demonstrated that the development of palliative care in Indonesia has been slow and this is likely due to lack of resources. Chapter two and three has highlighted that family support and involvement is an important element that can facilitate the provision of palliative care.

Chapter 4: Methodology

Introduction

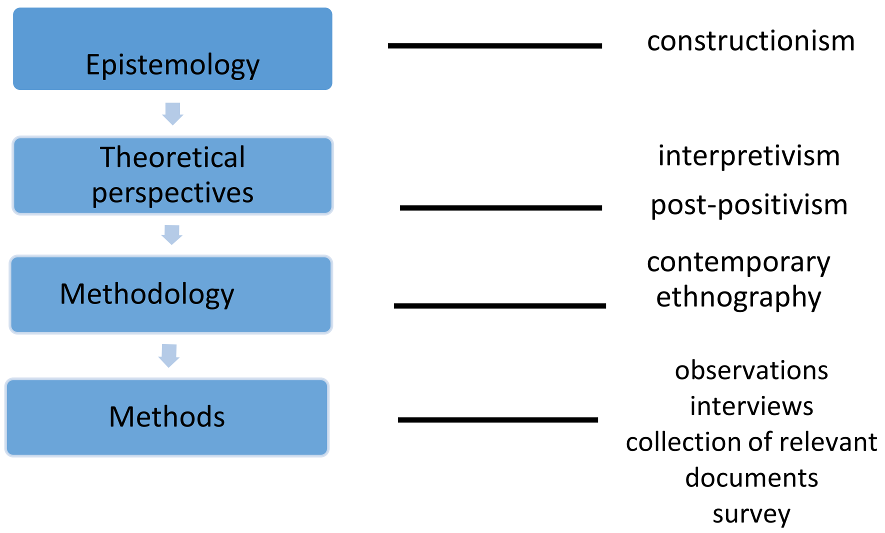
The study aimed to explore the provision of palliative care and the cultural aspects in two palliative care units in Indonesia. To fulfil the aims of this study, it was important to adopt a suitable methodology that allowed understanding of the construction of meanings and experiences of participants within the context of their worldview and cultural setting. An exploration and justification for the choice of the methodologies and methods, facilitated by an understanding of complex issues underpinning cultural aspects in the provision of palliative care, is provided in this chapter.

There are three major parts in this chapter. Part one provides an explanation of the research framework adopted for this study that includes epistemology, theoretical perspectives and methodology. Part two highlights the principal characteristics of classical and contemporary ethnography, and the use of ethnography in nursing and palliative care research. Part three discusses the issues of trustworthiness in relation to this methodological approach.

Research framework

This study adopts Crotty's (1998) research framework as his framework is clear and able to facilitate the researcher in justifying the decision regarding the appropriate research model. Crotty (1998) divided his framework into four stages including epistemology, theoretical perspectives, methodology and methods. Figure 1 describes the research framework for this study. The following sections provide explanations and the justification of research framework for this study, starting from the selection of epistemology and post-positivism and interpretivism theoretical perspectives.

Figure 1: Research framework for this study; epistemology, theoretical perspectives, methodology and methods (adapted from Crotty 1998)



Epistemology: Constructionism

Epistemology is a way of explaining "how we know what we know" (Crotty 1998, p. 8). Moreover, it provides the focus for a study (Schneider et al. 2003).

Crotty's (1998) three epistemological constructs comprise constructionism, objectivism and subjectivism. Constructionism is based on assumption that human beings seek understanding of the world in which they engaged and they are actively involved in constructing the meanings of reality (Cresswell 2009; Crotty 1998). These authors stated that the meanings of reality are not simply produced but they are formed through social interaction and are being constantly developed and revised. Thus, it is assumed that researchers need to address the process of interaction by participating in the world being investigated. Multiple and various meanings of the individuals lead the researcher to search for complexity of views rather than narrowing meanings into a few ideas (Cresswell 2009). In order to enable the understanding of complex views, the epistemology of constructionism allows the use of multiple methods and data sources to support and strengthen interpretations of findings. In summary, the epistemology of constructionism established an understanding that meaning and knowledge is acquired and constructed among group members of the subjective and objective world (Crotty 1998). Constructionist researchers focus on specific contexts in which people live and work, to be able to understand the cultural setting of participants and to construct patterns of meaning (Cresswell 2009).

Crotty (1998, p. p.5) defines objectivism as the belief that 'truth and meaning residing in them as objects'. The goal of objective research is to explain, predict, and control, and that such objective truth and meaning can be discovered through appropriate methods of inquiry (Levers 2013). Levers (2013) states those declaring objectivity claim to remove all contextual factors to observe and know the phenomena as it exists independent of the human mind. Removal of human bias leads to the discovery of knowledge. In this paradigm, what is observed is not changed by the observer, nor is the observer being influenced by the observed (Levers 2013).

Another epistemological paradigm is subjectivism. Subjectivism as defined by Crotty (1998, p. 43) as the 'meanings are created out of whole cloth and simply imposed upon reality'. The purpose of subjective research is to develop understanding, increase sensitization to ethical and moral issues, and personal and political emancipation (Denzin & Lincoln 2005). A subjective epistemology recognizes knowledge as value laden where unaffected and universal knowledge of an external reality is not possible beyond individual reflections and interpretations (Levers 2013). Further this author highlights that observations are influenced by the observer and the observer is influenced by the observed.

Among Crotty’s (1998) three epistemological constructs, the researcher adopted the constructionism as an epistemological stance for this study. This epistemology has been deemed appropriate as it allows the researcher to understand and construct the meaning of reality from the perspectives of different individuals who have experienced the phenomena being investigated, which was the provision of palliative care services.

Theoretical perspectives underpinning: post-positivist and interpretivism

The theoretical perspective is “a philosophical stance lying behind a methodology which provides a context for the process involved and a basis for its logic and its criteria” (Crotty 1998, p. 66). There are number of theoretical perspectives to shape a research methodology; for example, positivism, post-positivism, interpretivism and feminism. It should be noted that the use of these theoretical perspectives should be based on the research aims and questions seeking to answer (Saunders, Lewis & Thornhill 2007). Further, Saunders, Lewis and Thornhill (2007) and Weaver and Olson (2006) add that combining multiple perspectives will enable the researcher to meet demands for practice (i.e. nursing practice, business and management). Coming from a constructionist foundation, the notion of multiple perspectives was applied in this study to enhance the researcher’s interpretations. A mixture of theoretical perspectives between post-positivism and interpretivism were considered as suitable perspectives underlying this study to accomplish the aims. The following section provides a discussion on post-positivist and interpretive theoretical perspectives and the major critique of these perspectives. An explanation of the triangulation between two theoretical perspectives will be given in the section of ethnography and triangulation.

Post-positivism

Positivists seek objectivity and generally assume that reality is objectively given and can be described by measurable properties and hypothesis testing (Polit & Beck 2004; Warelow 2013; Weaver & Olson 2006). Positivist studies generally attempt to test theory and commonly undertake data collection in structured forms often with strong control such as experimental studies and survey (Welford, Murphy & Casey 2011; Young 2008). Therefore, the purpose is to derive findings from empiric studies to make generalisation about the concept beings studied (Young 2008). Positivism has, however, been criticised due to its inability to examine human beings and their behaviours in an in-depth way and particular in regard to concepts such as anxiety or well-being (Crossan 2003; Parahoo 2014).

The theoretical perspective of post-positivism has emerged in response to criticisms surrounding positivism (Crossan 2003; Forbes et al. 1999). This approach commits the generation of knowledge can be obtained by explaining and describing a phenomena of interest (Routledge 2007). Post-positivist philosophies shift the focus from measurement and causation to a more qualitative and interpretive method to elicit the knowledge of social phenomena (Crossan 2003; Warelow 2013). Routledge (2007), however, highlights that there is some agreement between positivism and post-positivism in term of methods for data collection. The post-positivism maintains belief in “observables” which refers to phenomena that can be measured using valid and reliable instrumentations or methods (Routledge 2007). The methods or data collection commonly utilised are observations, surveys and interviews.

The adoption of post-positivism in this study enabled the researcher to discover some observable characteristics and views of palliative care. In this study, the use of interviews and questionnaires to some degree were founded on this principle. The post-positivist element of the investigations was designed to obtain knowledge of the phenomena of interests (i.e. relatives' views and satisfaction of palliative care services and influencing factors of these phenomena).

A post-positivism approach is often criticised due to the proximity of the researcher to the investigation (Parahoo 2014). This proximity increases risk of researcher bias that may impact on the reproducibility and generalisability of research findings. Therefore, the use of flexible and multiple methods in-depth over a period of time is suggested to enable establishing understandings of the situations or phenomena under examination (Crossan 2003; Routledge 2007). For this reason, the interpretive approach was incorporated to counteract such criticism and to gain a broader understanding of the provision of palliative care in the two Indonesian palliative care facilities.

Interpretivism

The interpretive paradigm is a theoretical framework which builds from a constructionist foundation and it is defined as a process of interactively interpreting reality in the social world (Crotty 1998). Multiple interpretations of social reality are possible due to its complexity and context-dependency (Polit & Beck 2004). To understand the social reality, therefore, the interpretive framework stressed the importance to include researcher's tacit knowledge (intuitive, feelings) in addition to observations of verbal and non-verbal behaviors (Lincoln & Guba 1985; Petty, Thomson & Stew 2012a; Ritchie & Lewis 2003).

Some writers highlight that the interpretive framework upholds an understanding that reality is best explored when the researchers have experience in their lived situations, immerse themselves in the local culture and engaged in interaction with the world being studied (Crotty 1998; Petty, Thomson & Stew 2012a; Weaver & Olson 2006). The methods of data collection commonly used are observations and interviews. The interpretive researcher attempts to construct interpretations from the field through exposure to the phenomena of interests. This means that the researcher needs to have interaction and develop intimate familiarity with participants to find and interpret meanings of social reality. In addition, the interpretive framework allows researchers to utilise multiple methods to achieve research objectives (Russell 2004; Saunders, Lewis & Thornhill 2007).

According to the interpretive position, it was believed the adoption of this approach would enable the understanding of the context and meaning of palliative care provision in Indonesia. The interpretive element aimed to obtain a deeper understanding of the cultural group, in this case the palliative care professionals, patients and their relatives. Such a position alone, however, might not be adequate because it does not acknowledge the holistic issues underpinning cultural aspects in the provision of palliative care which can be complemented with a post-positivist perspective. In response, paradigmatic integration between post-positivist and interpretive paradigms which align with the fundamentals characteristic of contemporary ethnography was considered a pragmatic solution.

Methodology – ethnographic research

This section provides details on the definition of ethnography, cultural concepts and ethnography as a mode of inquiry for this study. Following this, genres of ethnography including classical and contemporary ethnography are discussed. This section highlights the use of ethnography in nursing and palliative care. A discussion of ethnography and triangulation is also addressed.

Ethnography

Ethnography is considered as the eldest tradition of qualitative inquiry (Patton 2002) and one of the oldest qualitative approaches used in nursing research (Oliffe 2005). The word ethnography originated from Greek “ethnos” (people or cultural group and their culture) and “graphic” (science of description) (Muecke 1994; Patton & Westby 1992). Accordingly, the term ethnography means the work or description of people and a cultural group.

Ethnography has its origins in anthropology and in 1920-1930 principles of ethnography were used by American sociologists to study cultural groups in USA (Petty, Thomson & Stew 2012b), and became the primary methodology used in anthropology and sociology research (Patton & Westby 1992). More recently, ethnography has been adopted in many different disciplines (Holloway & Todres 2010), which indicates that ethnography is not a static research approach. This flexibility arises because ethnography has been reinterpreted and recontextualised in various ways to deal with a particular contexts and disciplines (Atkinson & Hammersley 2007).

This adaptive history has made the term ethnography somewhat ambiguous and defining ethnography is problematic (Agar 1996; Atkinson & Hammersley 2007; de Laine 1997). Hammersley (1990) states ethnography can be viewed as a theory. Others consider ethnography as methodology of data collection, a style of written report (de Laine 1997), a process and product (Agar 1996; Fetterman 2010; Wolcott 1990). de Laine (1997) highlights that ethnography was the theoretical framework that was informed by many orientations and traditions such as cultural, symbolic interactionism and post-modern approaches. This combination of orientations and traditions made ethnography a well-established and well-suited approach used in qualitative health science and social research (de Laine 1997; Patton 2002; Thompson & Nelson-Marten 2011).

The concept of culture

Ethnography emphasises the understanding of a culture by studying human behaviour in a particular cultural context (Holloway & Wheeler 1996). Wolcott (1990) states that the distinguished characteristic of ethnography is its focus on cultural perspectives. Having said this, it must be asked, what is culture? In this study, culture was defined as a set of behaviours, attitudes, knowledge, beliefs and ideas that people use to shape their ways of living or actions they choose to make (de Laine 1997; Schensul & LeCompte 2013; Spradley 1980). In a cultural group, however, there may be people who do not believe the same things or act in the same way as other members. This is because people's beliefs, attitudes and behaviours vary depending on ethnicity, gender, educational levels and age. Therefore, to understand culture ethnographic researchers need to consider context and live within the context over a period of time as this contextualisation enables a more accurate description of culture (Fetterman 1981 as cited in Fetterman 2010; Kawulich 2005).

In the current study, the descriptions of the provision of palliative care will draw on the life, behaviours, practices and beliefs of the palliative care health professionals, patients and relatives under examination. Through describing and analysing the data from observations, interviews and review of documents, the culture of the palliative care provision, practices, belief and behaviour of palliative care health professionals, patients and relatives can be understood.

Ethnography as mode of enquiry

The focus of qualitative research is to understand human behaviour and how people are embedded in their own culture (de Laine 1997; Holloway & Todres 2010). Ethnography is a particular qualitative approach used to describe culture or subculture in a specific context (Oliffe 2005). Moreover, Cresswell (2009) states that ethnography aims to understand how people in their daily lives from their own perspective rather than the outsider's perspective. In addition, the principles of ethnography aim to capture a holistic understanding of the social and cultural world of people (Patton & Westby 1992). There are advantages in adopting ethnography as a research methodology, these include the ability to gain detailed data, and achieving holistic explanations (Savage 2006). Oliffe (2005) highlights the advantage of an ethnographic approach when exploring new and unknown things; in this case, the use of ethnography to explore palliative care in Indonesia is well suited due the limited availability of the information. Therefore, the methodology that was most appropriate for this study was ethnography as this study aimed to explore the provision of palliative care and what elements influence the practice of palliative care in Indonesia where information about these practices are limited.

Genres of ethnography

As discussed in the previous section, ethnographic methodology has been developed and reinterpreted in order to be relevant within particular circumstances and disciplines (Atkinson & Hammersley 2007). Historically, ethnography has been categorised into two main types; classical and contemporary (Picken 2009). The following section describes each type of ethnography and their commonalities and contrasts.

Classical ethnography

Classical ethnography is considered as traditional and anthropologically oriented (Picken 2009). It was originally developed in the 19th century when early Western anthropologist began to study non-Western societies and cultures (Agar 1996; Atkinson & Hammersley 2007; Speziale & Carpenter 2007). Classical ethnography is described typically as having prolonged contact with a particular cultural group under study, requiring extensive and intensive fieldwork to allow the ethnographer immersion into the culture. It is often an unstructured approach where the researcher needs to be explorative and flexible in term of the length of time in the field and the level of participation in observations (Atkinson & Hammersley 2007; Oliffe 2005; Roberts 2009). There are arguments, however, that classical ethnography is considered unsuitable for many research projects where researchers have significant time constraints, a more narrow focus and more defined objectives (de Laine 1997).

More recently, a different approach for conducting ethnography has evolved and changed to adjust to a modern world. Ethnography has adapted to meet research needs that are different in term of aims, scope, resources and time. For example, in recent years some of ethnographic studies have been conducted in a relatively short-term field visit and typically compensated by the intensive use of audiovisual technologies of data collection and data analysis (Knoblauch 2005). This approach has been applied in disciplines such as sociology, education and nursing to study health problems and social issues in modern and contemporary societies. The new trend which accommodates flexibility and uniqueness in modern world has been termed contemporary ethnography (de Laine 1997; Picken 2009; Speziale & Carpenter 2007).

Contemporary ethnography

Ethnography is considered both pragmatic and adaptive. The reason contemporary ethnography has developed is that the classical ethnography was unable to accommodate with a rapidly changing world (Picken 2009). Classical ethnographic approaches are not suited to the needs of researchers who explored aspects of culture with very different focus and scope than previously studied. Contemporary ethnography is more able to "address specific aspects of fields in highly differentiated organisations" (Knoblauch 2005, p. 2). Contemporary ethnography is an umbrella term that incorporates a number of different forms of ethnography, namely: focused ethnography, applied ethnography, rapid ethnographic assessment, online ethnography, experimental ethnography (Cruz & Higginbottom 2013; Goepp et al. 2008; Higginbottom, Pillay & Boadu 2013; Parahoo 2014; Savage 2006; Strang & Sherman 2004; Wittel 2000). These are often described as being hybrid in that they bring many of the tradition of classical ethnography but with new ways and methods.

Contemporary ethnography has two notable differences from traditional ethnography. The cultural diversity in the 21st century has changed the concept of cultural groups as unit of study and the notion that ethnography is no longer exclusively qualitative research (Parahoo 2014). The traditional ethnography was typically conducted in an isolated group which has clear boundaries; while contemporary ethnography is generally limited to small element of society (Knoblauch 2005), or looking at a distinct issue or situation within specific context among a small group who live in a bigger society (Roper & Shapira 2000). Ethnographic research can utilise both qualitative and quantitative methods where triangulation of both type of data establish validity and representation of the phenomena being measured (Bernard 2006; Fetterman 2010; Savage 2006; Thompson & Nelson-Marten 2011).

Contemporary ethnography is characterised by a short-term field visit, smaller scale research, involvement of a limited number of participants, and the flexibility to select very specific issue for investigation prior to entering the field (Higginbottom, Pillay & Boadu 2013; Parahoo 2014; Thompson & Nelson-Marten 2011). Bernard (2006) and Higginbottom, Pillay and Boadu (2013) add that in contemporary ethnography the researcher goes to the field with a list of specific and clear questions to answer or a checklist to complete. There is an argument that the shorter period in the cultural setting is possible because the researcher can have prior knowledge of the culture such as the language and etiquette of the group. Due to limited time frames, however, researchers should consider that they might lose the benefit of being able to adjust and refocus data collection when something does not go as planned (Wall 2015).

The ability of contemporary ethnography to capture data on specific topic of importance to researcher makes this genre suitable for health research (Cruz & Higginbottom 2013; Higginbottom, Pillay & Boadu 2013). Concerning all these positive features, contemporary ethnography was perceived as very appropriate to this study, particularly as the researcher had an understanding of language and other cultural aspects of the selected culture.

Similarities and contrast for classical and contemporary ethnography

Classical and contemporary ethnography share commonalities. Both classical and contemporary ethnography focus on culture and this is the basic tenet of ethnographic. Spradley (1980, p. 2) emphasises that ethnography is “the work of describe culture to understand another way of life from the (other person’s) point of view” using direct experience with a population or community of concern (Schensul & LeCompte 2013). Having direct experience in a cultural group, ethnographers are able to gain in-depth perspective including overt and covert (Higginbottom, Pillay & Boadu 2013). The overt refers to explicit dimensions of culture that are known to members while covert are tacit knowledge that shared by members of the culture but may not be articulated (Fetterman 2010). In the other word, ethnographers make tacit knowledge explicit (Holloway & Todres 2010). Spradley (1980) suggests using a combination of observing people’s behaviour, listening carefully of what people say and studying cultural artefacts to infer this tacit knowledge.

Another similarity between classical and contemporary ethnography is the researcher being the instrument for data collection. The researcher becomes a research instrument primarily through observing, recording data, interviewing people, and examining cultural artefact (Speziale & Carpenter 2007). Similar cultures can be seen differently by two researchers as their have their personal characteristic, experiences, cultural background and professional trainings. These factors are potential to influence the researchers’ assumptions about the nature of the reality, research questions and interpretation of data (Agar 1996; Schensul & LeCompte 2013). Clearly, ethnographers have influence on data and yet it is impossible to eliminate the influence of the researcher in ethnographic studies (Agar 1996). In the case of nurses undertaking ethnographic nursing research in their own areas, some ethnographers believe that is inappropriate because it will prevent participants for being explicit and will be seen as a nurse not as a researcher (Holloway & Todres 2010). To prevent these problem in this study, the researcher investigated palliative care in two facilities in which the researcher was unfamiliar with the situations. However, the researcher had prior knowledge such as native language and etiquettes of the groups and such knowledge could be positive as there is less time to learn about language and etiquettes

Despite having some similarities, there are also differences between classical and contemporary ethnography. The differences, however are not always distinct and it should be noted that rather than being opposed to, contemporary ethnography is a complementary to classical ethnography (Knoblauch 2005). Classical ethnographers usually spent a long period of time in the field, while the fieldwork in contemporary ethnography usually is shorter or in some conceptualisations, may be omitted (Higginbottom 2011; Knoblauch 2005).

In term of methods and strategies, classical and contemporary ethnography are different in which knowledge is constructed. As their main data collection methods, classical ethnographer usually use participant observations, informal conversations with one or a few persons from the selected culture, and collection of cultural artefacts (Muecke 1994). On the other hand, contemporary ethnographers undertake more focused and structured methods to collect data such as formal interviews and episodic participant observation and the use of audiovisual during data collection (Higginbottom, Pillay & Boadu 2013; Knoblauch 2005). In addition, contemporary ethnographers might involve quantitative elements such as surveys in their studies to be able to provide a more comprehensive understanding of the studied culture (Savage 2006).

Ethnography in nursing

In nursing research, ethnography was first used in the United States (Holloway & Wheeler 1996). Typically nursing research has used more contemporary approaches such as “focused ethnography” which has been increasingly acknowledged its contribution to the development of nursing knowledge and practice (Cruz & Higginbottom 2013; Higginbottom, Pillay & Boadu 2013; Holloway & Wheeler 1996; Savage 2006). Holloway and Todres (2010) emphasise that the nature of conducting ethnographic research is different between nurse ethnographers and anthropologists. First, nurse ethnographers do not solely aim to generate knowledge as the primary goal of ethnography (Atkinson & Hammersley 2007), but they also wish to change and improve professional practice through understanding the culture they study (Holloway & Todres 2010; Thompson & Nelson-Marten 2011). Second, Holloway and Wheeler (1996) state that nurse ethnographers have familiarity with the language and terminology used in the setting where the research takes place. In addition, nurse ethnographers only live with the informants during their work day and spend their private lives away from the location of the study.

Apart of nurses’ familiarity with the language and the setting, de Laine (1997) and Bassett (2004) concern challenges that might be encountered by nurse ethnographers when conducting their studies. de Laine (1997) identifies nurse ethnographers may have difficulties in conceptualising problems into broader perspectives because their prior professional nursing training generally focused on the individual rather than groups or communities. Bassett (2004) highlights the difficulties that might be encountered by nurse ethnographers during observations include; time constraints, conflict of roles, and ethical dilemma.

It is important for nurse ethnographers to understand the major epistemological, theoretical perspectives, principles and issues concerning ethnography. It is also important to acknowledge that the focus on culture remains as the fundamental principle of this research tradition.

Ethnography in palliative care

The ethnographic approach is less commonly used in palliative care research (Walshe, Ewing & Griffiths 2012). The ethnographic studies that have been conducted in palliative care were done in Western countries and have commonly focused on decision making, end of life and family caregiving (Adams 2013; Anagnostou et al. 2010; Emilsdottir & Gustafsdottir 2011; Sims-Gould et al. 2010; Waldrop 2010). To date, there is no ethnographic work on palliative care conducted in Indonesia. Therefore, the use of contemporary ethnography in this study would enable the exploration of the provision of palliative care in Indonesia. In addition, this study would enrich the use of ethnographic approach in palliative care research.

Ethnography and triangulation

The integration of theoretical perspectives and multi-method approaches is termed triangulation. The term triangulation was originally described in navigation and surveying to demonstrate exact position from two landmarks by forming a triangle (Atkinson & Hammersley 2007). According to Fetterman (2010, p. 94), triangulation is a basic feature of ethnographic research and "is the heart of ethnographic validity". The use of triangulation is suggested as it reflects an attempt to secure in-depth understanding of the phenomena and enhancing the quality of data and the accuracy of ethnographic findings (Denzin & Lincoln 2005; Fetterman 2010; Maggs-Rapport 2000). In this study, triangulation was conducted to improve the completeness of data collection and interpretation of findings. Moreover, triangulation enabled to the researcher to have a more comprehensive understanding of issues related to cultural aspects in the palliative care service.

It has been suggested that triangulation can be adopted in four different ways: methods triangulation, sources triangulation, theoretical/perspective triangulation, and analyst triangulation (Patton & Westby 1992). Following research framework from Crotty (1998) as discussed in earlier section, there were two types of triangulation underpinning this study: theoretical and methods triangulation. These triangulations in this particular study should be seen as complementary rather than exclusive. The adoption of theoretical triangulation drives researchers to use multiple theoretical approaches to examine phenomena, analyse and interpret the data (Patton 2002).

Theoretical triangulation leads to other elements in a research (i.e. the use of tool, type of data, and type of data analysis). In this study, theoretical/perspective triangulation was used by a combination of post-positivist and interpretivism perspectives. Such triangulation allows the researcher to capture a more holistic, contextual portrayal and complex of a given phenomenon (Monti & Tingen 1999). This combination has several strengths: ability to examine different dimensions of phenomenon and increase productivity, and ability to look deeper and more broadly at findings (Monti & Tingen 1999). Under such theoretical triangulation, the objective knowledge and quantifiable issues (i.e. type of cancer and relatives' satisfaction of the care) can be addressed by adopting the post-positivisms perspectives. In addition, the adoption of interpretivism perspectives will enable to address the subjective knowledge in the form of contextual issues (i.e. how palliative care being delivered) underpinning the cultural aspects of palliative care provision in Indonesia.

Second, methods triangulation was adopted in this study. In term of pragmatic issue, the use of multiple types of data in this study enables the researcher to add more depth, to verify, to cross reference and to back up. The method triangulation involved the use of multiple data collections to address different dimensions of a topic such as observations, interviews, document analysis and questionnaire. Schensul and LeCompte (2013) add that methods triangulation provides confirmation and completeness. In this study, the observations, the examination of existing document and interviews allowed the researcher to scrutinise factors such as interactions between health professionals and patient and relatives and situations. In addition, the questionnaire was able to provide accurate assessment of the views of patients' relatives of the provision of palliative care.

Translation and language issues

Central to any culture is the language specific to that culture. Conducting cross-language research requires researchers to work with more than one language ranging from data collection to analysis and representation of the findings in publications (van Nes et al. 2010). Twinn (1997) suggests using the original language in conducting, transcribing and analysing data in qualitative studies to keep the clarity of the data. The translation process, however, is required to transfer the research findings into another language and to enable understanding of such research. The translation process between languages should be conducted properly and accurately, otherwise the data might be useless (Al-Amer et al. 2015). In term of quantitative instruments translation, Beaton et al. (2000) developed guidelines to achieve accuracy in the translations process which included; translation, synthesis, back translation, expert committee and pre-testing. Details of each stage in this guideline which was implemented in this study will be described in the Research Methods Chapter.

In qualitative research, the process of translation is more complex due to finding the equivalent words from the source to the targeted language (Twinn 1997), as well as the translator and translation style (Al-Amer et al. 2015). These difficulties could impact the trustworthiness of a research and its reporting. In order to achieve good translation, Twinn (1997) argued that using one translator could maximise the reliability of the data to provide adequate and accurate translation. In addition, Chen and Boore (2010) developed procedures for translation particularly in qualitative nursing research. The procedures involve: (1) transcribing and analysing data (i.e. from observation, interviews) in the original language (i.e. Chinese, Bahasa Indonesia) until concepts and categories have emerged, (2) translating these concepts and categories into the targeted language (i.e. English), (3) conducting back translation of the concepts and categories, (4) repeating the first and second steps as necessary to reduce any discrepancies between the original version and the back-translation, and (5) involving an expert committee to gain conceptual equivalence. Explanations of the data collection and translations process of this study is provided in the Methods Chapter.

In regards to translation and ethnographic research, Sturge (1991) states that ethnography always involves translation. Furthermore, Churchill (2005) argues that literary translation is appropriate for ethnographic research. In literary translation, the translator’s primary work is interpretive where the translator needs to enter the space of his/her subject in order to be able to capture the subtle meanings of their actions and words (Churchill 2005). Churchill (2005) added that the literary translators must be at home in two languages, have ability to seamlessly shift between his/her own language to target language without feeling a sense of distance. In this study, the translation process was conducted by the researcher herself with several considerations: (1) the researcher is fluent in both Bahasa and English, and (2) the use of one translator could improve the reliability of data.

Nature of data analysis in ethnographic study

Data analysis is the most complex and labour-intensive stage of research which requires hard work, creativity and conceptual sensitivity (Profetto-McGrath et al. 2010). For research which uses multiple methods, such as this study, this not only involves planning for the analysis of both quantitative and qualitative data, but also how the multiple data will be incorporated to produce comprehensive, rigorous and authoritative evidence answer the research questions.

Analysing quantitative data commences with organising the data (i.e. coding and entering data in particular software program) to ensure the completeness of the data. Once the data is entered, a statistical analysis is performed based on the research questions. In order to enable incorporation with qualitative elements (i.e. observations, interviews), narrative descriptions from descriptive analysis are made. Narrative descriptions from the quantitative findings are incorporated into qualitative data and analysed accordingly.

Analysing qualitative data starts with reading the data repeatedly to obtain a general sense of the content. The next step involves researchers searching for meaning units that could be in words, sentences or paragraphs containing aspects that are related to each other through their context or content. These meaning units are labelled as codes, which are then organised and combined to compare and contrast in further analysis to generate broader cultural themes of the investigated phenomena (Roper & Shapira 2000).

There are different approaches that can be used to analyse ethnographic data. LeCompte and Schensul (2013) state approaches used by ethnographers have similarities with ones used by other qualitative researchers. Several common techniques utilised for ethnographic analysis including: thematic analysis (Parahoo 2014); domain, taxonomic, componential analysis and discovery of cultural theme (Spradley 1980) and item, pattern and structural analysis (LeCompte & Schensul 2013). These techniques have similar processes but there are differences in terms of focus and scope of analysis. Selecting an appropriate technique is important to meet the specific needs of the ethnography being conducted. The researcher in this study used the approach from LeCompte and Schensul (2013) combined with elements of Spradley’s (1980) approach because it enabled the researcher to provide clear descriptions from large amount of differing types of data collected. Detailed descriptions of data analysis in this study is provided in the research methods Chapter.

Trustworthiness in this study

Different philosophies and assumptions underpin quantitative and qualitative research, therefore, different criteria are used to judge between these two research approaches. The need to evaluate or judge rigour of qualitative research has fueled debate and proposed three positions. First, some writers argue that qualitative research should be judged against criteria that are congruent with the qualitative paradigm (Bradbury-Jones 2007; Holloway & Wheeler 1996; Houghton, Hunter & Meskell 2012). This is because qualitative and quantitative forms of research are underpinned by different assumptions and philosophies (Porter 2007). Rolfe (2006) highlights the need to replace epistemic criteria with aesthetic criteria to judge qualitative research. Second, some suggested that qualitative should be evaluated according the same criteria as quantitative studies (LeCompte & Goetz 1982). Third, some question the appropriateness of any predetermined criteria for judging qualitative research since there is no unified paradigm, methodology and methods that can be collectively described as qualitative research (Hammersley 1990; Rolfe 2006).

This study was primarily interpretive in nature, however there were also some elements of investigation that were quantitative. The assessment of trustworthiness in this study should therefore take into account both interpretive and post-positive aspects. Distinct procedures were undertaken to ensure the quality of the quantitative element which aims to maintain reliability and validity. For the qualitative components, four general criteria of trustworthiness from Lincoln and Guba (1985) were employed. Discussion on each procedure is provided in the following sections.

Data quality for quantitative elements: validity and reliability

The issue of quality for quantitative elements for this study was ensured with two concepts: validity and reliability. To ensure the external validity of the survey, the researcher utilised instruments that measures what they are supposed to measure (Polit & Beck 2004). For example, in this study, the researcher administered the Canadian Health Evaluation Project (CANHELP) instrument measure family caregivers' satisfaction and needs in relation to palliative care services because this instrument was developed to measure such topic (Heyland et al. 2013).

Reliability of quantitative instrument is a measure for assessing its quality that the instrument provides consistent and repeatable results (Polit & Beck 2004). Internal consistency is the most widely used for evaluating the reliability, and usually presented in Cronbach Alpha coefficient. The Cronbach Alpha of the CANHELP in this study was 0.879 meaning that this instrument was reliable.

Data quality for interpretive elements

Lincoln and Guba (1985) constructed four general criteria to determine trustworthiness of the interpretive paradigm including, credibility, generalisability dependability and confirmability. These criteria are explained in the following section.

Credibility (internal validity)

According to Fetterman (2010) ethnographic research is about telling a credible and authentic story. LeCompte and Goetz (1982) further highlight that credibility is the major strength of ethnographic study. Credibility refers to a fit between participants' experiences and how the researcher represents them (Bradbury-Jones 2007). LeCompte and Goetz (1982) asserts that ethnographic works have a high credibility which derives from the data collection and analysis techniques used by ethnographers.

Starting from data collection, classical ethnography generally involves extensive periods of data collection in the field providing opportunities for access to wide range of actions and continual data analysis. In a contemporary ethnographic study, the short-term visit in the field can be compensated by the intensity of data collection (Knoblauch 2005). In addition, field observations are conducted in natural settings facilitating interpretation and reflection of the reality of participants' life experiences more accurately than research conducted in the laboratory (LeCompte & Goetz 1982).

There are many sources of threats to the credibility of ethnographic studies as highlighted by many authors (Green & Thorogood 2004; Jootun, McGhee & Marland 2009; LeCompte & Goetz 1982). However, they also indicate strategies to overcome those threats (Table 2).

Table 1: Threats and strategies used to promote credibility in ethnography

Threats	Strategies used
Researcher bias; impact of researcher's own culture, personal history of the phenomenon	Developing self-awareness Keeping a written journal for reflexive accounts on the observations and interviews Providing an analysis of the research context Providing direct quotes as exemplar for a particular definition Recording and self-transcribing the interviews and observations Member checking
Observer effects; participants may behave abnormally, withhold information, what they say and do may be different	Prolonged engagement with participants Persistent observation in the cultural site Conducting method triangulation in data collection Validity check on data that seem ambiguous Selecting participants based on inclusion criteria
Selection and regression effect ; some components of population/setting/field may be omitted	Using triangulation and incorporating multiple data collection Prolonged engagement Persistent observation in the cultural site Methodological sampling

The first threat is a researcher's bias due to his/her own culture and personal history of the phenomenon. Lincoln and Guba (1985) and Houghton, Hunter and Meskell (2012) suggest prolonged engagement and persistent observations and triangulation as major strategies to resolve such threat. Prolonged engagement refers to spending adequate time at the field to experience activities relevant to research. The latter strategy (i.e. persistent observations) describes observations to identify characteristics and elements in the situations that are most relevant to the problem (Denzin & Lincoln 2005). Although the presence of the researcher in the field inevitably affects the participants' behaviour, the effects may decline after repeated and prolonged engagement. LeCompte and Goetz (1982) add that continued observation in the cultural site facilitates access to wide range of participants' action and interactions that enable deeper understanding of a reality and a refinement of cultural constructs.

In this study, the researcher undertook prolonged engagement and persistent observations. A typical day of field work in the palliative care unit would start at 8 am and continued until the last home visit, usually at 3 pm or 4 pm. The prolonged engagement facilitated access to a variety of actions and interactions and provided a more in-depth understanding of the palliative care service culture. This ensured the completeness of the data collected. By following health professionals to patients for home visit and observing care in the palliative care outpatient clinic, understanding of the whole palliative care provision was achieved.

Triangulation, which is a critical component in ethnography, is suggested as another strategy to counteract the threat to credibility (Bradbury-Jones 2007; Denzin & Lincoln 2005; Schensul, Schensul & LeCompte 2013). In this study, the use of multiple theoretical frameworks and methods (observations, survey, interviews and document examination) were conducted to improve the credibility (internal validity) of findings and interpretations of this study.

Reflexivity is also essential in increasing credibility of an ethnographic study to reduce the threat of researcher's effect (Green & Thorogood 2004; Koch 2006; Lee & Zaharlick 2013; Thomson 2011). "Reflexivity acknowledges that the orientations of researchers will be shaped by their socio-historical locations, including the values and interest that these locations confer upon them" (Atkinson & Hammersley 2007, p. 19).

Keeping a field work journal to improve reflexivity is recommended (Arber 2006; Jootun, McGhee & Marland 2009; Koch 2006). For this study, the researcher carefully completed a field notes journal after every episode of data collection. The field notes included the documentation of personal feelings, any ethical dilemmas, perceived bias, and rationales for decision making. For example …'*I (researcher*) *feel upset and tearful when looking at grieving relatives during a patient's funeral'* (Field notes on 3 Feb 2014 p 19. L 20-21) and in the first meeting … *'I* (researcher) *think she (palliative care nurse) is kind and amiable'* (Field notes 27 January 2014 p.5 l 33-34).

The second issue in credibility is observer's effect, where the participants behave differently with what they say or withhold information. LeCompte and Goetz (1982) suggest establishing field relationship by prolonged engagement with participants and persistent observation in the cultural site. Many authors indicate that member checking is another strategy to validate findings (Lincoln & Guba 1985; Rolfe 2006; Thomas & Magilvy 2011; Tuckett 2005). Member checking refers to returning interview transcripts to the participants to validate that study findings are true to their experience (Holloway & Wheeler 1996; Houghton, Hunter & Meskell 2012). Furthermore, Houghton, Hunter and Meskell (2012) suggest conducting member checks following the transcription rather than after analysis to ensure participants are able to recognise their own experiences. In this study, the researcher asked participants to read transcripts after each interview to verify the interview contents.

Another issue of credibility is selection and regression where some components of population/setting may be omitted. LeCompte and Goetz (1982) suggest to conduct methodical sampling to assure that data adequately represent the population being investigated. Methodical sampling may be in the form of cross-informant interviewing for confirmation and validation of observations, interviews or structured questionnaire (LeCompte & Goetz 1982).

Generalisability

The term generalisability in quantitative research is often compared to applicability. Holloway and Wheeler (1996) explain that generalisability is how study findings are applicable, to a certain degree, to other settings, theory, practice and future research. Koch (2006) believes that transferability relies on similarity of context; therefore, dense descriptions of the study context is required to judge whether contexts are sufficiently similar.

In particular, provision of a dense and thick description of the cultural context establishes the transferability of qualitative study findings (Houghton, Hunter & Meskell 2012; Koch 2006; Thomas & Magilvy 2011; Tuckett 2005). The descriptions should include sufficient information which include major dimensions of every social situation (Spradley 1980). Spradley's (1980) major dimensions include: actors (i.e. nurses, patients, relatives), place (i.e. hospital, patient's home), activity (i.e. greeting, family meeting), object (i.e. medicines, Qur'an, Bible), act (i.e. measuring blood pressure), event (i.e. discussion), time (i.e. morning, afternoon), goal (i.e. comfort, pain free) and feeling (i.e. happy, sad).

In this study, transcripts from the observation utilised nine major dimensions from Spradley (1980) to provide thick descriptions. The use of thick descriptions of information gathered from multiple type of data (i.e. observations, interview, and examination of related documents) provided rich and deep insights into the culture of the provision of palliative care service. The researcher also presents related verbatim quotations from this data in the findings chapter.

Dependability

The concept of dependability in qualitative research is equated to reliability in quantitative research and linked to the more conventional term consistency

(Houghton, Hunter & Meskell 2012; Koch 2006; Rolfe 2006). It should be noted, however, that it is impossible to replicate an ethnographic study as an ethnographer cannot go back to the same time and reconstruct unique situations precisely (LeCompte & Goetz 1982). The ethnographic process is personal, meaning each ethnographer will have different philosophical assumptions which impact on the interpretation of the data and findings (LeCompte & Goetz 1982).

Several authors indicated that dependability can be enhanced through strategies such as searching for patterns (Fetterman 2010), researcher's status position, participant's selection and low-inference descriptor (LeCompte & Goetz 1982) and decision trail (Koch 2006). Fetterman (2010) suggests that the searching for patterns in people's thoughts and behaviours repeated in various situations is a strategy to enhance dependability. In this study, the researcher compared and contrasted existing data when coding or sorting data into categories or theme. This enabled verification of the coherence of the data. Dependability can also be achieved by obtaining repeated data over a long period of time and in different situations.

Other suggested strategies including recognition of researcher's role and levels of participation throughout the study, careful selection of informants, precise explanations of research process and low-inference descriptor (LeCompte & Goetz 1982). This strategy refers to immediately recording of data after each observation, describing phrased as precisely as possible from field notes. Dependability can be enhanced through low-inference descriptors. Details of the researcher's role, levels of participation and selection of informants will be explained in the Research Methods Chapter.

Decision trail is another strategy to enhance dependability as it provides a means for the researcher to establish audit trail linkages (Koch 2006). The audit trail can be maintained through comprehensive and explicit notes related to the contextual background of the research, as well as decisions and rationales taken about theoretical, methodological and analytic choices throughout the study (Houghton, Hunter & Meskell 2012; Koch 2006; Ryan-Nicholls & Will 2009). Several authors note that NVivo software program can be a valuable means for advancing the dependability of qualitative research (Bergin 2011; Houghton, Hunter & Meskell 2012). They believed that the query tools in NVivo enable the qualitative researcher to audit findings and the process during data analysis.

Decision trail refers to provision of explicit information on decision taken about the theoretical and methodological strategies used to collect and record data, and analytic choices throughout the study. All this information is made available in this ethnography. In this study, audit trail and the use of NVivo are methods for ensuring confirmability of the study. Decision trail including audio recording, verbatim transcripts and field notes has been documented and maintained for future audit. In addition, the use of NVivo for data analysis in this study promotes the ability to trace decisions which were made during data collection and data analysis.

Confirmability

According to Given (2008, p. 112) confirmability refers to

> Providing evidence that the researcher's interpretations of participants' constructions are rooted in the participants' constructions and also that data analysis and the resulting findings and conclusions can be verified as reflective of and grounded in the participant's perceptions.

Confirmability occurs when credibility, transferability and dependability have been established in a qualitative study (Guba & Lincoln 1989 as cited in Koch 2006).

Data quality for integrated elements

Contemporary ethnography incorporates multiple types of data collection methods; in this study the researcher also included a component of survey in addition to qualitative methods. To improve data quality in multiple type of data, triangulation is suggested as another strategy to counteract the threat to credibility (Bradbury-Jones 2007; Guba & Lincoln 2005; Schensul & LeCompte 2013). In this study, the use of multiple theoretical frameworks (interpretivism and post-positivism) and methods (observations, survey, interviews and document examination) were conducted to improve the credibility (internal validity) of findings and interpretations of this study. Multiple methods allow for two things to occur: provision of a more complete picture of situations and allowing process of comparison and contrast for data verification.

Ethical issues in ethnographic palliative care research

In an ethnographic research, ethnographers generally spend a considerable amount of time talking to people about what they think, observing what they do and how they interact with others. The data collected can be very sensitive and confidential. Some authors highlighted that undertaking research in palliative care is challenging due to the vulnerability of the population (Lee & Kristjanson 2003; Whiting & Vickers 2010). Lee and Kristjanson (2003) identify challenges from study participants such as patients who are often distressed due to their complex symptoms; family caregivers due to physical and emotional burdens from caregiving; and even health care professionals due to physical and emotional demanding jobs. While their conditions are deteriorating, palliative care patients might still take part in research for various reasons such as maintaining their contribution and being altruistic (Bellamy, Gott & Frey 2011). Consequently, scientific and sensitive research protocol and practical strategies need to be designed to ensure participants are both protected and feel able to participate in research (Wilkie 1997).

Several strategies have been suggested by previous researchers in palliative care settings; these include adopting appropriate methodological approach, obtaining consents, maintaining autonomy, being attentive/vigilance, and maintaining confidentiality (Hickman et al. 2012; Lee & Kristjanson 2003; Whiting & Vickers 2010; Wilkie 1997).

Whiting and Vickers (2010) stated that researchers should able to defend the scientific principles for their investigative work by considering appropriate the methodological approach that will be used. This study drew upon a contemporary ethnography comprising qualitative and quantitative element as this approach was felt to be appropriate to explore the provision of palliative care service in two palliative care facilities. Lee and Kristjanson (2003) and Wilkie (1997) indicated that qualitative methods might be the most appropriate to use in palliative care research because these methods allow in-depth investigation and can be designed to suit the available energy and resource subjects. In addition, this ethnographic study utilised observations where the researcher observed the interactions and activities of palliative care provisions in their natural environment without intervening any situations. In addition to methodological approach, Whiting and

Vickers (2010) highlighted that a study should only be undertaken if it aims to increase body of knowledge for a particular discipline. These authors emphasised the conduct a comprehensive literature review to enable identification of the scope of investigations. Whiting and Vickers (2010) acknowledged the necessity to conduct further examination of palliative care patients and their families within a unique geographical area. In this study, following a literature search, the researcher considered that it is important to conduct a study in Indonesia due to its unique geographical area, limited palliative care facilities availability, and limited published paper found.

Obtaining consents is challenging in palliative care research. Palliative care staff could be the gatekeepers to contact patients and their relatives by identifying and confirming that they are eligible to be involved in a study (Hickman et al. 2012). In regards to obtaining consent from palliative care patients, Seymour and Ingleton (1999) offer an unusual path when conducting research with palliative care patients by obtaining surrogate consent or consent by proxy. These authors argued that obtaining direct consent from palliative care patients might be impossible due their severe conditions. In addition to this, Hickman et al. (2012) state that patient's consent could be obtained by health professionals.

Respecting people's autonomy is a fundamental principle of research (Hammick 1996 as cited in Whiting & Vickers 2010). Components in respecting autonomy are respecting participant's decision whether or not to become involved in a study. During the research process, researchers need to preserve patient's autonomy and privacy (Seymour & Ingleton 1999) by focused on the activities and interactions between palliative care staff and family caregivers rather than only on the patients themselves.

Another strategy in conducting palliative care research is being attentive/vigilant. When participating in a research, the palliative care patients are potentially liable to experience physical and psychological distress as a result of research and their illness (Whiting & Vickers 2010). Therefore, researchers should increase their vigilance of possible effects of study participation on the participants' physical and emotional wellbeing (Hickman et al. 2012). As palliative care research generally also involves family caregivers and palliative care staff, researchers also need to be attentive to emotional needs of the relatives and palliative care staff (Hickman et al. 2012).

All participants in research have the right to privacy, anonymity and confidentiality (Seymour & Ingleton 1999; Whiting & Vickers 2010). In maintaining confidentiality researchers need to be aware of the source of information and ensure that all data are securely stored (Whiting & Vickers 2010). In regards to anonymity, palliative care researchers might experience difficulty in maintaining anonymity due to small number in sample so that individual participant might be identified (Bellamy, Gott & Frey 2011; Seymour & Ingleton 1999). The use of pseudonyms to denote settings and participants might be useful, but this strategy could raise another issue, for example, the potential for lost positive publications that could be of benefit patient care and staff morale. Seymour and Ingleton (1999) therefore argued that anonymity must be subject to negotiation between researchers and study participants. Researchers could decide whether or not to reveal the location/setting following careful consideration, however special attention and attempts must be made to ensure that individual anonymity is preserved (Seymour & Ingleton 1999).

Summary

In the first section of this chapter, the research paradigm and philosophical principles underpinning this study was described. It was then followed by a discussion about two genres of ethnography; classical and contemporary ethnography. The final aspects of this chapter addressed the issue of rigour and strategies to enhance the trustworthiness of this study and ethical issues in conducting ethnographic palliative care research. The following chapter focuses on the detailed and descriptions of procedures for conducting this study.

The adoption of ethnography provides a holistic and in-depth understanding about complex interactions between people in a particular cultural site (i.e. health professionals and patients/relatives) and their behaviours (i.e. family caregiving, spirituality). In addition, ethnography also provides in-depth understanding about the context in which behaviours occur, and this could offer implications to improve these behaviours. It was considered that contemporary ethnography based on theoretical perspectives of interpretivism and post-positivism, was the most appropriate methodology to explore the provision of palliative care service in this study.

Before embarking on a discussion of the findings of the research, which commences in Chapter 6 and 7, the next chapter, Chapter 5, describes of the methods to conduct the research project.

Chapter 5: Research methods

Introduction

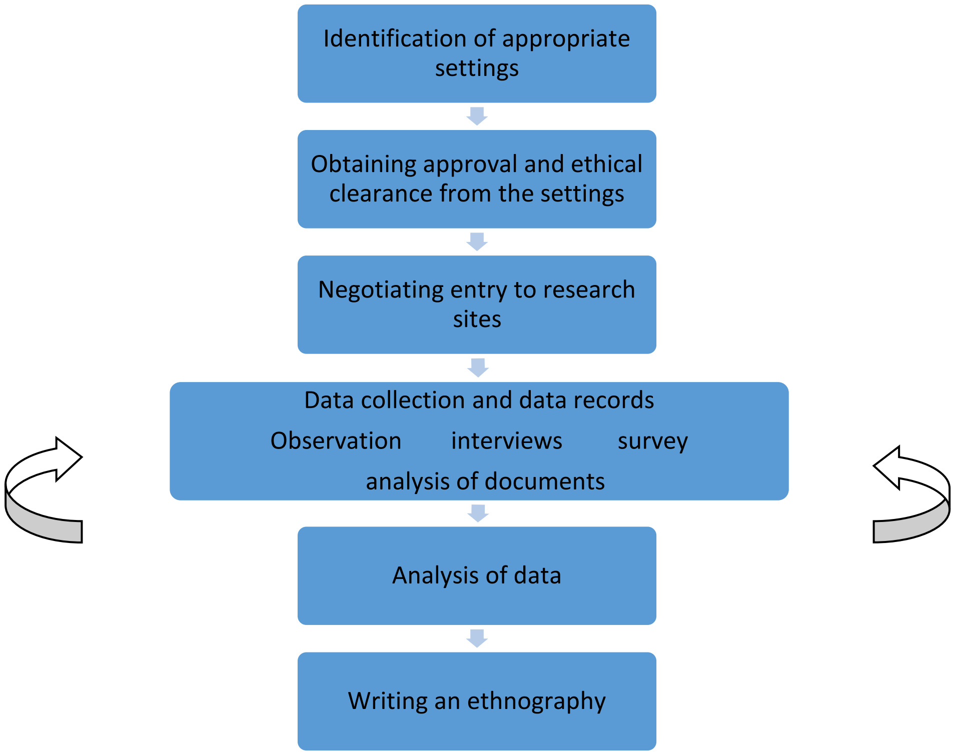
The previous chapters have provided the background and theoretical frameworks for this study. This chapter provides details of the conduct of the research. The methods were designed to provide a comprehensive picture of cultural aspects of the provision of palliative care for cancer patients. Data collection was conducted from January to March 2014 at two Indonesian palliative care facilities. The principal research methods used in this study were observations, interviews, surveys and document analysis.

This chapter begins with an overview of the research process, followed by the criteria for the choice of research settings and research participants. The ethical implications of the study and the steps to ensure the research was conducted in an ethical manner are discussed in detail. Gaining entry to the field is also discussed. The methods used for collection, management and interpretation of data for this study conclude this chapter.

Overview of research process

This section provides brief explanations of the research process used in this study (Figure. 2). Identification and selection of appropriate research settings was the first step of the research process. The researcher identified potential organisations that provide palliative care services in Indonesia, including six hospitals and two non-profit organisations (Asia Pacific Hospice and Palliative Care Network 2012). Considering time and geographic constraints, the researcher decided to select two organisations, one major hospital and one non-profit organisation in the Jakarta metropolitan area which provided palliative care services.

Figure 2: Research process for this study



The next step involved obtaining approvals and ethical clearance from the university and the research settings. The ethical approvals were granted from the University of Adelaide and the hospital ethics committees. Permission to conduct the research was obtained from both the management of the hospital and the hospice. Once ethical approval and permission to conduct the research had been granted, the researcher gained access to both research sites. Four types of data collection were used: observations, interviews, survey and collection of relevant documents.

Observations were made as the health care professionals from the hospital-based palliative care service were preparing for and providing care for the patients and their relatives either in the wards, the palliative care outpatient unit or in the patients' homes. Semi-structured interviews were conducted with the palliative care team from both palliative care facilities. Surveys were conducted to investigate each family's satisfaction and needs in relation to palliative care services. Relevant documents (i.e. brochures, information on websites) were collected to support and validate other data. Following data collection, data analysis was conducted. Each element of the quantitative and qualitative data was analysed and integrated, and further analysis was conducted accordingly. Ethnographic analysis frameworks from LeCompte and Schensul (2013) and Spradley (1980) were used and combined for the data analysis in this study to enable a holistic and comprehensive picture of palliative care provision in two Indonesian palliative care facilities. The last step involved writing the ethnography from this data.

Research settings

This section discusses identification and selection of the research settings. The researcher identified six hospitals and two non-profit organisations that provide palliative care services in Indonesia. Effendy et al. (2015) state that these palliative care services are available where most cancer facilities are located: Surabaya, Jakarta, Bandung, Yogyakarta, Semarang (on the island of Java), Denpasar (on the island of Bali) and Makassar (on the island of Sulawesi).

In considering the length of time available for field work, and the logistics of attending sites across the archipelago, it was decided that the study would be focused on two of the eight facilities available. The two facilities (one hospital-based and a non-profit organisation) were selected because they were formally designated as providing palliative care, were located in the same city, and the model of care provided and the population cared for were quite different.

The hospital was a major public hospital in the Jakarta metropolitan area that had a dedicated palliative care unit. The palliative care unit provided a home visit service, a hotline service, and outpatient services. The palliative care unit personnel included one head palliative care specialist physician, one rotating physician, two nurses and one clerk.

The non-profit organisation was operated and managed by a private foundation providing free palliative care services, particularly for paediatric patients from economically disadvantaged backgrounds. The personnel included two coordinator nurses, three nurses, one general manager, and one consultant for community networking and liaison. This palliative care service had two part-time medical consultant volunteers.

Participant selection

Identification of participants

The term 'study participant' is used to refer to individuals who play an active role in qualitative research (Streubert & Carpenter 2011). Typically, in ethnographic studies participation by those from the cultural group varies considerably in relation to the type and scope of data collection. Some will have a peripheral role while others are key informants that will take a more significant role in relation to data collection. The study participants were the patients and their relatives, and the palliative care team. Participant recruitment was opportunistic and purposive due to their involvement in the culture and their specific knowledge or experience related to the cultural setting (Higginbottom 2004). In this ethnographic study, individuals in both palliative care services was involved to varying degrees. For example, the patients' relatives from the hospital were involved in the observations and survey, and the patients were only involved in the observation due to their conditions.

In this study, study participants (i.e. patients, family caregivers and health professionals and the hospice manager) were all involved in palliative care service. An important consideration of the recruitment of participants was the safety of those involved. In the case of patients particularly approval to undertake the study was conditional on the health professionals being able to make a judgment about whether it was appropriate to involve patients directly. Permission was given to involve patients in the observations from the hospital service, however the non-profit palliative care service withdrew permission for this to occur with their patients. To clarify which participants were involved in the various types of data collection refer to Table 2.

Table 2: Sources of data, inclusion and exclusion criteria for participants

Palliative care services	Participants	Source of data	Inclusion	Exclusion
Hospital-based palliative care service	Healthcare professionals	Field observations, interviews	- Health professionals who work in the palliative care unit - Health professionals who consent to participate	Health professionals who are not willing to participate in the study
	Patients	Field observations	- 16 years old and older - Diagnosed with cancer - Receiving palliative care	- Patients who are not willing to participate in the study - Patients with deteriorated condition
	Families	Questionnaires, Field observations	- Family members who were primary family caregivers for the patient - Older than 16 years	Families who are not willing to participate in the study
Non-profit palliative care service	Healthcare professionals	Interviews	- Health professionals who are involved in the palliative care service - Health professionals who consent to participate	Health professionals who are not willing to participate in the study
	Patients	-	-	-
	Families	-	-	-

Ethical clearance and approval

This study was guided by the National Statement on Ethical Conduct in Human Research (NHMRC 2007). The participants' rights for their participation were ensured throughout the study. Ethical approvals were obtained prior to the commencement of the study through the Human Research Ethics Committee of the University of Adelaide (No. H2013-05). Following this ethical approval (Appendix I) the researcher sought ethics approvals from the palliative care settings. An ethics approval was granted by the hospital's Ethics Committee (No. 004/KEPK/1/2014). The palliative care service from the non-profit organisation-did not have its own ethics committee; however, the researcher obtained approval from its management to conduct the study in their facility.

Ethical research guidelines from the National Health and Medical Research Council (NHMRC 2007) including participants' right of autonomy, privacy, anonymity and confidentiality were ensured and maintained throughout the study. All potential participants' autonomy in this study was preserved by respecting their decision to participate or not to become involved in this study. In regards to privacy and confidentiality, all data were stored securely. Raw data including questionnaires, interviews, transcripts and notes of field observations were stored in a locked locker while in Indonesia. This written data then was brought to Australia to be kept by the researcher in a locked cabinet in the School of Nursing, University of Adelaide. All electronic data were secured on a password-protected computer file. In regard to anonymity and confidentiality, particularly the identification of the settings, the researcher chose to adopt pseudonyms.

Ethical consideration for health professionals

Information about the study (Appendix III) was provided to health professionals in the palliative care facilities prior to the commencement of the study to communicate the study's nature, including objectives and processes of the study. Throughout the study period, none of the staff refused to be involved in this study. All participants gave permission for interviews to be digitally recorded. Confidentiality, privacy and anonymity were maintained at all times throughout the study. Identities of all participants were protected by the use of a pseudonym in the field notes and verbatim transcripts, and any identifying information has been removed from this thesis. In addition, special attention was made in describing particular events or people to ensure that individual anonymity was not breached. Due to the small number in the sample, there is a potential that information about participants could be identified in any presentations and publication arising from the findings of this study.

Ethical consideration for patients and family caregivers

This section provides explanations of ethical considerations pertaining to the patients and the family caregivers. All the patients and the family caregivers involved in this study were from the hospital-based palliative care unit because the researcher was unable to obtain approval to access patients from the hospice. Prior to contacting the patients and their families, the researcher discussed with the palliative care team the patients' and their families' eligibility to be involved in this study. Subsequently, information about the study was provided to the patient's relatives in plain language (Appendix II). The family caregivers were also informed about the withdrawal options and were informed that if they chose not to participate, there would be no adverse effects on the patient's care. Consents from the family caregivers (Appendix III) were obtained at the time of the home visits; while the patients' consents were obtained from the relatives as proxy due to the patients' deteriorating condition.

Confidentially, privacy and anonymity were maintained at all times throughout the study. For the survey, family caregivers' names were removed and an individual number was allocated to each of them. The raw data collected has been stored in a locked cupboard located in the School of Nursing, University of Adelaide and will be retained for five years. For interviews and observations, the identities of all participants were protected by the use of a pseudonym within the study, and identifying information has been removed from this thesis. Any presentations and publications of the findings from this study will not include any identifiable information about the participants.

Gaining access

This section discusses how the researcher gained access for this study. Apart from obtaining approval from the appropriate ethics committees, gaining access to a setting, particularly a health care setting, can be time-consuming and complex (Mulhall 2003; Thomson 2011). The success of gaining access depends on the type of setting, the researcher's relationship to the setting and negotiation between several sets of health professionals, including managers, nurses and doctors (Mulhall 2003; Thomson 2011).

Prior to the researcher travelling to Indonesia and commencing of data collection, the researcher had considerable communication with the managers of the non-profit palliative care service to negotiate access to the site, as well as to the patients and nurses. Approval to access patients and nurses was initially granted. When the researcher went to this organisation in December 2013 and met the general manager and the consultant, however, there were some changes made in the terms of accessibility. There was a major concern about maintaining the patients' confidentiality and their comfort should they be included in the study. In response, the researcher assured them about the purpose of the study and the processes to maintain confidentiality of the participants. The decision of this organisation was to approve this study with the provision that the researcher could only access the staff rather than the patients and their relatives.

In the hospital, the ethics committee approved this study and appointed a local supervisor for the researcher. Following this approval, the researcher met the managers, the head nurses in the wards, the head of the palliative care unit and the nurses in the unit. Based on one head nurse's suggestion, the researcher wore a white coat throughout the data collection. In Indonesia, a white coat is generally associated with a healthcare professional's uniform. Therefore the use of a white coat could remind the study participants of the researcher's role and identity.

During the first week of the field work at the hospital the researcher spent time informing the palliative care team about the research and provided an opportunity for questions. The researcher used this time to become familiar with the palliative care team and so that they could also begin to know the researcher. During this first week, the researcher also spent the time orienting herself to the physical layout of the palliative care unit and the hospital in which it was situated. In the first week, the palliative care team started to accept the researcher's presence and understood her purpose in the palliative care unit. At this point the palliative care team started asking the researcher to go with them to patients' homes for the home-based care service. During home visits the palliative care team explained to both the patients and family caregivers about the researcher's role. The explanations facilitated the participation from patients and family caregivers.

Data collection methods

Ethnography has wide-ranging methods which give flexibility and openness to a researcher to use various methods and approaches to data collection (Atkinson & Hammersley 2007; Thomson 2011). In this study, the researcher employed observations, questionnaires, collection of relevant documents, and interviews (formal and informal). Formal interviews were conducted by having semi-structured interviews with the selected participants. Informal interviews were conducted during or after participant observations to clarify, support and validate the observations.

Participant Observations

This section provides a brief overview about participant observations, duration of observation, type of observation and process of observation.

Participant observation, traditionally, is the central technique in ethnographic research. It is a crucial process and a starting point in ethnographic research. This method involves engagement in the routine daily life of the people under study that allows adequate observation and recording of data (Fetterman 2010). Observation provides the researcher with cultural experiences that improve understanding of the situation, actions, roles and behaviours (Atkinson & Hammersley 2007; Schensul, Schensul & LeCompte 2013; Walshe, Ewing & Griffiths 2012).

Duration of observation

In planning for this study the researcher allocated three months of observation with 40 hours of observations per week (from January 2014 to March 2014). Although Fetterman (2010) suggests doing ethnographic research over periods of time from six months to a year or longer, in the case of this study, such a period of observation would not have been feasible considering the time restrictions of the PhD program and associated financial burden of living away from home during the field work. A total of three months' intensive field work was decided as being practicable for this study as it was concerned with a very discrete area of health practice. Roper and Shapira (2000) state that ethnographies that aim to answer specific questions can be conducted in a shorter time than traditional ethnography. Previous ethnographic studies in palliative care settings (Dean & Major 2008; Wright 2012) had used from 72 to 300 hours of observation.

In this study, participant observations were undertaken every day on weekdays from 8am to 4pm with the average of 35 hours of field work per week. The duration of each observation was primarily influenced by the length of interaction between health professionals and patients/family caregivers, which depended on the patient's condition. The minimum duration of each observation was 15 minutes and the maximum duration was approximately 90 minutes. A total of approximately 260 hours was completed, at which time the researcher determined that questions had been answered and no new information was being discovered.

Types of observation

There were three types of observation adopted in this study: descriptive, focused and selective observations (Spradley 1980). The general guide for observations was informed by Spradley (1980) and included observations of space, actors, activities, events, objects, acts, time, goals and feelings (Appendix V). For this study, the starting point was a general descriptive observation regarding the outpatient palliative care clinic and patient's home. It involved asking general questions to observe and record a situation as much as possible, such as *who are involved in the palliative care service*?

For this study, after documenting and analysing the descriptive observations, the researcher conducted focused observations and collected additional data regarding a domain. Focused observation involved asking the structural questions, for instance, *what are all the activities of palliative care health professionals?* Following a number of analyses and repeated observations, the researcher narrowed the observations to selective observations to refine the data. The selective observations were chosen from focused observations and review of the related documents. It involved asking contrast questions, which are based on the similarities and differences that exist in the analysis; for example, *how does care provided by the health professionals differ*?

Participant observations in the field

The goal of the observations in this study was to systematically observe and record the interactions in the selected setting. While most of the observations were conducted during the provision of care by the hospital-based palliative care team either in the wards, outpatient clinic or in the patient's home, a few observations were conducted in the hospice. During the observation in the field, the researcher observed actors, place, activity, object, act, event, time, goal, and feeling (Appendix IV). The researcher observed all actors who were involved in this study, including the palliative care team (i.e. doctor, nurse, and clerk).

Regarding place and object observation, the researcher observed the overall environment in the office of the non-profit organisation and the hospital including the outpatient palliative care clinic and the patient's home. An overview, of the situation, the placement of physical objects in space and the social structure and atmosphere of the outpatient palliative care clinic were observed and recorded. The observations in the patient's home included recording the number of family caregivers, the availability of home nurse and non-family caregivers, the presence of religious symbols and health care equipment in the patient's home (oxygen cylinder, wheelchair, patient's bed and nebuliser). This was noted at least once during each observation.

For other observations (i.e. activities, events, feelings), palliative care health professionals–patient/family caregiver interactions either in the ward, the outpatient clinic or patient's home formed the major part of the observations. The interactions between palliative care health professionals and patient and family caregivers in the patient's home and outpatient clinic were varied, depending on the patient's condition. For example, the interactions and care provision might take longer if the patient had more complex symptoms or if the patient/relative wanted to have a discussion about experienced symptoms and practical care.

During observations, the researcher did not interrupt the interaction between health professionals or patients/family caregivers as it would interfere with the interactions. This allows the ethnographic scene to occur 'naturally' (Atkinson & Hammersley 2007). In making these observations, the researcher sat or stood near the health professionals. The researcher spoke to the health professionals to clarify and verify some of the observations after the interactions finished. Clearly, the researcher needs to write and observe simultaneously. Brief records of any activities were made immediately after the observations, either in an electronic device or handwritten. Some of the notes were made on the way from one patient's home to another patient's home. The researcher then systematically typed and saved in MS Word all the details of the observations together with a reflexive account immediately after each field work episode.

During the process of observation, the researcher had informal discussions with the palliative care team, the patients and relatives in order to clarify and validate observations. Informal discussion was conducted throughout the data collection period. In the hospital, all palliative care unit staff such as physicians, nurses, and a clerk were involved in some form of informal discussion with the researcher. The researcher had informal discussions with the general manager and the consultant of the hospice. Informal discussions were carried out during the observations to clarify observations, feelings, unclear activities, and obtain their demographic data (e.g. years of experience and qualification).

Survey

The second method of data collection was by survey. The survey was planned to include the health care professionals, the patients and the family caregivers to determine their demographic components and other elements. Due to issues around the patient's condition, access to the patient/relatives and health professionals, and small number of the palliative care team, the researcher needed to modify the plan. The survey was only conducted with the patient's family caregivers in the hospital-based palliative care service. The Canadian Health Care Evaluation Project (CANHELP) (Appendix V) survey was used with the family caregivers which aimed to measure symptoms and the patients' and family's level of satisfaction . Domains in the CANHELP include: relationship with doctors, illness management, communication and decision-making, and spirituality and meaning (Heyland et al. 2013). Prior to approaching the family caregivers to be involved in the survey, the researcher had discussion with the palliative care team to decide whether or not the family caregivers would be included in the survey. The researcher then approached the relative, provided them with information and asked to obtain their consent. Of the 11 eligible family caregivers, one relative refused to participate because he/she did not feel comfortable participating in the study. Accordingly, ten family caregivers were included in the survey component. During the questionnaire administration, the researcher accompanied the participants to enable quick response if any questions and discomfort were raised.

Interviews

The third method of data collection was interviews. This study involved semi-structured interviews that were characterised by a clear plan in the researcher's mind and minimum control over the informant's response. This type of interview was chosen because it enabled the researcher to obtain targeted information that would complement observations. The interviews were conducted with health professionals from both palliative care services.

The semi-structured interviews were conducted face-to-face with health professionals who were involved in palliative care provision in the hospital (25% of health professionals, n = 1) and in the hospice (20% health professionals, n = 1) and managerial staff from the hospice (n = 2). The other health professionals involved in palliative care provision were unable to be interviewed due to limited access and their overall busyness. The interview times were varied and arranged according to the informants' schedules. The interviews were conducted in a meeting room for comfort and confidentiality reasons. Prior to the interviews, the researcher carefully explained the aims of the study, provided interviewees with an information sheet and gained their informed consent. Each interview lasted about 40–60 minutes and all participants agreed that the interviews would be recorded. A digital recorder was used to record interviews with the permissions of the informants.

The researcher used an interview guide where questions that needed to be addressed were formulated. Due the different nature and characteristics of the two palliative care facilities, not all questions were the same for all informants.

There were similarities in the order in which the questions were posed that could be changed according to how informants reacted. This flexibility allowed the researcher to be more natural and responsive. The researcher had specific objectives and was fully in control of what was intended from an interview (i.e. to obtain information about facilitators and barriers of palliative care service). There was, however, the possibility to expand and enhance the interviews for both the researcher and informants.

The questions for the semi-structured interviews are shown in Table 3.

Table 3: Questions for semi-structured interviews

Both palliative care services	- What services are provided by this facility? - Please explain the model of palliative care service employed by this facility - What do you think might have contributed to the provision of palliative care?
Non-profit palliative care service	- How is the relationship with the primary health institution? - Please tell me the criteria for patients to obtain palliative care from this facility
Hospital palliative care unit	- Please tell me the roles for doctors and nurses

Recorded interviews were duplicated after the interview for back-up in case of any accidental erasure or damage of the original copy. The interviews were transcribed verbatim by the researcher immediately after leaving the venue, on the same or following day. The verbatim transcriptions were sent to the interviewee for validation and clarification.

Collection of relevant documents

The fourth method of data collection was the collection of relevant documents. These could be used to enrich, support and link data from other elements (i.e.

observations and interviews) to provide more comprehensive descriptions about the phenomena under examination. It was planned to collect relevant documents such as procedures, policy, and reports from both settings. It was hoped that nursing protocols could be analysed for this study; however, due to frequent changes the latest nursing protocol for the hospice was still in progress.

In this study, relevant documents were collected from both facilities. Related documents from the hospital were brochures advertising the palliative care services that were available in the palliative care unit, and previous research conducted by the palliative care health professionals. The documents from the hospice were websites content and nursing guidelines. The available nursing care protocol in the hospice provided a clear description of the insights and philosophy of the hospice culture.

A flow chart of patient admission to the palliative care unit and the organisational structure of both facilities were obtained. This assisted the researcher in displaying consolidated information about the palliative care unit hierarchy. All information from collected relevant documents was used to enrich, support and validate data from observations and interviews.

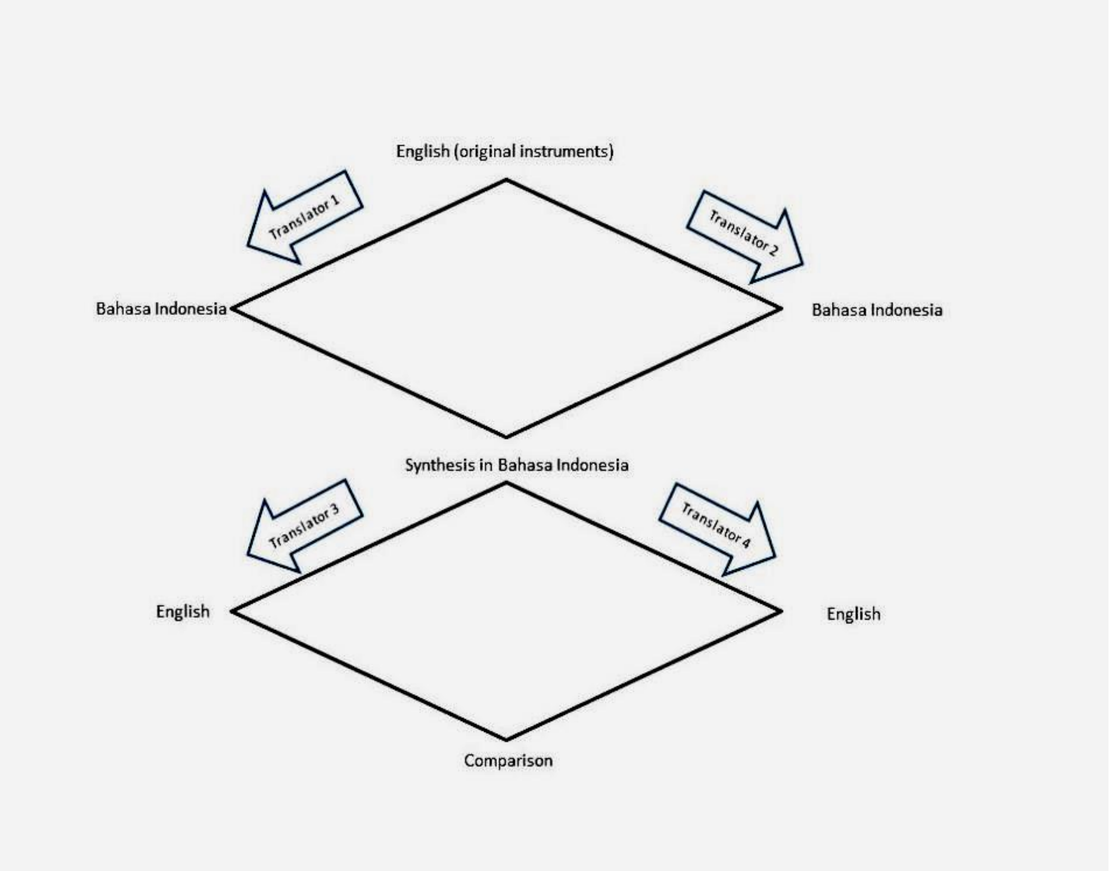
Translation of instruments, field notes, verbatim and document reviews

This section provides detailed descriptions of the translation process of instruments used in the survey, field notes, verbatim transcripts and collected relevant document. Descriptions of the tools will be provided followed by details of translations of qualitative elements.

Translation of instruments

Prior to commencing the data collection, the researcher translated all of the instruments into Bahasa Indonesia using guidelines from Beaton et al. (2000). The process of translation is presented in Figure 3.

Figure 3: Process for instrument translation



Permission to use the pre-existing instruments was granted by the developers. Two native Indonesian-speakers, one with a non-health background (Translator 1) and one with a health back ground (Translator 2) translated the original instruments into Bahasa Indonesia. Then, two versions of the translation were synthesised and any differences were resolved. Subsequently, a back-translation process was undertaken where two English native speakers (Translators 3 and 4) translated the Bahasa Indonesia version into English. The back-translation results were compared and discussed, with minor changes made as required. The last stages of Beaton et al.'s guideline (2000) of pre-testing of the instrument was not conducted due to the small number of participants involved in the survey.

Translation of field notes, verbatim transcripts and relevant documents

Qualitative elements (i.e. observation, interviews) were conducted in Bahasa Indonesia, which is the mother tongue of the researcher and all participants. By using this language the researcher could understand and more precisely keep the real meaning of the words by considering the use of the language and context (Twinn 1997). The procedures of translation in qualitative research from Chen and Boore (2010) were adopted in this study. The first step, transcribing (i.e. field notes transcripts, interviews, survey and document review) and analysing were conducted in Bahasa Indonesia. When key concepts emerged – including the meaning units or items of the original text, patterns and structural level of analysis – these key concepts then were translated into English, the second step in Chen's and Boore's (2010) guidelines. Instead of using back-translation, the researcher had regular and continuing discussion with the academic supervisors to verify the appropriateness and gain equivalence of the conceptual meanings and terminology. This process also enabled clarification of information from the data and ensured accurate meaning of the data from the field notes or interview transcripts. In the findings chapter, the quotes were provided in both English and Bahasa Indonesia to improve the accuracy of the translations.

Data management

There were two types of data in this current study: quantitative and qualitative data. To manage the quantitative data, all responses from the survey were entered to MS Excel 2011 to ensure the completeness of the data. In this study, all data from observations and interviews were transcribed verbatim by the researcher due to her familiarity with the language and the selected settings. This was conducted to minimise transcription error, as (Poland 1995) stated that transcription errors can be produced due to unfamiliarity with a particular topic. The verbatim interview transcript and the field notes were saved in MS Word format. To enable management of the volume of these records, the researcher organised these files in the computer by its type.

Data analysis framework for this study

Discussion of data analysis considerations for this study is presented in two main sections. The first section outlines quantitative and qualitative analysis. The second section discusses data incorporation using the data analysis framework from LeCompte and Schensul (2013) and Spradley (1980).

Quantitative analysis

Following the screening and checking for irregularities, a descriptive analysis was conducted using IBM SPSS Statistic version 21. The family caregivers' demographic data and responses for the CANHELP tool were summarised as percentages. The researcher then made narrative descriptions from this descriptive analysis to enable incorporation into qualitative data and analysed this accordingly.

Qualitative analysis

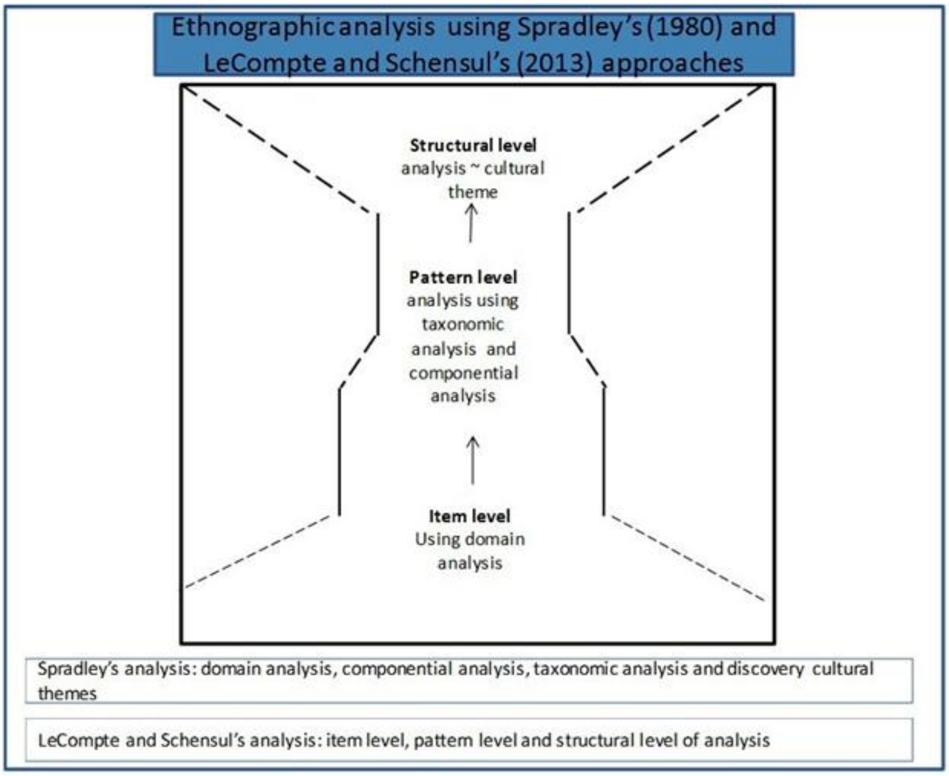
At the beginning of the study, the researcher undertook data analysis by hand to enable the identification of important categories or themes. To facilitate data analysis, the NVivo 10 qualitative computer program was then used. All transcripts of field notes and interviews and narrative description were transferred to the NVivo 10 program to facilitate coding, indexing and sorting a rich amount of data into analytic categories. Coding is "an analytical process in which data are fractured (divided into abstract bits), conceptualised (abstracted grouping of data) and integrated (linked) by the researcher" (Annels 2003, p. 171). The researcher constantly moved between identifying categories, sorting data and searching examples in the NVivo 10 and this was conducted back and forth. Identified codes were then used as items for further integrating the analysis using guidelines from

LeCompte and Schensul (2013) and Spradley (1980). A total of 227 different free nodes were developed.

Integrated analysis using LeCompte and Schensul's, and Spradley's approaches

This study adopted and integrated approaches from LeCompte and Schensul (2013) and Spradley (1980) as the data analysis framework. The overall concept and structure of analysis was mainly derived from their approach, but the actual steps in analysis of the data used Spradley's (1980) approach. The ethnographic analysis from Spradley (1980) consists of domain, taxonomic and componential analysis and discovery of cultural themes; while LeCompte and Schensul's (2013) approach includes item, pattern and structural level of analysis (Figure 4).

Figure 4: Framework for ethnographic analysis (adapted from Spradley 1980)



Steps in LeCompte and Schensul's (2013) ethnographic analysis are more global, which provide greater flexibility. In addition, LeCompte and Schensul's (2013) approach provides more choices in terms of technique and concept used to determine the constructs and the relationships among them. The steps involved in Spradley's (1980) approach are more concrete and structured. This approach is efficient to sort large amounts of data because it provides systematic strategies to determine parts, the relationship among parts, and relationship of parts to the whole.

In this study, the use of ethnographic analysis approach from LeCompte and Schensul (2013) provided a broad framework for analysis and the use of steps from Spradley (1980) within the framework assisted with more detailed analysis. Detailed descriptions of each step are provided in the following sections.

Item level of analysis

The item level of analysis and domain analysis are both the first steps in analysing ethnographic data. These steps begin when a researcher reads repeatedly, tidies up and organises the data. This first step aims to identify naturally occurring items or units in the data, and attempts to classify order and code items (LeCompte & Schensul 2013). This involves a reduction of large chunks of data which are then converted to smaller manageable sections (LeCompte & Schensul 2013). The activities in the item level of analysis include reviewing data line-by-line or event-by-event to establish items or free nodes. A free node is "a shorter meaningful description for a line using the participant's words" (Gulati et al. 2011, p. 541).

In this item level of analysis, the researcher identified items using Spradley's (1980) domain analysis. Spradley (1980) states that domain analysis is valuable, particularly for novice ethnographers, due to its systematic steps in analysing ethnographic data. Domains consist of three elements: cover terms (general term), included terms (smaller categories), and semantic relationship (connecting together two categories). In this study, the process of domain analysis involved a cyclical and iterative process where items were reviewed, updated, and applied as data analysis progressed. The process of domain analysis included five steps that were cyclical and recurrent: (1) selecting a sample of data from either interviews or field notes, (2) underlining and giving meaning to all basic categories/items, (3) searching possible cover terms for all basic categories/items, (4) repeating the steps searching more included terms and creating new cover terms from data collected, and (5) listing all identified domains.

Descriptions of each step in this level of analysis are provided below.

Step 1. Selecting a sample of data from either interviews or field notes. For example:

> The palliative care physician shook the patient's hands and asked '*How are you today'* and kissed the patient' cheeks. The patient replied weakly with a soft voice '*My condition is average*". When seeing the patient's leg dangling, the physician said '*Your leg is dangling and it can make you uncomfortable*'...*'Can you move your leg?*' The nurse said "*That's right madam'...'Can you try to move by yourself*?'...*"Can you please bend your leg first then move it?"...* The patient bent her legs and moved upward. Her position looks more comfortable. (Field notes on 4 Feb 2014, p. 28 : L. 1-6)

Step 2. Underlining and giving meaning to all basic categories/items. For example:

The palliative care physician shook the patient's hands and asked '*How are you today'* (**Greeting***)* and kissed the patient' cheeks (comforting physical touch). The patient replied weakly with a soft voice (**physical symptom**) '*My condition is average*". When seeing patient's leg dangling, the physician said '*Your leg is dangling and it can make you uncomfortable*' (**being responsive**) ...'*Can you move your leg by yourself?'* (**assessing**). The nurse said '*That's right madam'...'Can you try to move by yourself*?' (**Assessing**) ..."*Can you please bend your leg first then move* it?" (**Instructing**)... The patient bent her legs and moved upward. Her position looks more comfortable. (Field notes on 4 Feb 2014, p. 28 : L. 1-6) Step 3. Searching possible cover terms for all basic categories/items. For example:

Table 4. Identifying domain using semantic relationships

Included terms	Semantic relationships	Cover terms
Phone contact texting sending email	was a way to	communicate between patients/family caregiver and palliative care team
Hugged patient's wife, stroked patient's hand, kissed patient's cheek	was a kind of	comforting physical contact
Ringing patient/family Responding to phone, texts, and email from family/patient directly Suggesting to contact palliative care team if anything happen	was an attribute of	Palliative care team's efforts to provide support to patients/relatives

Step 4. Repeating the steps, searching for more included terms and creating new cover terms from data collected.

Step 5. Listing all identified domains. Examples of identified list of domains:

1. A way to communicate between patient/family caregiver and palliative care team
2. A kind of comforting physical contact from the health professional

Detailed steps and examples for discovering cultural domains as the first level of analysis have been described. The second step in this study was the pattern level of analysis using Spradley's (1980) componential and taxonomy analysis and will be discussed in the following section

Pattern level of analysis

Following item-level analysis, the pattern level of analysis was conducted. This level aims to create associations among groups of items that have been classified (LeCompte & Schensul 2013). The pattern level of analysis is similar to Spradley's (1980) taxonomic and componential analysis.

This level of analysis involves: (1) organising all items and examining if there are any relationships or any association, and (2) Creating explanation from the relationship by use of a tree diagram. The first step involve activities of comparing, contrasting, integrating, associating, and linking identified items to form a higher order of patterns (LeCompte & Schensul 2013). Patterns may emerge in several ways, including by declaration, frequency of occurrence, similarity, omission, sequence, and congruence with prior hypotheses (LeCompte & Schensul 1999). Patterns consist of groups of items that fit together, expressed a particular theme or constituted a consistent and predictable set of behaviours (Bjorklund 2006). Emerging patterns can be supported with explanation of theories from various paradigms, and other rationales to support their existence (LeCompte & Schensul 2013). The second step of the pattern level of analysis included creating explanation from the relationship or associations through use of a tree diagram. In this level of analysis, the researcher identified the relationships using Spradley's (1980) taxonomic and componential analysis. Examples of two steps in the pattern of analysis are provided below.

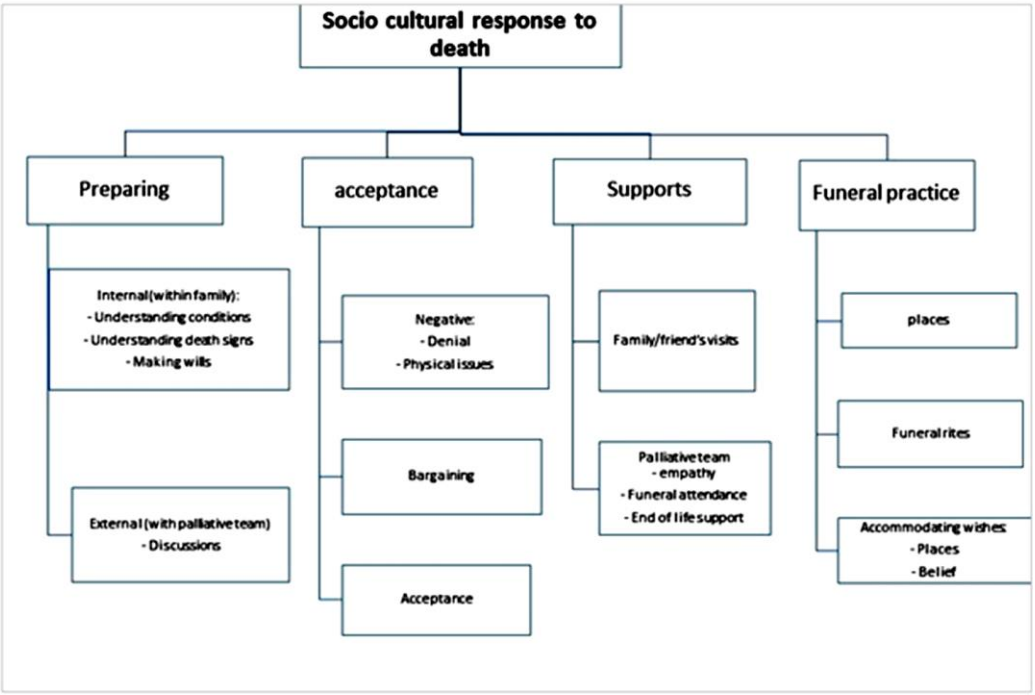
Step 1. Organising all items and examining if there was any association and relationship among items.

Table 5. Identifying pattern by examining relationships among items

Items/facts/cover terms	Unit/variables	Pattern
Accommodating patient's wishes Making decisions Assessing patient's wishes	Preserving patient's autonomy	Meeting the needs of the patients around care for dignity
Concerning patient's comfort Prioritising patient's wellness Concerning patient's safety Suggesting to minimise visitors	Promoting patient's wellbeing	
Dominance in deciding patient's treatment	Limited control of patient	
Want to do the best for patient Motivating patient and families Suggesting to refocus hope	Preserving hopefulness	
Maintaining patient's grooming Preserving patient's cognitive capacity Preserving patient's functional capacity Supporting patient in maintaining simple activity daily livings (ADLs)	Preserving continuity of self	

Step 2. Creating explanation from the relationship, which can be facilitated using a tree diagram. The tree diagram provides the conceptual taxonomy for particular pattern at a glance.

Figure 5. Taxonomy for socio cultural response to death



Structural level analysis

The last step in LeCompte and Schensul's (2013) approach is the structural level of analysis. This level of analysis is parallel to the discovery of cultural themes in Spradley's (1980) approach. The structural level of analysis, however, appears to be more comprehensive as it incorporates the findings within a broader framework to recognise the implications of the study. A comprehensive level of analysis is crucial as it demonstrates the potential of the research findings to contribute in the field and to bridge the gap between knowledge and practice.

Spradley (1980) suggests both general and specific strategies to discover cultural themes. General strategies involve listening and reading the data over and over again, while specific strategies include making taxonomic analyses to see if domains might fit into a taxonomy, examining domains that have been analysed and making a schematic diagram of the cultural scene.

In LeCompte and Schensul's (2013) approach, the structural-level analysis aims to correlate and find consistent relationships among patterns. The process includes reviewing items and patterns regularly to understand how they correlate and address the research questions (Gulati et al. 2011). In this study, the process of discovering cultural themes involved making taxonomic analyses of all domains. As the analysis progressed, complete understanding of the overall story emerged from structures. Five major cultural themes emerged from this ethnographic analysis: '*the provision of care: meeting many challenges*'; '*building relationships'*; '*family caregiving'*; '*spirituality/religious practices'*; and '*dealing with dying and death'*. The description of these cultural themes will be presented in Chapter 7: The Practice.

Summary

This chapter has provided a detailed description of the structured data collection procedures and the research setting. Identification of participants for the study has also been discussed. At all times the participants' human rights were protected and respected. This chapter provided an overview of gaining access to the scene. The major methods of participants' observations, survey, interviews and analysis of related documents were used to explore, and understand the provision of palliative care and the cultural aspects in the provision of care. This chapter has also provided explanation and justification of the data analysis framework for the study, which was based on the integration of frameworks from LeCompte and Schensul (2013) and Spradley (1980) The next two chapters describe the findings of the study. Chapter 6 provides descriptions of actors and the space of the cultural groups. The descriptions of exploring a range of cultural themes using vignettes and applying a cultural lens to palliative care services is provided in Chapter 7.

Chapter 6: The Place and The People

Introduction

The aim of this chapter is to establish the contexts in which the palliative care services were provided, including the people, the place and the environment of the cultural groups. The place refers to the physical environment where those involved in palliative care interacted. Details of parent organisations, features of the two palliative care units and their immediate surroundings are provided. A scene at a patient's home and at the inpatient service are provided to familiarise the reader with the setting where the central act of providing palliative care occurred.

Another important aspect in ethnographic writing is the people or actors with whom the researcher interacted and observed (Spradley 1980). Where possible, the researcher has provided demographic profiles of the participants (Appendix VI and VII). The people involved in this study fell into three categories, palliative care team, patient and family caregiver. The palliative care team encompassed those people who were employed by the palliative care facilities, including doctors and nurses. Patients were those individuals who received palliative care at home or as outpatients or inpatients, whereas family caregivers were those involved in providing care to their dying relatives.

There were two organisations involved in this study, the hospital and the non-profit organisation. As discussed in the previous chapter, the issue of confidentiality and anonymity are of concern. The researcher chosen not to use the actual names of the parent organisations or the palliative care services but to adopt pseudonym, however the location of the services are located. The pseudonyms are given in the following table (table 6)

Table 6. Pseudonyms for parent organisations and palliative care services

	Parents organisations	Palliative care services
Hospital	Garuda Hospital	Jasmine palliative care clinic
Non-profit organisation	Cendrawasih Foundation	Rose palliative care service

Detailed descriptions of the context in each organisation are provided in the following sections.

Garuda Hospital, Jasmine Palliative Care Clinic: the place

One palliative care unit in which this study was conducted was part of the Garuda Hospital. The hospital was one of major public hospital in Jakarta. It had more than 109,000 attendances each year; about 88,000 in the outpatient units, more than 16,000 in the inpatients unit and about 4,800 attendances in the emergency department (document analysis, RR2, 14 March 2014). Outpatient clinics were located on the basement and first floor while wards for hospitalised patients were located in the fourth, fifth, and eighth floors. The outpatient clinics were located under the main areas of the hospital (patient administration, banks, information centre) and had stair and lifts as access (Field notes on 27 January 2014, P.6: L.30-33).

The palliative care unit, in which this study was conducted, was established in 2005. The aim of the palliative care unit was to provide comprehensive and integrated care that included physical, psychological, social and spiritual care to alleviate burdens of patients and relatives. The philosophy of the palliative care unit was based on the motto of the hospital, namely, ‘Smile and be ready to give service, prioritise quality of care and patient safety, be sincere, be loyal and dedicated, be excellent in service, education and training, be optimistic and continuous improvement (SMILE!&C)' (document analysis, RR2, 14 March 2014).

The grounds and buildings of Garuda Hospital

The hospital was located in the city and surrounded by high-rise buildings. The hospital had seven building blocks; the main building, staff dormitory, auditorium, funeral home, two engineering buildings, and sewage facility. The main building consisted of eight floors and two basements. The second basement was for utilities. The first basement was the home of diagnostic and radiotherapy departments, specialty outpatient clinics and the central sterile service department (CSSD). The Palliative Outpatient Clinic was located in the first basement of the main hospital building and it was adjacent to the Complementary Therapy Outpatient Clinic and the Radiology Unit. Other outpatient clinics, administration department, pharmacy department, banks and a convenience store were located on the first and the second floors. The third floor contained the central surgery department, Intensive Care Unit (ICU) and managerial office. The fourth, fifth and eighth floors were the inpatient wards and every floor was painted in a different colour, for example the seventh floor was painted in green while the eighth floor was in blue. The outside of the building was covered with a dark grey pavement-like surface. The hospital had a front courtyard which was used for car parking. In front of the main building was the drop-off point to access the hospital, which had stairs as well as a lane for wheelchairs (Field notes on 29 January 2014, P.6; L. 22-34, P.7: L. 1-4).

The first floor was like a vestibule and was open to the public so there was a constant movement of patients and staff in this area. All staff and visitors to the different wards, including the outpatient palliative care clinic, used the same main entrance to access the building. The entrance door was always opens. There was one big, rectangular, dark coloured floor mat before the entrance to the building. One tall receiving desk sat in the left side of the entrance door. Behind the receiving desk, there was an officer who was always ready to help visitors such as providing directions and bringing wheelchairs. In addition, there were two security officers in the entrance who controlled the drop-off cars and whom visitors could ask about locations they wanted to visit (Field notes on 29 January 2014, P.7; L. 6-15).

There was constant movement of cars to drop-off or to pick up staff or visitors. In the middle of the vestibule, after the entrance, were waiting rooms and the patient admissions sections. Inside the vestibule was covered with maroon marble and the inside was painted in a creamy white colour. It was clean and comfortable. On the right-hand side of the vestibule, there were two passageways (one lift and one stair). The lift, which was in the rear of the vestibule, could take people to every floor to go to wards, ICU, operating room, or convenience stores. The stair on the right-hand side after the entrance to the building could take people to the outpatient palliative and complementary therapy clinics and the radiation and diagnostic departments. Most staff and visitors used the lift rather than the stairs (Field notes on 29 January 2014, P.7; L. 7-26).

The Jasmine palliative care clinic

The floor area of palliative care clinic was approximately 50 square metres in a rectangular shape. The palliative care unit had one main door facing the corridor. On the top of the door was a sign which indicated the name of the clinic. The palliative care clinic and all area in the first basement were covered with white ceramic floor tiles and painted a creamy white colour. Sunlight could not enter into this unit directly because of the layout of the building. The clinic was, however, well-lit by fluorescent lights. The palliative care clinic had central air conditioning that made this unit cool and comfortable (Field notes on 28 January 2014, P.6: L.12-14).

There were three artificial leather sofas set against the wall outside the palliative care clinic that were usually occupied by people who attended the palliative care clinic or other units located on the same floor. On the wall, there were two big posters presenting research findings conducted by the health professionals in the palliative care clinic. One poster was about clinicians' perceptions and expectations of palliative care. The other poster presented findings on the impacts of family caregiving on family caregivers' lives (Field notes on 30 January 2014, P.16; 33-34, P.17; L. 1-2, 17 Feb 2014. P. 70: L.19, P.128: L.9-16).

Palliative care staff and visitors entered the palliative care clinic through the main door. After entering the main door, they could see two main areas inside the palliative care clinic. Main area one was for the provision of palliative care such as patient examination and consultation. Main area two was for administration (e.g. patient's registration, patient's invoice) and was separated from main area one with a partition (Field notes on 30 January 2014, P. 16: L. 23-31).

The area for the provision of palliative care was like many other outpatient clinics with examination area and waiting area. The examination area had three sides of wall with the right-hand side holding an examination table with blood pressure cuff and stethoscope. There was a partition next to the examination table which set the examination area apart from administration. On this partition, there was one research poster against the wall. To maintain each patient's privacy there was a protective curtain that could be pulled around the side of the examination table if an examination was conducted. On the front-side wall, there were three frames against the wall consisting of an organisation structure, patient admission flow chart and referral flow chart. There were also some patients' pictures sent by the patients and relatives. On the left-hand side, there was a cupboard containing medical supplies and medicines. These pictures and medicines could be seen by the patients and the relatives. Over the cupboard, the principles of palliative care printed in a white paper was attached to the wall. These principles were similar to those from the World Health Organization and included: providing relief from pain and other distressing symptoms, intending neither to hasten nor postpone death, integrating the psychological and spiritual aspects of patient care, and offering a support system for patients and their family. The waiting area had a set of fabric sofas offering four seats and a wood table. On the table, there was educational information for patients and relatives in the form of pamphlets and flyers, artificial flowers and tissues. There were two research posters behind the sofa and against the wall (Field notes on 30 January 2014, P. 16: L. 17-34, P.17: L.1-3).

Main area two was for administration and comprised three sets of office desks and chairs, one round table for discussion and a mini library. This area was separated using a partition. There were two computers, one was for the clerk for administration purposes and the other for the palliative care team. One set of office desks and chairs with computer was located close to the waiting area and this was for the administrative staff. The other two desks were located more remotely and could not be seen from the waiting area. One of these desks was for the head of the palliative care clinic and the other could be used by the team. Behind the head of the palliative care clinic's table, several thankyou cards were placed nicely with some patient's pictures and some small office decorations. There was quite a big photo frame attached on the wall comprising various pictures of the palliative care team and patients. The round table was also close to the waiting room. Nurses usually sat in this area. It was specifically designed in this way so that people who came to the palliative care unit could go straight to the administration and nurses could easily observe and keep track of those who were present. From this area, it was very easy to see patients or relatives who were sitting in the waiting area. The mini library was in the corner, close to the round table. There were books related to cancer, palliative care, and pain management in the cupboard (Field notes on 30 January 2014, P. 17: L. 4-21).

Every newly referred patient was assessed in the palliative care unit. Palliative care nurses assessed each patients' health history while other data such as laboratory results, and X-ray results were copied from their medical records. It was noted that occasionally the waiting room was used to conduct assessments where other people in the room could hear the conversations. New patients had physical assessments on the examination bed and some privacy could be maintained by using the curtain. During the assessment, the palliative care team not only asked about the patient’s physical health but also asked about their psychological health and sometimes about family support and housing for patients who came from other cities (Field notes on 30 January 2014, P. 16: L. 23-31, 12 March 2014, P. 169: L.25-31).

The palliative care clinic was usually open from 7.30 am to 4.00 pm. Generally, the palliative care staff conducted home visits for patients from around 9.30 am to 4.00 pm. The patients who wanted to visit the palliative care clinic usually made an appointment before or after the home visit schedule. In the early opening hours, the palliative care nurses prepared for home visits, including preparing required health equipment based on patients’ conditions, patients’ records and home visit invoices (Field notes on 30 January 2014. P.16: L.15-16).

The environment in the palliative care clinic was mostly calm and quiet. Soothing music was played in the day, which was intended to create a comfortable and relaxed atmosphere. Many patients and relatives, however, would become anxious. Staff were seen talking with these patients and relatives while they waited for their problems to be sorted out. Once there was a situation which was quite chaotic, where a patient arrived and was really upset, being very vocal and loud. Accordingly, the health professionals worked hard to manage the situation to calm the patient down (Field notes on 19 Feb 2014, P.81: L.6-16, 28 Feb, P. 130: L.1-2).

In the ward

The inpatient ward observed in this study was on the fourth level of the hospital building. This ward had two wings; the right wing was divided into sections each with four smaller rooms. The left wing had sections with six smaller rooms in each. The rooms had an adjustable bed, a small table and a chair for an accompanying relative. In general, the ward was for patients with cancer, in some case, these patients were referred to the palliative care doctors (Field notes on 27 January 2014, P.4: L.33-35, P.5: L. 1-7).

The health professionals who were involved with the referred patients were the doctor from the palliative care unit and the ward nurses. The nurses from the palliative care clinic were not involved in the care for patients in the ward. The palliative care doctor visited the patients regularly, which usually occurred in the early morning or in the afternoon after home visits (Field notes on 30 January 2014, P.16; L.15-16).

The home visit

Observations of the provision of palliative care occurred mainly in patients' homes. The following is an example of a situation in an observed home visit.

The palliative care team arrived at a patient's home which was located in a smaller road of a housing complex. It had a yard with several trees and smaller plants. There was a veranda with two white chairs and a table. The house was quiet. The main door was open. The palliative care team knocked on the door to announce their presence. The relative greeted the palliative care team warmly, and asked them to come in. The relative said that the patient was in her room. The palliative care team asked about the patient's condition. The relative described the patient's conditions and then let the palliative care team to go to the patient's room.

The palliative care team knocked on the door and then entered the patient's bedroom accompanied by the relative. There were some printed prayers attached to the door. The floor was covered in a soft green ceramic tiles and the walls were painted with a similar colour. The room was air-conditioned and well-lit with fluorescent lamps. The room did not have direct access to the outside and sunlight. On the right-hand side from the door, the patient was on the bed (an adjustable bed) with the head of the bed slightly raised. The patient looked very frail. The patient's bed was quite close to the wall with only a small space left, approximately 50 cm. On this side, there was an oxygen tank beside the patient's bed. On the left-hand of patient's bed, there was a shelving unit with a mirror. A home-care nurse was employed to provide care for the patient. The home-care nurse put the patient's medicines and medical supplies in this shelving unit. On the top side of the shelving unit there were pictures of patient with her children and her grandchildren. Next to the shelving unit was a wash-stand. The room also had an ensuite bath room. On the left-side from the door, there was another shelving unit that was used to store other medical supplies such as diapers, weigh scales, stethoscope and sphygmomanometer. In the corner, there was a folded mattress for the home-care nurse (Field notes on 18 Feb 2014, P. 73: L.33-34).

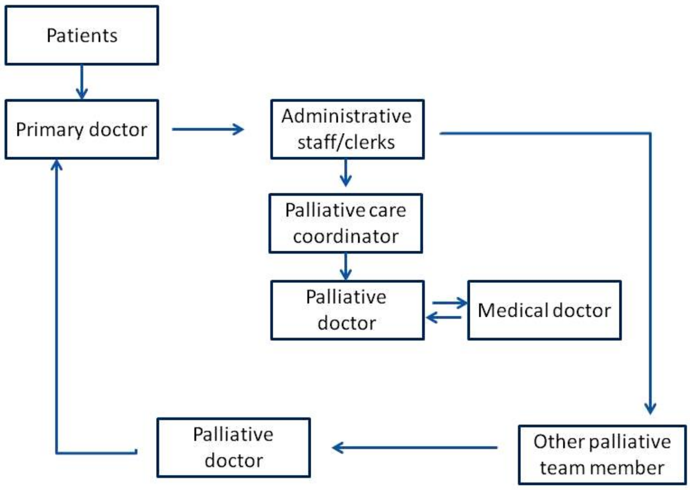
As well as taking care of patients directly, the health care professionals also talked with relatives. It was common that there was a discussion regarding to the patient's condition, how to manage the patient's symptoms, and discussion about family caregiving-related problems. The discussion was usually in either the living room or in the patient's bedroom (Field notes on 18 Feb, P.75: L.20).

Due to the nature of the home visit, the health professionals had long personal involvement with patients and relatives. They gave their mobile numbers to patients and relatives during their first home visit. This was a measure to enable relatives to contact them and get advice quickly if unexpected circumstances happened to the patients (Field notes on 28 Feb 2014, P.133: L.4-5).

The admission process in the Palliative Care Clinic

The process of admission is presented in Figure 6. All of the patients were referred by their oncologists, generally with many symptoms and after the cancer treatment was either unsuccessful or had ceased. When the palliative care unit received a referral from the oncologist, the administrative staff (clerk) put the new patient's data (name, diagnosis, number of medical record) into the computer. Following this, the patient was asked to meet with the palliative care team.

Figure 6. The process on admission



The palliative care nurse coordinator made an initial brief assessment to gain an overview of the patient's condition. This initial assessment could be conducted in the palliative care clinic, in the ward, or at a patient's home depending where the first interaction between patient-palliative care team was conducted. The first assessment was often conducted at the patient's home as the patient's condition made her/him unable to go the palliative care clinic. Generally, the first assessment focused on the patient's physical condition and symptom management; the staff also focused on developing trust with patients and families. Information from the initial assessment was shared with other members of the palliative care team. In the following interactions, the palliative care team conducted a more comprehensive assessment including assessing psychological, social and spiritual needs (Field notes on 17 Feb 2014, P.71: L.25-34).

The people in the Jasmine Palliative Care Clinic

The doctors and the nurses were the central figures that provide care in the palliative care unit at Garuda Hospital although other people were also involved.

Patients and relatives would often first see a clerk at the administration desk. The clerks always wore a hospital uniform of buttoned-up shirt and pants. In addition, the clerks also wore an official name tag with the clerks' name and the hospital tagline 'SMILE!&C' (the C stands for continuing improvement). The clerks had direct interactions with patients or relatives because they dealt with the financial aspects of care. They also gave additional information to patients or relatives about matters such as health insurance and funeral homes. The clerks also documented all patients who had been visited on a daily basis. They also documented patients' deaths including date, place and where the funeral would take place. There were also two drivers who drove the health professionals to the patients' homes, but they did not have direct contact with the patients and relatives. During the period of field observation, another clinic, a complementary therapy clinic was occasionally involved in the provision of palliative care (Field notes on 6 March 2014, P. 135: L.21, P.138: L.13-14).

The doctors

Routinely there were two doctors in the palliative care unit, one was the palliative care physician who was also the head of the palliative care unit and the other was a medical doctor on rotation. All the doctors were female. The palliative care physician had a master's degree in palliative care and had extensive experience in the field. She was the only palliative care physician in this hospital. The doctors did not only work in the palliative care clinic; they also had to visit patients in the wards. The palliative care doctor worked on weekdays while the rotating doctor occasionally worked on shifts during the weekend.

The doctors generally stayed in the palliative care clinic in the morning before conducting home visits. They always wore their white coats when dealing with patients and their relatives but would occasionally remove their coats in the clinic particularly when there were no patients attending. They wore casual business attire, blouses or buttoned-up shirts and skirts or pants, for ease of movement.

The head of palliative care clinic usually arrived at 7.30 am each morning and then visited palliative care patients in the wards. Occasionally, she had to attend meetings in the morning due to her position as head of the unit. Around 9.30 am, the nurses and the doctors started their home visit services until about 4.00 pm. The availability of the physicians in the team affected the patient's access to opioids. In this study site, the patients were able to get opioids easier because the doctor could directly evaluate, modify and prescribe opioids based on the patient's needs

(Field notes 30 January 2014, P.16: L.15-16, 26 Feb, P.116: L.3-6).

The nurses

There were two full-time nurses working in the unit and occasionally there were two or three nurses from other wards supporting them with the home visit service. They were appointed by the hospital management to the palliative care service due to their previous extensive experience in the ward. Both of the permanent nurses had more than ten years working experience in the hospital. One of the nurses had a bachelor degree in nursing and just finished studies as an advanced practitioner in oncology nursing. The other nurse had a diploma degree in nursing. Both of these nurses had attended training in palliative care that was conducted either by the hospital or by external organisations, however, neither had a formal palliative care qualification. The palliative care nurses usually worked from Monday to Friday, but sometimes worked on Saturday or Sunday as shift supervisors in the wards. They had 14 days holiday per year.

The nurses' uniforms consisted of a green colour suit, with long sleeves and darker green pants. During the period of field observations all the palliative carenurses wore a head scarf that was a matching colour. Every Friday, the hospital's policy required its employees to wear the uniform of a *batik* (traditional Indonesian fabric with a printed pattern) suit with plain cotton pants as a form of appreciation of Batik as Indonesian heritage. However, the batik pattern uniform was only worn in the hospital. During home visits, the nurses always wore the plain suit uniform.

(Field notes on 26 Feb, P.116: L.3-6, 6 March 2014, P. 135: L. 7-9, 10 March 2014: L.24).

The patients from the Jasmine palliative care clinic

There were 21 patients involved in this study with ages ranging from 35 to 87 years. The patient's demographic data is summarised in a table (Appendix VI). The majority of patients were female. The patients' religions varied although the majority were Muslim; other patients identified themselves as Catholics, Christians and Buddhists. Most of these patients were still participating in religious practices either by themselves or with their family caregivers' help. For example, a Muslim patient who was very weak still did five daily *prayers* and read praying (*dua*). Another Buddhist patient had the family invite the Buddhist priest to the home so they could pray together.

All patients were living with incurable cancer. Breast cancer was the most common type of cancer among the patients receiving palliative care from the hospital. The other common types of cancer were lung and nasopharyngeal cancer. The majority of symptoms experienced by the patients were pain, fatigue, loss of appetite, sleep disturbance, and impaired mobilisation.

The majority of the patients had a reasonably high level of dependency (Appendix VII). The patients were assessed using McGill Quality of Life Assessment Tool. During the observation period, several patients were in a somnolent state. Other patients had a moderate level of dependency, while only one patient had low level of dependency. Many of the patients were referred to the palliative care unit only after curative cancer treatment had failed. Eight of the 21 patients died during the period of field observations.

Patients paid for their cost of care in two ways: *Badan Penyelenggara Jaminan Sosial Kesehatan* or *BPJS Kesehatan* (Healthcare and Social Security Agency) and private insurance. The palliative care clinic provided a free outpatient service for the patients who had a BPJS Kesehatan card. For those with private insurance, the cost was based on the type of service provided. For example, the consultation with palliative care doctor was IDR 85.000, - (± AUD 8.50) or the nursing intervention fee was IDR 75.000, - (± AUD 7.50). The total cost of the home visit service was based on type of package and transport. Patients with private insurance paid the total cost for the home visit service. For patients with the BPJS *Kesehatan* card, health professionals often did not ask for this fee when conducting home visits to patients due to their circumstances.

(Field notes on 5 Feb 2016, P. 35: L. 12-16, document analysis, RR2, 14 March 2014)

The family caregivers

The majority of the primary family caregivers were female and all were adults (Appendix VIII). Most were the patient's spouses, others were patient's children or parent. The majority of the family caregivers were Muslim, some identified themselves as Christian and Catholics, while others were Buddhist. All the family caregivers had some formal education, ranging from high school to postgraduate degree. Some of the family caregivers were self-employed, some were retired and others did not work.

Most of the primary family caregivers had support from other family members, although there was one relative who gave care on her own without any additional support. Extended family providing support included brothers or sisters, in laws, and nieces or nephews. Many were also supported by non-family members such as home-care nurses and non-health house assistants.

The daily routine in the Jasmine palliative care clinic

Due to the nature of the work in the unit, there was no shift work. The nurses usually started their work at 7.30 am to finish at about 4.00 pm. There was a team leader who was responsible for the whole team in the unit. The team leader allocated nurses and doctors to visit patients' homes based on areas. Generally, each team of nurses and doctors visited up to three patients a day.

Most mornings, at 7.30 am, the doctors, nurses and clerks gathered in the room for a meeting, which usually took about 10 to 15 minutes. The leader of the meeting rotated between the physicians, the nurses and the clerk. The meeting leader opened the meeting by asking every member to pray based on their religions/faiths. The palliative care doctor, as the head of palliative care clinic, used this occasion to share updated information from the hospital management. Every member of the team had the chance to ask questions and share information. The meeting was closed with wishes of having great day and for patients' and relatives' wellbeing. After finishing the meeting, everyone in the unit started their jobs. The nurses started to ring patients/relatives who would be visited or to check on other patients. For the patients who were to be visited in that day, the nurses would enquire about how they were managing. This allowed them to determine the patient's condition and to confirm the nursing care plan for the patients. During the interaction, the patient's relatives occasionally sought advice about their loved ones. The nurses gave what advice they felt was appropriate to the relatives, or sometimes handed over the phone to the doctor to provide medical advice. The nurses reminded relatives of their home visit schedule. For the first home visit, the nurses usually asked the best route to reach the patients' home. The nurses also rang patients who were not in the list of daily home visits. The nurses monitored these patients' conditions and provided advice about care. If needed, the nurses offered the patients a home visit or requested the patients to come to the palliative care clinic. Following this, the nurses documented the information in each patient's record.

Around 9.30 am, the nurses and the doctors started their home visit service. The palliative team always brought medicine and equipment (e.g. for intravenous therapy, nasogastric feeding, etc). They always greeted the patients and relatives warmly. As the doctors and nurses went about their work they were very respectful while also displaying compassion and empathy; for example, the touch of an arm and listening to the patients and relatives carefully about their problems and responding in plain language to be sure of being understood.

Communication between doctors and nurses in the Garuda Hospital palliative care clinic appeared to be open and supportive.

(Field notes on 30 January 2014, P.16: L. 15-16, 24 Feb 2014, P. 89: L. 5-16, 27 Feb 2014, P. 124; L. 3-16)

Cendrawasih Foundation, Rose palliative care service: the place

The second organisation involved in this study was Rose palliative care service of Cendrawasih foundation. The following description is the non-profit organisation headquarters. There was no clinical care provided in the headquarters office as it was for administrative and managerial purposes. It is not as detailed as the previous descriptions of the Garuda Hospital and its palliative care clinic due to the limited access approved by the hospice management.

The parent organisation of the hospice service was the Cendrawasih Foundation. This was a charitable organisation that provided free palliative care services, particularly for children. The organisation was established in 2004 and became a registered non-profit organisation in 2006 under the name of the Cendrawasih Foundation. The organisation's main office was located in Jakarta. The organisation focused on delivering palliative care for children aged range from 0 to 16 years with life-threatening illness who could not afford medical care. The Rachel House Hospice provided a free home-care service for children with life-threatening illness, with services that included symptom management, visiting doctor service, guidance for families, a loan service for medical and nursing equipment, and providing emotional support for patients and families. The average number of active patients who received palliative care from the Rose palliative care service was about 10 patients per week.

The vision of the Cendrawasih Foundation was to never see a child die alone without love and care. It was built on the principle that the hospice did not add days to the children's lives but to added life to their remaining days. Their stated mission was to provide palliative care for children with life-threatening conditions and allowing them to live with joy and dignity in a non-discriminatory, safe and loving environment. The goals of the Rachel House Hospice were to advocate and raise awareness of the need for palliative care in Indonesia, and to conduct multi-disciplinary training in palliative care. Other goals included reinforcing the local community's capacity to care for children, and to collaborate with other organisations that added value to its mission. It is the first paediatric palliative care service in Indonesia. The Rachel House Hospice Service's pioneering team of nurses were trained by overseas palliative care professionals from Singapore, Australia and New Zealand. In relation to one of its goals, this organisation ensured that there was participation from health professionals from public hospitals, health education institutions and other parties in every training opportunity.

The headquarters office of the Cendrawasih Foundation was located on the fourth floor of a tower building, which was located in the city and surrounded by low-rise houses and high-rise buildings. The office was mainly for administrative purposes as all the palliative care services were provided in the patient's homes. In the physical building there were three cubicles and two meeting rooms. The nurses used these cubicles when they documented assessment and care provided to the patients. The meeting rooms were used for weekly staff meetings and for training purposes.

The admission process for the Rose Palliative Care Service

The foundation had collaboration with public hospitals or primary health care services around Jakarta to provide free palliative care for children from economically disadvantaged families. The oncologist from the collaborating hospitals would notify the patients' families about the hospice service. Similar to what happened in the Garuda palliative care service, most of the patients were in the late stage of cancer when being referred to this hospice. A meeting between the staff from the hospice and the family was conducted to inform them about the services they provided. If the family agreed to receive the palliative care service, the nurses allocated the patients to various categories, which then directed the goals of care. The patient's category determined the number of home visit that should be conducted each week. The frequency of visits could be changed based on the patient's condition. The nurse from the hospice then coordinated care and liaised with the oncologist about the patient's management based on their condition.

Another service provided by the hospice was equipment loans. If the patients needed particular medical equipment such as wheelchairs and oxygen tanks, the hospice provided this equipment to the patients. The patients could borrow and use the medical equipment for as long as needed but then it must be returned once it was no longer needed.

The people in the Cendrawasih Foundation

The Cendrawasih Foundation included the operational team, an international panel of advisors and board members. The operational team included five full-time nurses and two part-time medical consultants. The nurses were central figures of care provision in this hospice.

The nurses

There were five full-time nurses who worked in the Cendrawasih Foundation. The palliative care nurses usually worked from Monday to Friday, however, sometimes they worked on Saturday or Sunday based on patient's urgent requirements. All the nurses had attended palliative care training conducted by the Cendrawasih Foundation, however, none had formal palliative care qualifications.

There were two nurse coordinators who had responsibility for the whole team in the unit, one coordinator for the community and one coordinating the home-care service. The community coordinator nurse provided health information for the community to increase awareness about palliative care. This nurse also liaised with the community so that the patients and their family received emotional, social and spiritual supports from the community. The home-care nurse coordinator allocated nurses to visit patients' homes based on location. This nurse coordinator always communicated with the nurses, either to update the patient's status or to manage any difficulties during the provision of care. The nurse coordinator communicated with the oncologist and the consultant doctor for care management and decision-making.

(Interviews, PCT1, 09:30, PCT 3, 15:00).

Others involved in the Rose palliative care service

Although the nurses were the central figures in the care provision, there were other team members involved in the parent organisation of Rose palliative care service , including an international panel of advisors and board members. During the period of observations, the international panel of advisors were from Singapore and included medical and operational advisors. The medical advisors provided mentoring, advice and training in palliative care. Overseas palliative care experts (i.e. from Singapore, Australia and New Zealand) were regularly invited to train the nurses and other staff. During the period of field work, an expert from New Zealand was invited to train the nurses and staff in improving their resilience working with end of life patients. The role of operational advisors was to provide advice in hospice administration, accounting, branding and corporate identity. The board members dealt with fundraising and supervised with the overall running of the organisation.

Being physically and structurally separated from any hospitals seemed to provide a greater opportunity for relationships with other organisations and services. Cendrawasih Foundation had several collaborating partners that included several public hospitals, primary health centres, other non-government hospitals and some universities.

The palliative care service in the Cendrawasih Foundation reflected nurse-led palliative care where the nurses were the central figures in the care provision. The interviews with the nurse, the general manager and the consultant from the Cendrawasih Foundation showed that there was a multidisciplinary approach between these nurses and doctors from external organisations (interviews, PCT1, 09:30, PCT 3, 15:00). In addition, the interviews revealed that the communication channel between the nurses, the oncologist from collaborating hospitals and the part-time medical consultant was open and supportive. All the care decisions for patients required input from the part-time medical consultants. For example, the nurse coordinator gave the following description about supportive communication and multidisciplinary approach… *'we will discuss with the oncologist about the patient's conditions and symptoms after the initial assessment..*.'(interview, PCT3, 15:00). […'*kami akan mendiskusikan dengan dokter onkologi tentang kondisi dan gejala yang dialami pasien setelah pengkajian awal*…]' (*wawancara*, PCT3, 15:00) and ...*'on the process of delivering palliative care, we coordinate care with the oncologist if needed, for example discussion about a patient's medicines*' (interview, PCT3, 15:15). [...*'dalam proses pelayanan paliatif, jika perlu kami berkooordinasi dengan dokter onkologi, misalnya mendiskusikan tentang obat pasien*'] (*wawancara*, PCT3, 15:15).

Summary

This chapter has provided descriptions overviewing of the physical aspects of the two palliative care services and the people who participated in this study. The researcher spent a considerable of time conducting field observations in the hospital, however, in the Rachel House Service, access was limited so that the researcher was unable to see direct care being provided to the patients.

There were a number of elements that have been described in this chapter. Examination of the cultural scenes in the study sites reflected two different approaches towards care provision. The palliative care in the Garuda Hospital was run by a hospital and the service was physician-led care. This service did not seem to have many interconnections with other local health care providers or organisations. In contrast, the Rose palliative care service had regional support for mentoring about palliative care and providing operational advice. The palliative care provision in the Cendrawasih Foundation was nurse-led care where the nurses not only provided care but also negotiated with people from other collaborating organisations and the community to increase awareness about palliative care and, importantly, they coordinated the care for patients.

Further examination of palliative care practice and other cultural domains is explored in the next chapter ‘The practice’. The next chapter is important for understanding the provision of palliative care in the two Indonesian palliative care facilities.

Chapter 7: The Practice

Introduction

The purpose of this study was to explore the culture of palliative care provision for people with cancer in two Indonesian palliative care facilities. The previous chapter has described details of major features 'the people and the place' in two palliative care facilities in Indonesia, these were the cultural scenes, actors and some activities to orientate the reader to the settings.

This current chapter will explore a range of cultural issues in greater depth. In particular, this chapter will explore the interplay between those providing palliative care, the patients and their relatives, and members of the community. Five major cultural domains will be explored: '*the provision of care: meeting many challenges', 'building relationships', 'family caregiving'*, '*spiritual and religious practices'*, and '*dealing with dying and death*'*.* Each domain will begin with a brief description, then detailed explanations will be provided by recalling a vignette, this will be followed by more detailed descriptions of aspects within each cultural domain.

The provision of care: meeting many challenges

The first cultural domain of 'the provision of care: meeting many challenges' relates to challenges faced in the provision of palliative care and how the palliative care team met those challenges in providing care for patients and their relatives. Palliative care principles acknowledge the need for comprehensive and holistic care that includes psychological and spiritual care for the patients and their families in addition to physical care. In this study it was evident that the palliative care team worked hard to meet the patients' and relatives' needs.

Building relationships

‘Building relationships’ relates to the nature of relationships within the palliative care team, between the palliative care team and the patients/relatives and also with the community. Relationships within the palliative care team were characterised by an understanding of each other’s roles and mutual respect for expertise. The relationship within the palliative care team influenced how the relationship with the patients/relatives was developed. The palliative care team often had deep and intense relationships with the patients and their relatives. There were techniques used in communication that were more likely to result in rapport with the patients/relatives, such as respectful and prompt responses to patients’ needs. Understanding and respect were also elements that are demonstrated in the cultural domain of relationships between the palliative care team and the community.

Family caregiving

The cultural domain, ‘family caregiving’, relates to how providing care at home was experienced and managed by the patient’s relatives. The relatives’ ability to understand the patients’ needs, and the way they responded and managed the provision of care were affected by their perceptions of family caregiving. There were three elements in this specific cultural domain; ‘obligation’, ‘burdens’, and ‘support’. The patients’ relatives perceived family caregiving as an obligation influenced strongly by their culture. Family members provided physical, spiritual and psychological care. For many this was clearly a burden that could be physical, emotional or financial; however, there were supports coming from others including the extended family, the palliative care team and others in the community.

Spiritual/religious practices

The cultural domain of 'spiritual/religious practices' relates to how the palliative care team, the patients and their relatives perceived and undertook spiritual/religious practices. There were many situations which demonstrated that religion and spirituality were very important for the patients/relatives and the palliative care team involved in this study. These included acknowledging the importance of religious practices, enabling and/or sharing the performance of religious practices (e.g. worshipping and prayers), and providing spiritual/religious supports to the patients.

Dealing with dying and death

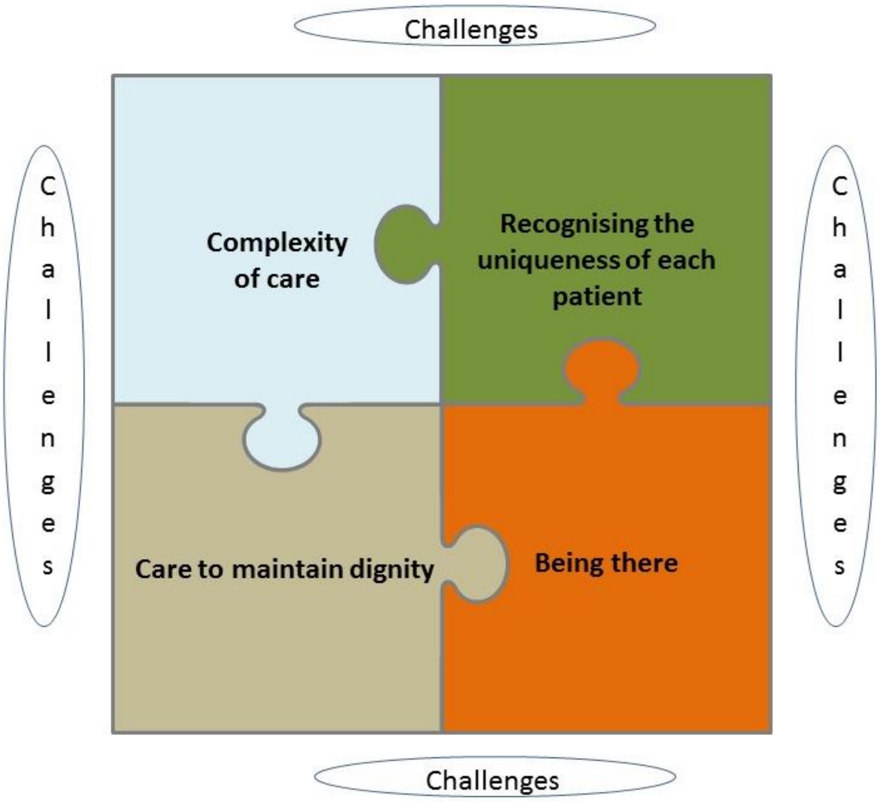
The last cultural domain 'dealing with dying and death' relates to how dying and death were perceived, experienced and managed by the patient's relatives and the palliative care team. The family caregivers' perception of death and dying affected how they responded. The acceptance of death and dying by the patients and relatives was often quite difficult. Once the patient's relatives had accepted that death was imminent, the palliative care team moved to providing support to assist relatives to prepare for the death. When the death did occur, the palliative care team managed to attend the funeral as their final act of compassionate care. The palliative care team continued to show their support of the family by providing grief and bereavement counselling to relatives when needed.

Details of all cultural domains will be explained in the following sections.

The provision of care: meeting many challenges

The cultural domain, 'the provision of care: meeting many challenges', relates to the provision of care for the patients and their relatives and many challenges faced by the members of the palliative care services. There were five elements in this specific cultural domain: challenges, comprehensive and compassionate care, recognising the uniqueness of each patient, being there and caring with dignity. Figure 7 illustrates the provision of care.

Figure 7. The provision of care: meeting many challenges



Challenges

There were many challenges in the provision of palliative care as patients were often referred to the palliative care team quite late in their illness. Resources were limited, particularly in relation to the number of health professionals providing care. Access to opioids was also limited for some patients. Other particular challenges were the integration of palliative care with the mainstream health service providers and the complexity of care that was provided.

During the period of fieldwork, there were many examples that referral to palliative care was often quite late in both the hospital and the hospice services.

For example, most patients in the participating hospital were referred to the palliative care team after active cancer treatment had ceased or was unsuccessful, only two of 21 patients who were referred to the palliative care unit while were still receiving active cancer treatment. One of these patients was very weak and had hydronephrosis in both kidneys due to metastatic cervical cancer. She was still in her last cycle of radiotherapy. Potentially as the result of the radiotherapy, the patient had diarrhoea several days prior the home visit. The palliative care team's efforts were to manage the patient's symptoms and to make her comfortable. The patient then died only two weeks after the referral.

The late referral was likely caused by differing perceptions of the nature of palliative care and uncertainty about appropriate timing of referral. Document analysis from a report on the hospital-based palliative care unit indicated that most of the oncology physicians in the hospital considered that palliative care was only for patients with advanced or terminal stage cancer where no further curative treatment was appropriate (document analysis, RR1, 30 January 2014).

In the hospital-based palliative care unit, the palliative care service comprised only two doctors, two nurses and two administrative staff and thus the number of health professionals was limited. As a result, the coverage of service was low, which meant that there were only a small number of patients who could be visited each day. The palliative care team was divided into two smaller teams where each team could only visit up to three patients per day. In the participating hospice, there were five nurses who worked full-time and two volunteer doctors working as part-time consultants. It was revealed from the interviews that the hospice could only serve ten patients due to the limited staff numbers at any one time.

As stated in the previous chapter there was a lack of formal palliative care training within the teams in the participating palliative care facilities. For the nurses in the participating hospital, there was a palliative care interest group that was designed to support nurses involved in palliative care that has regular meetings. However, this group was still in its early stage of development (informal interviews, PCT 4, 26 Feb 2014).

Another challenge was integration of the palliative care unit with mainstream health care providers. Such integration was still limited with the hospital-based palliative care service being essentially a stand-alone unit. It did have communication with other departments/units within the hospital (e.g. complementary therapy units, rehabilitation medicine and pharmacy); however, the palliative care unit did not have direct communication with external health care services such as primary health providers (Field notes on 19 Feb 2014, P.86: L.23-26). A different situation was observed in the participating hospice-based palliative care service. This hospice had a stronger communication and collaboration with external organisations (e.g. local public hospital, primary health centers, and charity organisations) (interviews, PCT1, 09:30, PCT 3, 15:00).

This study found that access to opioids was still limited for a number of patients. For example, one patient who lived quite a distance from the hospital-based palliative care unit was referred to the nearby district hospital for supply of opioids. While the patient had a prescription for opioids from the hospital-based palliative care unit, he could not get the opioids from the nearby district hospital as the pharmacist was not willing to dispense them for use in the home (Field notes on 5 Feb 2014, p.32; L.15-20).

Another challenge was addressing the many needs of the patients. The palliative care team made efforts in providing care to address the patients' needs while maintaining their dignity at the same time. Sometimes there were conflicting views about how those needs should be met. For example, when the patient's cancer metastasised to the bone, the palliative care team suggested to use a walker or wheelchair, but often the patient did not want to because he/she did not want to look weak (Field notes, 19 Feb, P. 169: L. 34, P. 170: L.1-3). In addition, in addressing the patient's needs there were occasions when interventions were offered or employed by the palliative care team that may have been seen as unnecessary or even aggressive care in the context of patients who were at the end of life. Examples of these interventions include the use of antibiotics and anti-cancer treatments, laboratory tests and the use of feeding tubes.

Complexity of Care

The complexity of care was another challenge in providing palliative care for the patients and their relatives. The complexity of care does not only describe *wha*t care was being provided but also *how* this care was provided. The following vignette demonstrates the complex nature of the care provided by the palliative care team during a typical home visit, including the many needs of the patient and interventions employed to address their needs.

> The palliative care team arrived at one of the patients' homes. This was the first home visit. The patient's husband opened the door welcoming the palliative care team. At that time, another relative (the patient's sister) was also there. She came out from the patient's bedroom, greeted the palliative care team and asked the team to come in. Entering the room, the patient, who had been discharged from the hospital several days prior to the visit, was in the bed. The patient had metastatic breast cancer. She patient looked very weak with paraplegia. She had oxygen, a feeding tube and urinary catheter in place. The palliative care team greeted the patient attentively and then asked the patient's husband and the other relative about her condition. The husband explained that his wife's condition was better than when she was hospitalised as that she could open her eyes and respond during communication. The palliative care team listened attentively. When noticing the patient's leg looked swollen, the doctor explained that it might due to her position. The doctor showed the relatives how to position the patient's leg and to support the limb with a pillow to prevent the oedema and make her comfortable.

Then the nurse took the patient’s pulse and blood pressure while the doctor assessed lung sounds. After assessing the patient, the doctor told the relatives that there were coarse rattling sounds in her lung (rhonchi). The doctor explained to the patient’s husband that the sound was caused by secretions in the lung and that she required a nebuliser procedure to release the secretions. The husband nodded in agreement for the procedure. The doctor asked the nurse to administer a nebuliser and to show the procedure to the patient’s husband. The nurse demonstrated the nebuliser procedure while the husband observed and listened carefully to the nurse.

At that time, the patient had several blisters on both arms and a pressure ulcer on her back. The nurse assessed the wounds and then commenced wound care. When the patient’s husband explained that he changed the wound dressing every day, the palliative care team suggested only doing it once every 2-3 days unless the dressing leaked. During the wound care, the patient’s husband helped to hold the patient so she was able to stay lying on her side. The nurse used the opportunity to explain several wound care tips to the patient’s husband such as using a particular powder to reduce the wound odour and using double dressings to prevent leakage.

After finishing all the interventions, the palliative care team moved to the living room to document the patient’s condition and the interventions provided. The palliative care team used this opportunity to explain the patient’s condition, possible interventions (e.g. pain relief) and the main goal of palliative care (e.g. the patient’s comfort). When the palliative care doctor prescribed some medicines for the patient, the patient’s sister asked why the patient’s mouth was dry and had a slightly bad odour prior to the visit. The nurse then indicated the patient needed additional care for her mouth and asked the husband if the patient had a particular mouth care product. The husband replied they had one but he was scared to use it because he was not sure that it was appropriate for the patient. The nurse then reassured the husband that the mouth wash was appropriate in caring for the patient’s oral hygiene. The nurse provided mouth care including the mouth wash.

The palliative care doctor then offered to perform prayers with the patient’s relatives for the patient’s wellbeing and to be more comfortable. They nodded in agreement and then went to patient’s room with the palliative care doctor to pray together.

(Field notes on 20 Feb 2014 p.83: l.31-34; p.84: l.5-9, l.17-24, l.31-33)

The above vignette demonstrates that the patient was given a range of interventions to manage various symptoms.

During the period of field observations, in most cases, pain management was a strong focus in the care provision. In a typical home visit, the palliative care doctors assessed the patient’s pain levels. One patient had a recurrence of cancer with metastases to his hip. He said that his pain was unbearable and rated it as 10/10. The patient also said he had oral morphine every 4 hours and it caused him to feel drowsy. Considering the level of pain, the current pain management and the metastases in his hip bone, the doctor then modified his pain management. The doctor also recommended that the patient should have palliative radiation therapy in addition to pharmacologic management.

As the patients were closer to their end of life, their symptom burdens often increased. On many occasions the palliative care team employed interventions to manage these symptoms. There were many examples in the home visits where the patients looked very weak, had lost their appetites, had diarrhoea or vomited. The palliative care team employed a range of interventions (e.g. conducting laboratory tests and prescribing antibiotics) which were used for patients who were very weak and could be perceived as being inappropriate or aggressive care. Such examples describe the major challenges in the palliative care provision.

While providing physical care to the patients, the palliative care team made sure to include the family in the care process and in making decisions. As illustrated in the above vignette, the palliative care team made sure the family were involved in the care by asking the husband to assist in positioning the patient. The palliative care team also made sure that the husband received practical instructions in how to manage symptoms experienced by the patient including wound care and administering mouth care.

In addition to physical care and interventions, the palliative care team worked to meet the psychological needs of the patients and their relatives. The above vignette demonstrated the manner of the palliative care team in dealing with questions from the patient's relatives and how the palliative care team provided honest information to them (e.g. providing information that the patient's condition had deteriorated). On another occasion, the palliative care team employed simple strategies, both verbal and physical, in managing a particularly difficult situation. Measures such as gentle rubbing of arms and hugs were used by the palliative care team to comfort the patients or the relatives, but care was taken to ensure this was appropriate in terms of gender. For example, during one home visit the patient began to cry when the palliative care doctor performed an assessment. The patient said that she knew she would die soon as she had been referred to palliative care. Knowing this the palliative care nurse closed the door of the palliative unit to provide more privacy to the patient. The palliative care doctor stopped her assessment, maintained eye contact with the patient, showed concern and gently stroked the patient's back. In addition, the doctor acknowledged that being referred to palliative care did not always mean that the patient would die soon and further explained the aims of palliative care provision. The manner in which this information was given had a calming effect on the patient. Once the patient had settled, the palliative care doctor continued with the assessment.

Providing psychological care was also seen through organising a family meeting. Generally, a family meeting was planned soon after patients were referred and admitted into the palliative care unit to discuss the patients' status and goals of care. Often, however, the family meeting happened when a particularly difficult situation had occurred and critical decision-making was needed. For instance, the palliative care team became aware that a patient was upset because she felt that she did not have enough support from the family. The palliative care doctor invited the patient's relatives (i.e. spouse, children, siblings) to have a family meeting. In the meeting, the palliative care team discussed the patient's condition, the care that was required, and what family members could do to support the patient. The family meeting had a positive outcome. The patient's relatives stated that they had greater understanding of the patient's condition and committed to provide better care and support to the patient (Field notes on 11 March 2014, p.161: L.3-22).

In addition to physical and psychological care, the palliative care team demonstrated how important they felt spiritual care was for patients and their relatives. The palliative care team would routinely ask what religious practices were performed by their patients. As illustrated in the vignette it was not uncommon during a home visit for the palliative care team to perform prayers together with the patients and relatives. In addition, the palliative care team encouraged relatives to help the patients perform religious practices. The palliative care team also worked with the local chaplaincy in providing spiritual care for patients. For example, a female local Muslim chaplain visited a patient while the palliative care team were there and the palliative care doctor asked her to lead prayers. They very much encouraged the provision of pastoral care for patients and their relatives.

The above sections have provided detailed descriptions about the complex nature of the palliative care being provided by the palliative care team. To address patients' complex needs, some interventions employed by the palliative care team may have been perceived as an aggressive care in other contexts of palliative care. Although physical needs might have taken priority to be addressed, the other aspects of care were not neglected. The palliative care team worked to ensure that all aspects of care -including physical, psychosocial and spiritual- were provided in an integrated manner. The next section will provide descriptions of how the palliative care was provided care in a compassionate manner.

Compassionate care

Compassionate care is a term used to describe care that is centred on the relationship between the palliative care team and those in their care. The palliative care team showed their compassion by recognising the suffering and the hardship experienced by patients and their relatives. The palliative care team were aware of each individual's needs and provided care to meet these needs, which then resulted in the patients'/relatives' comfort. Several strategies that were employed by the palliative care team included addressing fundamental care needs and a willingness to have a fully engaged relationship that was based on good communication.

Compassionate care was underpinned by providing the patients with the fundamentals of care. The palliative care team always ensured that fundamental needs such as pain management, nutrition, hydration, mobilisation and elimination were addressed in a timely manner. For example, in one home visit the patient described having severe pain. The relative added that the patient had lost his appetite. The palliative care team evaluated the patient's pain management and then modified it so that the patient could be more comfortable. Then the palliative care team provided suggestions to the patient's relative about preparing a meal for the patient (e.g. menu variation, favourite meals) so that the patient could eat well (Field notes on 12 March 2014, P.172: L. 9-13).

The palliative care team always maintained good communication and relationships with the patients and their relatives. As illustrated in the above vignette the palliative care team made sure the family had sufficient information about the patient's condition. The palliative care team also provided the family with instructions and information about caring for the patient. This level of communication and demonstration of respect resulted in the patient's and the relatives' strong sense of trust in the palliative care team, 'Regarding *my wife's treatment, I really trust you (*the palliative care team*)'… 'if there are other* *treatments planned by the oncologist , I will consult with you first' ['Terkait penanganan untuk istri saya, saya mempercayakannya pada anda (*tim paliatif*)'…'jika ada rencana tindakan dari dokter onkologi, saya akan konsultasi dengan anda* (tim paliatif) *terlebih dahulu']*. Clearly, the family had great trust in the palliative care team in providing the care *(*informal interview FCG3, 10 Feb 2014).

The palliative care team demonstrated a fully engaged relationship with the patients and relatives. In the provision of care, the palliative care team employed strategies to develop rapport and good communication with the patients and their relatives by methods such as introducing themselves, tailoring communication to suit the patient's cultural background, prompt responses and providing sufficient and appropriate information. For instance, on several occasions, the palliative care team responded promptly when the patient's relatives contacted them either by phone, texting or email. This strategy resulted in the relatives' high level of satisfaction and trust in the palliative care team which was also identified in the survey. The nature of a fully engaged relationship will be further explored in the cultural domain: 'Building relationships'.

The illustrations of the compassionate care in the above section were reinforced by the findings from the survey. The survey findings suggested the patients' relatives felt that the palliative care team were able to control the patients' physical and emotional symptoms appropriately. In addition, the responses indicated that the relatives were satisfied that care being provided the palliative care team to the patients and the relatives was in accord with the patient's wishes.

Recognising the uniqueness of each patient

The palliative care team provided care that recognised the uniqueness of each patient. Care was delivered based on the patients' specific needs. For example, when knowing that a patient who had metastasis liver cancer had lost her appetite during the days prior to the home visit, the palliative care team explored the situation further. The palliative care team examined the patient's mouth and they also asked what the patient felt about her daily meals. The assessment indicated that the patient had a sore mouth and was bored with her daily meals. The palliative care team prescribed medicines to ease the soreness in her mouth and suggested smaller meals of the patient's favourite foods.

In addition to providing care based on the patient's specific needs, the palliative care team worked to understand the patient's history and cultural background. During the period of observations, the palliative care team often tailored their communication to show their understanding and respect for the patient's history and cultural background. Examples of these strategies included using *kromo inggil* (a formal level of Javanese language to communicate with older people) when communicating with an elderly patient with a Javanese background. Another example was when providing a care for a retired primary school teacher, the palliative care team said that the patient should be proud that she had taught many students and that many of them had gained good careers. An understanding and respect of the patient's religious background was also demonstrated when the palliative care team gave advice based on the patient's religious background.

Many of the patients were very keen to use complementary therapies. Knowing this, the palliative care team were happy to accommodate the patients in using such therapies when it did not affect palliative pharmacologic interventions (e.g. pain relief) and could improve the patient's physical comfort. For example, on several home visits, the patients and relatives spoke of the use of complementary therapies (e.g. music therapy, massage oils and medical marijuana) to make the patients more comfortable. The palliative care team encouraged them to continue using their complementary therapy preferences for their comfort.

The palliative care team also recognised that complementary therapy could improve psychological comfort. For example, the palliative care doctor suggested that a patient and his wife should undertake meditation using guided imagery and progressive relaxation breathing. After the patient and his wife agreed, the palliative care doctor led the meditation. Finishing the meditation, the doctor asked the patient and his wife how they felt. Both of them replied they felt more relaxed and were grateful of having each other.

Being there

This section explores the availability of the palliative care team when needed. Findings from the survey indicated that the relatives had a high level of satisfaction related to the availability of the palliative care team when they were needed and the palliative care team's listening skills. This was reinforced by illustrations from the observations that will be provided in the following section.

'Being there' is a term used to describe efforts of the palliative care team providing support as much as they could along the patient's illness trajectory. 'Being there' in this study has two aspects. The first aspect is the palliative care team's efforts to be available outside their routine visits, particularly when the patient and relatives were distressed or in emergency situations. The other aspect is the manner employed by the palliative care team when visiting the patients, for example, using active engagement and relationship-building, listening attentively to the patient and relatives, and not rushing care.

Regarding efforts to be available when the patients and relatives were distressed, the palliative care doctor often commented that visiting patients and relatives, particularly when their death was imminent, was what differentiated palliative care from other areas of health care. The palliative care doctor regularly reinforced to other members of the palliative care team the importance of this type of visit. Others in the palliative care team accepted this and tried their best to comply (Field notes on 25 Feb 2014, P. 115: l. 3-5).

The palliative care team also tried their best to manage emergency and unscheduled visits. For example, a relative rang one of the palliative care nurses telling her that the patient was in pain and had constipation. The palliative care nurse had a busy schedule visiting other patients that day so she rang another nurse who had just finished their home visit service. She updated the other nurse on the patient's condition and asked if this nurse was able to visit the patient. The other nurse agreed to visit the patient, when the palliative care nurse rang back the patient's relative to advise them of a visit, the relative was very relieved (Field notes on & March 2014, P. 142: L. 12-20).

Sometimes these situations happened on the weekend but even then the team would manage to undertake these unscheduled visits. When doing such visits on the weekend, the palliative care team did not receive any additional payment because as government employees they only received fixed monthly wages. The palliative care team was happy to do this, as they understood the difficult situations faced by relatives. For example, on one weekend, the patient's relative rang one of the palliative care team telling them that the patient's condition had deteriorated. One doctor and one nurse were able to make the visit. The palliative care nurse arrived at the patient's home first and provided assistance and support to the relatives as the patient was dying. The doctor arrived when the patient had passed away. The doctor provided psychological support for the relatives. The relatives very much appreciated the assistance and support from the palliative care team during this stressful time (Field notes on 14 Feb 2014, P. 32: L. 24-27).

During the period of field observations, there were many examples where the palliative care team demonstrated that they provided care based on the patient's needs but made sure to avoid rushing the care. The length of each episode of care provided by the palliative care team varied depending on the patient's condition and needs. For instance, in one home visit, the palliative care team only spent about 30 minutes as the patient's condition was quite stable and well managed.

In another encounter, the palliative care team spent 45-60 minutes with the patient and/or the relatives. For instance, relatives of a patient who had passed away (the patient's wife and daughter) visited the outpatient palliative care clinic for consultation following the patient's death. The palliative care team conducted a detailed assessment of the family's needs. The patient's daughter had influenza and woke several times in the night after the patient's death. She felt guilty that she had not done her best when her father was dying. The palliative care team reassured the daughter that she had done her best for the patient. The patient's wife cried when the doctor asked how she was feeling. The doctor moved her position to hug the patient's wife. The doctor told her that she could cry to release her emotion naturally. At the end of the meeting, the doctor asked the patient's wife to involve her daughter more in her daily life and asked her to make sure to support her mother as her mother now lived alone. The doctor told them that they could visit the palliative care clinic for a follow-up. The palliative care team did not rush the conversation. The patient's daughter said that she felt better and was committed to being more attentive to her mother (Field notes on 20 Feb 2014, P. 90: L.1-31).

Care to maintain dignity

Principles of palliative care emphasise that health professionals should maintain the dignity of patients and families. Dignity is one of the basic values in the provision of a palliative care service. On entering the outpatient clinic there was a sign on the wall that listed the values of palliative care which included 'care with dignity'. Although, it was not explicitly discussed among the team, it was apparent that the principle of dignity was important in the provision of care, even though there were often challenges in maintaining the patients' dignity. Caring with dignity in this section relates to aspects of how the palliative care team maintained the patients' state of being worthy and honoured. These aspects included preserving autonomy, maintaining functional and cognitive capacity, preserving continuity of self, and preserving the patient’s identity. Detailed descriptions of the aspects will be provided based on the findings of the observations and survey.

The palliative care team attempted to preserve the patients’ autonomy throughout the provision of care. This included providing the opportunity for the patients to make decisions about their treatment and care, respecting those decisions, and accommodating and implementing the patient’s wishes. This was most difficult when not all would agree on the treatments being proposed. Certainly, maintaining the patient’s dignity was sometimes difficult and complex. One of the challenges here was balancing the patient’s wishes, the family’s views, the belief about what was good practice and what should be done by the palliative care team. Often these views were not the same. For example, when a patient had a difficulty swallowing due to a tumour in her neck, the palliative care team assessed her daily intake, her ability to swallow, the condition of her mouth, and her tumour. After the assessment, the palliative care doctor considered that a gastrostomy could be the best nutritional palliation option for the patient, as it was considered a minor procedure and would make the patient more comfortable. The palliative care doctor then asked the patient…’*Madam*, *what about if we make a small hole in your abdomen to insert a tube so that you can eat sufficiently?*’ [‘*Ibu, bagaimana jika kami membuat lubang kecil di perut ibu untuk memasukkan selang kecil sehingga ibu akan mendapatkan makanan yang cukup*?’]. The patient shook her head many times and said softly ...’I *do not want to have that procedure, I am scared’ [... ‘Saya tidak mau dilakukan tindakan tersebut, saya takut’]*. The palliative care team reinforced to the patient that the procedure was only a minor intervention but the patient kept shaking her head. The team explored the patient’s reason for refusal. The patient’s husband said that she refused the procedure because she was scared. After hearing this, the doctor offered the patient subcutaneous therapy and explained the reasoning for the procedure. Although the palliative care team considered that, clinically, gastrostomy could be the best intervention for the patient, they felt that it was important that the patient should still have a say in the decision making. Clearly, the patient did not want to have the gastrostomy procedure. The palliative care team respected this and then offered subcutaneous therapy to at least maintain the patient's hydration. After the patient agreed, the palliative care nurse completed the subcutaneous therapy. The patient looked relieved when she realised she would not have the procedure she did not want (Field notes on 10 March 2014, P. 54: L. 1-8. L. 18) . The described interventions that were offered and employed by the palliative care team were another example of interventions that could be seen as being inappropriate or even aggressive care for the patient at the end of life.

The palliative care team believed that maintaining functional capacity was important for the patient's dignity and they implemented several strategies to maintain it. For example, the palliative care team encouraged the patients to use orthotics, wheelchairs or walking sticks. While the palliative care team believed that maintaining functional capacity promoted the patient's dignity, they still needed to consider the patients' wishes. It was not uncommon that the interventions to maintain the patient's functional capacity might not be in accordance with the patient's wishes. There was often a fine balance between promoting a particular intervention and the patient's wishes. During one outpatient service, a relatively young female patient was referred to the palliative care unit. After conducting an assessment, the palliative care team found that the patient had severe pain in her back due to metastases of the bone. The patient still had another 15 treatments of radiation scheduled and lived far away from the hospital. The doctor assessed and evaluated the patient's current pain management, which consisted of several pain-relieving medications. The doctor then modified the pain management by increasing the dosage of some pain medications and changing some of the pain relievers to an alternative. In addition to this, the palliative care team were also concerned about the patient's safety and wanted to maintain her functional capacity. The palliative care team suggested the patient use orthotics and a wheelchair to prevent bone fractures, but the patient refused to use the wheelchair, ...'*I do not want to look that weak*...' [*...' Saya tidak mau terlihat terlalu lemah...']*. The palliative care team explained to the patient that it was for her own safety but the patient then looked so sad. Seeing this, the palliative care team respected the patient's wish. They encouraged her to use the orthotics and gave her the information about temporary housing that was close to the hospital. The patient said she would consider the temporary housing options (Field notes on 12 March 2014, P. 170: L. 1-34). Understanding that the patient had her own preferences, the palliative care team respected her wishes.

There were particularly difficult cases when the patients had delirium. The palliative care team believed that, where possible, the patient's cognitive state should be maintained. For example, the palliative care team was contacted by a patient's relative telling them that the patient had delirium, was agitated and confused. The palliative care team then visited the patient at her home. In the home visit, the palliative care doctor prescribed haloperidol for the patient's delirium and agitation. Non-pharmacological management was also implemented that included; suggesting family caregivers not to give the patient many instructions at the same time, and also encouraging them to show pictures of family members and to ask the patient to explain what was happening in the pictures to try and orientate the patient. When the palliative care team performed this strategy, the patient was still able to remember her family and looked more settled and was happier (Field notes on 25 Feb 2014, P. 112: L. 22-30).

There were interventions that were implemented by the palliative care team to preserve patients' continuity of self. The palliative care team often encouraged the patients to do simple daily routines (e.g. mobilisation, feeding themselves, grooming). In the case of those patients unable to mobilise by themselves, the palliative care team encouraged family caregivers to assist. For instance, a relative reported that …'our *aunty (*the patient*) looks so much happier and fresher when* *we bring her outside…'* [...'*tante kami (*pasien*) terlihat lebih ceria dan segar saat kami membawanya ke luar rumah...*'] (Field notes on 11 March 2014, P. 164: L. 12-13).

When a patient stated that he regularly attended *pengajian* (religious meeting in Indonesian language), the palliative care team encouraged the patient to continue this activity for as long as he could. The palliative care team also asked the patients to talk about their life achievements. When knowing a patient was a retired teacher the palliative care team asked her to tell about her experiences. The patient said that she had taught lots of students and many of them were successful members of the community. The patient was proud to talk about this. She smiled when the palliative care team responded…*'You are a really good teacher and this becomes your good deed*' [...*'Anda seorang guru yang baik dan ini akan menjadi kebaikan/pahala untuk anda'*] (Field notes on 10 March 2014, P.152: L. 33-34).

Regarding the provision of dignity in care, the palliative care team demonstrated their efforts to maintain the patient's dignity and these mostly had positive outcomes. The practice of caring with dignity as illustrated above was reinforced by the survey (Appendix IX). The survey suggested that all the relatives were satisfied with how the palliative care team maintained the patient's dignity during the provision of care such as how the patients were being treated, consistent quality of care being provided and care that matched with the patient's wishes. However, issues could arise particularly around decisions about treatments where there was some disagreement.

The cultural domain 'the provision of care: meeting many challenges' highlighted the challenges in the provision of palliative care to meet the patient's complex needs while also maintaining his/her dignity. The view that addressing a patient's symptoms was important affected the care provision and interventions employed by the palliative care team. There were interventions employed by the palliative care team that may have been viewed as being inappropriate and aggressive care. This was one of the major challenges facing all involved in palliative care provision.

Instead of the challenges, this cultural domain had demonstrated the good communication and manners of the palliative care team in the provision of care. The nature of building relationships will be explored in the next cultural domain, ‘Building relationships’.

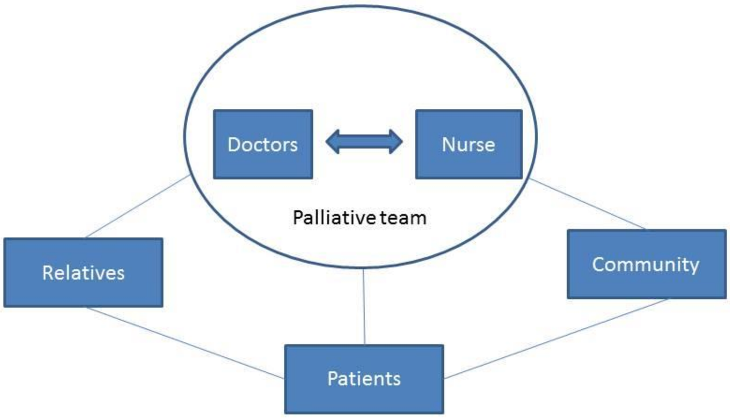
Building relationships

> It was raining when the palliative care team, a doctor and a nurse, arrived near the patient’s home. This was the first home visit for this patient. The patient’s husband brought several umbrellas for the palliative care team as they needed to walk some distance to reach the patient’s home. The patient’s husband walked in front of the palliative care team and went into the home and left the front door open. Although the door was left open, the palliative care team knocked on the door. When a woman opened the door and asked the palliative care team to come in, the palliative care doctor asked if she was the patient’s daughter and she nodded. The palliative care doctor asked the patient’s daughter to sit down with the team for a couple minutes. The doctor asked her about her mother’s condition and the family history. The patient’s daughter replied and then asked permission to continue to care for her mother.
>
> Then the patient’s husband came and sat down. The doctor asked about the patient’s grandchildren and his job. The husband replied that he had six grandchildren and both he and his wife were retired teachers. The doctor said that their children must be smart because they were teachers. The husband smiled. The doctor then asked about the patient’s medicines...*’Sir, can I look at your wife’s medicines?’ [... ‘Bapak, bolehkah saya melihat obat-obatan istri anda?’]* After the husband gave them the medicines, the doctor and the nurse checked if those medicines were appropriate. The husband asked the palliative care team to check his wife. He brought some chairs to the patient’s room for the palliative care team.
>
> Coming to the patient’s room, the doctor assessed the patient (specifically her pain, swallowing difficulty, mucositis and the tumour in her neck) and the nurse measured her vital signs. The doctor said that the palliative care team would do a blood glucose

> test because the patient looked weak. The nurse prepared the required equipment for the test and then performed the test while the doctor checked the patient's sclera. Based on the results of the test, the doctor asked the nurse to administer subcutaneous fluid therapy to the patient. The patient said she was okay for the fluid therapy. The doctor asked if the patient felt tired, she said no. When the nurse prepared for the procedure, the doctor demonstrated a simple set of exercises. The doctor encouraged the patient to do the exercise several times per day and the patient nodded her head. The nurse then administered the subcutaneous fluids. Once the infusion was set up, the nurse explained and demonstrated things related to the procedure to the patient's husband related (i.e. replacing the fluid, calculating the drips). The patient's husband nodded and told her that he would ask a nurse relative to help him doing this. The nurse explained to the patient's husband about the medicines (i.e. kind of medicines and the time). The team then said goodbye to the patient and went into the living room.
>
> The patient's husband asked the palliative care team to come back to the living room because there were cups of tea and some snacks. The palliative care team sat down and explained to the husband that they had changed some medicines for better pain relief. The palliative care team said goodbye to the patient's husband. When the palliative care team was in the front yard, the doctor provided her phone number and said that the husband could contact her at any time. The husband said that he already had the nurse's number. The doctor explained that the palliative care service was a team so he can contact either doctors or nurses.
>
> (Field notes on 10 March 2014, p. 143, l. 9-32; p. 144, l.14-30; p. 10-34; p.147, l.1-13)

'Building relationships' was the specific cultural domain related to interactions between the palliative care team and the patients/relatives and community (Figure 8). Relationships between the palliative care team and the patients and their relatives were often deep and intense. Three common themes of building relationships were identified in this study: 'relationships within the palliative care team’, ‘relationships between the palliative care team and the patients/relatives’, and ‘relationship between the palliative care team and the community’.

Figure 8. Model of building relationships in palliative care provision



Relationships within the palliative care team

The palliative care team demonstrated a good team spirit and a supportive relationship and it was obvious they had respect for each other. The palliative care team used professional titles and first names to refer to each other throughout their interactions. This was part of the Indonesian culture and considered to be respectful. In addition to having good professional relationships, the palliative care team also had good interpersonal relationships where the team often asked about and shared aspects of their personal lives.

The palliative care teams that conducted outpatient clinics and home visits included a palliative care doctor and palliative care nurse. There were many examples that demonstrated a good relationship between the palliative care team members and understanding of each other's roles. For example, the doctor as the team leader managed the patient's symptoms by prescribing medicines that were needed (e.g. pain relief, laxatives, and anti-emetics). In the case of difficult situations (i.e. complex problems, psychological problems, family related problems), the doctor led the interventions. The nurse performed hands-on nursing care such as wound care, fluid administration, and gave health education to the patient's relatives or carers based on the patient's symptoms and needs. In addition to this, the nurses spent considerable time encouraging the relatives to help with the care, using the opportunities to teach practical care and providing emotional support to the relatives.

The findings of the survey indicated the patients' relatives considered that the palliative care team worked well as a team (Appendix VII). This was reinforced by many examples during the period of field observations. In providing care, it was observed that the palliative care team offered to help each other, solved problems together and actively listened to each other as they had discussions. It was common that the palliative care team discussed the patients' conditions either in the palliative care unit office or while travelling to the patient's home. On one occasion, a patient's relative contacted the palliative care nurse because the patient had constipation and wanted to have the home visit service, the nurse then discussed this with the doctor and the other nurse prior giving interventions. This was also evident in the hospice service where the nurses often had discussions with the patient's oncologist about what care and medications were provided. It was important that the relationships between nursing staff and the referring doctors were strong as the nurses from the hospice conducted all the home visits themselves.

Relationships between the palliative care team and patients/relatives

The survey of patients' relatives indicated their satisfaction with the palliative care team in regard to the level of information provided, the honesty when explanations were given and the staff's attention when listening to relatives. This was also illustrated in the observations where interactions between the palliative care team and the patients/relatives were warm, friendly, respectful and prompt.

When dealing with the patients and their relatives, the palliative care team always introduced themselves at the beginning of interactions. The palliative care team also referred to themselves by their professional titles and their first names throughout any interaction, such as when the palliative care doctor asked the nurse to do an intervention, ...*'Nurse Dian (pseudonym), could you check this patient's blood glucose?'* [...'*Suster Dian (samaran), dapatkah anda mengecek kadar gula darah pasien ini?']*. Although it seems a simple strategy in communication, this strategy is likely to have significant effects on the patient-health professional relationships by increasing trust and comfort for the patients and their relatives and showing the palliative care team's level of trust.

There were many examples that showed the warm and friendly relationships between the palliative care team and the patients and their relatives. The palliative care team would ask about non-clinical aspects of the patients' and relatives' lives in order to build rapport. The palliative care team asked the patient's husband about the family and his job. When knowing that both the patient and her husband were retired teachers, the palliative care doctor commented that their children must be smart after being raised by teachers (Field notes on 10 March 2014, P.152: L. 33-34). This type of interaction was clearly welcomed by the patients and relatives.

The palliative care team also tailored their communication style to suit the patient's cultural background. For example, when visiting an elderly patient from a Javanese background, the palliative care team utilised *krama inggil* (a form of the formal Javanese language used to show respect for older people). For example, …*'Ibu ingkang diraoske menapa?'.* The informal form of Javanese language used to communicate with young person would be, '*Opo sing tok rasakne*?' Both can be translated as '*Is there anything that you experience*?' The palliative care team were also considerate about the patients' ethnic backgrounds. For example, when visiting a Chinese patient around the time of Chinese New Year, the palliative care team greeted them and wished them '*Gong Xi Fat Choi' (a Chinese greeting for New Year and wishing for prosperity)*. The patient and relatives looked happy when the palliative care team did this (Field notes on 3 Feb 2014, P. 25: L. 5-6, on 4 Feb 2014, P. 28: L. 25-27).

The palliative care team employed verbal and physical comfort measures during the interactions to provide support for the patients and their relatives. For example, when a patient's wife cried because she felt disappointed with her husband's previous treatment and felt she was not doing her best for her husband's care, the palliative care team calmed her down by giving her a hug. The palliative care team told the patient's wife that she had done her best for her husband. The palliative care team also told her to focus on the current situation and the future. Apparently, these verbal and physical comforting measures had positive results the patient's wife was calmer after a couple of minutes (Field notes on 29 Jan 2014, P. 13: L. 2-4).

The manner in which the palliative care team delivered information was a feature of the provision of palliative care. It was evident that information provided to the patients and relatives was appropriate and up to date. The palliative care team used plain language terms to explain medical conditions to the patients and relatives to enable and improve their understandings. For example, during an out-patient palliative care clinic, the palliative care doctor explained to a patient … *'Madam, I would like to tell that based on the current examination the cancer has spread to the spine' [...'Ibu, saya ingin memberitahukan jika berdasarkan hasil* *pemeriksaan terbaru kanker yang ibu derita sudah menyebar ke tulang belakang].* The term 'metastases' was also used in Indonesian medical and health terminology, but is not a term that would be well-understood by relatives and patients without any knowledge of medical terminology (Field notes on 10 March 2014, P.152: L. 33-34).

One of the central aspect in the relationship between the palliative care team and the patients/relatives was respect. Most of the palliative care service was delivered in the patients' homes. The palliative care team were acutely aware that the context in which the care was provided was very different from the hospital. For example, in the vignette when the palliative care team arrived at a patient's home, although the door was left open by the husband who had already entered the house the palliative care team still knocked on the door and waited to be invited in.

When they addressed the husband the palliative care team used the term *Bapak* (Sir) to address the patient's husband. On every occasion, the palliative care team always used madam (*Ibu* in Indonesian language) or sir (*Bapak* in Indonesian language) and their given name to address both patients and their family member. For example, *'Do you feel any pain at the moment Bapak Aryo (pseudonym)*?' ['*Apakah Bapak Aryo (nama samaran) saat ini merasakan adanya nyeri?*']. Similarly, the patients and their families used 'doctor' or 'nurse' to refer to the palliative care team during interactions. This was part of the Indonesian culture where calling someone madam, sir, and using professional titles is common and considered to be respectful.

The family caregivers considered that providing drinks (e.g. tea, water, and coffee) was part of respecting the palliative care team. During almost every home visit, the relatives provided drinks and a snack to the palliative care team. Commonly, the palliative care team had the drinks and snack at the end of providing care while they had discussions about the patient's condition with the family caregivers.

The last aspects in the building relationships between the palliative care team and the patients/relatives was the level of access to the team at any time and the recognition that the team would respond promptly. The palliative care team, either doctors or nurses, would routinely give their mobile numbers to the relatives. They would tell the relatives … '*This is my mobile number, you can contact us at any time.' […* *'Ini nomor telepon genggam saya, anda dapat mengontak saya setiap waktu']* (Field notes on 12 March 2014, P.166: L.10-12*).*

Frequently, the family caregivers would ring or text the palliative care team during the day, however, there were also occasions where the relatives contacted the palliative care team on the weekend or in the middle of the night. There was no policy that indicated the palliative care team were obliged to take calls from patients or relatives after hours. The palliative care team, however, were happy to do this even when they were not on duty. In Indonesia, this would be considered extraordinary as even in an emergency situation people generally went to the hospital by themselves rather than calling the ambulance.

In addition to phone calls, email was also used for communication. The palliative care team considered that it was important to use any type of communication to keep the relatives informed about the patient's condition. For example, the palliative care doctor communicated via email with a patient's daughter to provide updated information as she lived overseas (Field notes on 6 March 2014, P. 139: L. 19-20).

The accessibility of the palliative care team made the family caregivers feel more secure and supported. Whenever they needed assistance and help, their requests mostly were granted right away. A family caregiver stated, '*I am really satisfied with the service provided by the palliative care team particularly their communication, because any time I contacted them either by phone or texts, I got the response straight away and they came up with suggestions for how to manage my wife's symptoms'… ['Saya sangat puas dengan pelayanan yang diberikan oleh tim paliatif terutama untuk komunikasinya, karena setiap saat saya mengontak* *baik melalui telepon atau pesan singkat, saya selalu langsung direspon dan mendapatkan saran bagaimana menangani gejala yang dialami istri* saya'] (Field notes on 10 Feb 2014, P. 50: L. 10).

Relationships between the palliative care team and the community

The community in this study referred to the patient's friends, neighbours, local neighbourhood leaders or local informal chaplains. On many occasions the palliative care team acknowledged and encouraged members of the community to be actively involved with the patients. This could be by emotional, spiritual or practical support and these interactions were warm and respectful. For example, in one typical home visit, some visitors came to the patient's home. The patient and the visitors were well known each other and had been chatting. The patient's niece told the palliative care team that the visitors were the patient's friends since high school. The palliative care team smiled, introduced themselves and shook hands with the visitors. After finishing the interventions, the palliative care team had a conversation with one of the visitors, explaining to her about palliative care provision and what she could do to support the patient (Field notes on 18 Feb 2014, P. 76: L. 22-25).

In another example, a local community leader drove the patient to the outpatient clinic. The palliative care team were quick to acknowledge this action and said to the community leader that driving the patient to the hospital really helped the patient (Field notes on 27 Feb 2014, P.98: L. 10).

The palliative care team also recognised the role members of the community played in terms of spiritual support. In one typical home visit, the patient was visited by an *ustadzah* (informal female Muslim chaplain). The palliative care team recognised that the *ustadzah* had been providing spiritual support to the patient and they very much encouraged this. The palliative care team asked the *ustadza*h to lead a prayer for the patient (Field notes on 10 March 2014, P.157: L. 2-6).

The above section has provided illustrations of how the palliative care team built rapport and relationships with the patients and their families/relatives. Several strategies were employed by the palliative care team such as providing appropriate information, using plain language, tailoring communication, being respectful and providing prompt response. The findings from the survey reinforced this illustration. The next sections provide descriptions of the cultural domain 'family caregiving'.

Family caregiving

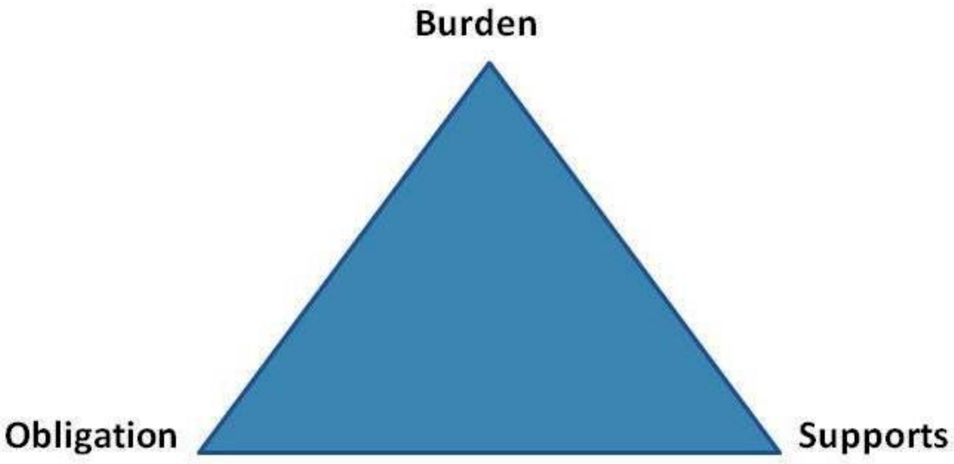
The following is an example of an observed family caregiving process.

> The palliative care team arrived at the patient's home. The patient's husband, who was in the front yard, greeted the palliative care team and asked the team to come in. The team enquired about the patient's condition. The doctor asked the husband, '*Who helps you in providing care to the patient?*' ['*Siapa yang membantu anda merawat istri anda*?']. The husband replied that he took care of his wife, he said, '*I must take care of her as it is my responsibility. I have to be with her during happiness and sorrow*' ['*Saya harus merawat istri saya karena itu kewajiban dan tanggung jawab saya. Saya harus bersamanya saat bahagia dan sedih*']. He added that he did all the basic care for his wife such as feeding and hygiene as his wife was unable to do these things for herself. The husband added that he did have other relatives supporting him in providing care for his wife. At that time, the patient's brother-in-law was there helping care for the patient. The patient's husband explained that his in-law had come from another city to help look after his wife when he was away from the house.
>
> The palliative care team went to the patient's bedroom. The patient had oxygen, a feeding tube and urinary catheter. Based on the physical examination, the palliative care team wanted to administer a nebuliser and it was apparent that the patient's oxygen was nearly finished. The patient's husband asked his in-law to change the oxygen. He also asked the relative to dispose of the water from the humidifier tube. The palliative care nurse did the nebuliser procedure and explained to the relative

> about the procedure. The patient's brother-in-law asked the nurse about the relationship of fluid in the lungs with feeding. He was scared that he might do the feeding incorrectly. The palliative care nurse explained that the fluid in the lungs was due to infection. The nurse further explained that the digestion and the respiratory system had a different tract and that with the feeding tube placed correctly, there was little risk that the food would go to the lungs. After the explanation, the patient's brother in law looked more relieved.
>
> The palliative care team then moved to the living room and had a discussion with the patient's husband and relative. The doctor emphasised that the focus of care was that the patient should be as free of pain as possible. The doctor then discussed the patient's condition and other possible interventions (e.g. pain relief) that may be used for the patient's comfort. The patient's husband indicated that he trusted the palliative care doctor so that if someone else suggested other interventions for his wife he would ask and discuss this first with the palliative care doctor. The palliative care doctor nodded and smiled attentively. The doctor prescribed some medicines and the patient's relative said he would get the medicines from the hospital.
>
> (Field notes on 20 Feb 2014, p.85: l.12-21; p 87: l.14-29, 13 March 2014, p.166: l.27-31; p.167: l.11-20; p.168: l.1-9)

The cultural domain, 'family caregiving', relates to the provision of care by the patient's relatives. The families of patients were generally very involved in providing care, both emotionally and physically. There were three elements in this specific cultural domain. For relatives there was a strong sense of obligation to provide care but they also recognised the burden of providing that care. The burden was in turn counterbalanced by the support coming from the palliative care team, the extended family and others in the local community. This relationship is illustrated in Figure 9.

Figure 9. Model of family caregiving process



Obligation

As illustrated in the above vignette, the husband perceived that providing care for the patient was his obligation, during happiness and sorrow. In another case, this obligation was expressed by a patient's wife ... '*I will provide care for my husband by myself, this is my duty'. [... 'Saya akan merawat suami saya sendiri, ini adalah kewajiban saya']*. In these two cases this sense of obligation was expressed by the immediate partner, the husband or wife, as a commitment to their marriage; however, other relatives also felt this strong sense of obligation.

The illustrated vignette shows that the care was provided by the patient's husband along with the assistance of other relatives. The strength of family ties was reflected in observations where immediate family members, the spouse or children, were not available. It was not unusual for extended family members to then provide the care for the patients. For example, there was one case where a patient was cared for by her nieces. These nieces stated that the patient's children lived overseas and they wanted to make sure that the aunt was well cared for.

Burdens

The previous section dealt with family caregiving as an obligation for the patient's relatives. The following section is concerned with a range of care that was being provided by the family and the impacts experienced by the family caregivers.

In the process of family caregiving, relatives provided a range of care such as physical care (e.g. personal care, nutrition, mobilisation), spiritual care (e.g. helping the patient to perform religious practice, inviting the local chaplain to do prayers together) and other practical aspects of managing the patients' care (e.g. health insurance, transport to hospital). This care was either provided by a single primary family caregiver or shared with others (e.g. home-care nurse, other relatives and informal carer). The above vignette illustrates that the patient's husband and relatives provided a range of care such as physical care, spiritual care and health management. It was demonstrated that although the husband did all the personal care he did get assistance from relatives for other aspects of care.

The relatives considered that caregiving affected them in many ways. Many of the patient's relatives experienced physical and mental exhaustion. For instance, a wife related how she was always staying at home ...'*after his condition (*patient*) deteriorated, I never left the house, not even for grocery shopping. [...'setelah kondisinya (pasien) menurun, saya tidak pernah keluar rumah, bahkan untuk berbelanja'].* This family caregiver added that she felt physically exhausted because she never had time off from providing care to her husband, ...*'I never have a day off. Even on the weekend, I could not have a rest because many relatives visited my husband (*patient*)*' [...'*Saya tidak pernah istirahat. Bahkan saat akhir pekan, saya tidak bisa beristirahat karena banyak keluarga yang mengunjungi suami saya (*pasien*)]'*. Mental exhaustion was also a problem. For example, the patient's wife said …'*so far I always hold back my tears because of I am afraid that my husband will be sad if I cry'* [... *'selama ini saya selalu menahan untuk tidak menangis, karena saya takut suami saya akan sedih jika saya menangis']* (Field notes on 29 Jan 2014, P. 9: L. 26-27, on 5 Feb 2014, P. 36: L. 31-33).

As discussed in the previous section, a sense of duty and responsibility was one of family caregivers' reasons for providing care for their loved ones. This also created financial difficulties for some family caregivers. A patient's son, who was the primary family caregiver, stated that he did not work because none of his siblings were able to do the caregiving so he had to care for his mother. Another example was that a family caregiver had to sell his trucks for his wife's treatment (Field notes on 7 March 2014, P. 142; L. 28-29). In another case a patient's wife had to close down the shop that was the family income to care for their loved one.

Strained relationships was another impact for some family caregivers. It was observed that strained relationships often happened when many family caregivers were involved with different opinions and views on how to look after the patient. It was also evident that on some occasions, when things were not going well family members would blame each other for what was happening. For example, on one occasion, a patient's son (Mr Bayu – pseudonym) who was contacted by the palliative care team blamed his brother for taking their mother to the hospital emergency department. The patient's son told the palliative care team that his brother had done a similar thing several times without any family discussions. Mr Bayu added that his brother did that because his brother was not responsible for the cost of their mother's treatment. When the palliative care team offered to have a family meeting with all the patient's children of the patient this was rejected (Field notes on 13 march 2014, P. 174; L.28-30, P. 175; L. 8-12).

While many family caregivers struggled with the burden of caring for their loved ones there were supports from others. The next element, 'supports' for family caregivers, examines specific supports from other family/friends, the community and, importantly, the palliative care team.

Supports

The vignette in the beginning of the section demonstrated that the primary caregiver had support from other relatives in providing care for the spouse. In other cases, support came from the palliative care team, the extended family and the community.

It was evident that the palliative care team gave whatever support they could to the family members, as described in earlier sections. In addition, the most obvious support for the family caregivers was by addressing the patients' and relatives' needs in a timely manner.

Most of the family caregivers stated they received sufficient support from the palliative care team. They also shared their satisfaction with support provided by the palliative care team. The survey component in this study showed that most family caregivers were either completely or very satisfied with the adequate control of physical and emotional problems received by the patients (Appendix IX). In addition, family caregivers stated their satisfaction with the prompt assistance provided by the palliative care team during phone consultations. For example, …'I *am really satisfied with the palliative care service. Every time I ring or text to consult symptom management, the team gives direct answers/solutions'* *(informal interviews, FCG3, 10 Feb 2014). [...'Saya sangat puas dengan pelayanan paliatif. Setiap saat saya menelepon atau mengirimkan sms untuk konsultasi tentang penanganan gejala, tim selalu memberikan jawab dengan cepat' (wawancara informal, FCG3, 10 Februari 2014)].* Another example of satisfaction was the thankyou cards that were sent by the patient's relatives to the palliative care team. These cards were kept by the palliative care team and placed in the visible area of the palliative care clinic office.

During the period of observation, many examples had shown that the patient's extended families provided support in helping care for the patient. These extended relatives included patient's brothers or sisters, the in-laws, and nieces or nephews. A varied range of supports provided by the extended family caregivers, including helping with the patient's direct care, providing spiritual supports and visiting the patient regularly. For example, in one occasion, a patient's sister who lived in a different town visited the patient. She stayed several weeks in the patient's home to help the patient's husband providing care to the patient (Field notes on 7 March 2014, P. 143: L. 16-17).

It was apparent that the community (e.g. neighbours and patient's friends) also provided support in the process of family caregiving. Such supports included visiting a patient at home, giving a hope and motivation to the patients and relatives, and bereavement support. For example, it was observed on several occasions, that patients were visited by their friends and neighbours. In addition, community support was often in the form of helping a patient go to a hospital. In one instance, a local community leader drove a patient and her relative to the hospital (Field notes on 27 Feb 2014, P.98: L. 10).

The cultural domain of family caregiving highlighted issues that directly influenced the provision of family caregiving. Obligation was perceived by the family caregivers as a legitimate reason to deliver caregiving. Providing several types of caregiving to the patients led to a burden for caregivers, so support from relatives and community were likely to ease the family caregiving process. Another support was from the palliative care team whereby the palliative care team was fully engaged and had a good relationship with the patients and their relatives. The good relationship was based on how the palliative care team building relationship, which was discussed in the section '*building relationships*'.

Spiritual/religious practices

The vignette below describes how the spiritual/religious care was occurring during the provision of palliative care. In the vignette, those involved in the provision of spiritual care included the palliative care team and the *ustadzah* (informal female Muslim chaplain). In Indonesia, it is usual to have a female Muslim chaplain. The informal Muslim chaplains are generally Islamic scholars who have an education background in the Islam religion; for example, they graduated from Islamic boarding schools or have a bachelor degree in Islamic religion.

> The palliative care team entered the patient's bedroom with patient's husband. There was a copy of the Quran on the bedside table. There was one female visitor sitting near the patient's bed. Apparently, the patient and the visitor had known each other and had been chatting. The patient's husband introduced the female visitor to the palliative care team as a local *ustadzah* (informal female Muslim chaplain). The palliative care team including the nurse and the doctor smiled and shook hands with the local chaplain.
>
> After finishing all required interventions, the palliative care team sat down near the patient and asked if the patient had any wishes. The local chaplain responded that the patient wanted to perform *Hajj* (an Islamic pilgrimage to Mecca, Saudi Arabia which is a mandatory religious duty that must be carried out at least once in their lifetime for adult Muslims who are physically and financially capable) and had made arrangements to undertake the Hajj in 2019. The patient nodded weakly and said, '*Yes, I want to go for Hajj*' ['*Ya, saya ingin pergi haji*'] but seemed unsure if she could undertake the Hajj due to her condition. The doctor asked the local chaplain if there was a priority for the patient to undertake Hajj as it was the patient's wish. The local chaplain replied that the patient's obligation to perform Hajj had lapsed because the obligation to perform Hajj was for those who were both healthy and financially able to do so. The local chaplain added that the patient might already receive the reward of the Hajj because of her intention to go and because she had registered and paid for the Hajj. The local chaplain said the patient could ask her family to perform Hajj

> on her behalf. The local chaplain also reminded her that if she was healthy enough she could undertake the *Umrah* (a pilgrimage to Mecca, Saudi Arabia that can be undertaken at any time of the year, in contrast to the Hajj). The chaplain rubbed the patient's hand during the discussion. The patient nodded her head and then cried. The palliative care team came closer to the patient, sat down at the patient's bed, looked attentively and showed concern. The doctor asked how the patient was feeling. The patient responded that she missed her former students. The doctor said that the patient must be a great teacher as she taught the first year in the primary school and had taught many students. The doctor further added that what the patient had taught was most useful. The patient nodded her head and smiled.
>
> The palliative care doctor asked the local chaplain, '*Could you lead a prayer for us?*' [*Maukah anda memimpin doa untuk kita?*] The local chaplain nodded her head. The local chaplain led a prayer for the patient's recovery, for health of the patient's husband and the palliative care team. Before finishing the prayer, she asked, '*Could you all please read Al-Fatiha (the first surah in the Quran) in your heart?'* [*Bisakah anda membaca Al-Fatiha (surat pertama di Al-Qur'an) dalam hati?'*]. After completion of the prayer, all who were in the patient's bedroom said, '*Amen'*. The palliative care doctor, who was Catholic, moved her palm forming a cross.
>
> (Field notes on 10 March 2014, p.147: l.3-31)

There were many situations that demonstrated the importance of religion and spirituality for the patients/relatives and the palliative care team involved in this study. These included not only the acknowledgment and support by the palliative care team for the patients and their relatives' religious practices but also how religion and spirituality were central to the team's life and their practice.

Patient's and relatives' spiritual and religious practices

In Indonesian culture religion is very important in everyday life and becomes increasingly important in times of illness. During this study the patients and relatives paid a significant amount of attention to religious practices. The above vignette shows that there was Quran on the bedside table near the patient's bed. In most patients' home, there were printed prayers (i.e. *Dua* in Islam, or verses from Bible) attached to the wall close to each patient's bed. This was done by the family caregivers to enable immobile patients to keep conducting prayers as the patients could see and read the printed prayers. Even when the patient was unconscious, relatives played recordings of religious music (i.e. Quran recital, Christian songs) in the patient's room to comfort the patient (Field notes on 29 Jan 2014, P. 8: L. 33-34, on 4 Feb 2014, P. 29: l. 9, 14 Feb, P. 61: L. 13-14, on 10 March 2014, P. 153: L. 10-11).

Most patients tried to keep performing their religious practices until their end of life. As illustrated in the above vignette, the patient expressed her wish to do Hajj in the near future despite her condition. The wish to perform religious practices was also demonstrated by other patients. …*'I still perform my five daily prayers (*Salat*) by myself but sometimes my son helps me to do wudhu (*ablution*) before performing Salat …'* [...*'Saya masih melaksanakan shalat lima waktu sendiri, namun terkadang anak laki-laki saya membantu saya berwudhu sebelum shalat*...'] (Field notes on 10 Feb 2014, P. 49: l.6-14).

The family caregivers considered the importance of performing religious practices for the patients. In addition to providing support and assistance themselves they would often invite chaplains to the home. One patient's relative said…*'I helped my brother-in-law (*the patient*) to do the prayers and I invited a Buddhist monk to lead a prayer at home…' [...'Saya membantu kakak ipar saya (*pasien*) untuk berdoa dan saya sudah mengundang biksu untuk memimpin doa di rumah...']* (Field notes on 29 Jan 2014, P. 12: l.18-21).

The examples above illustrate the importance of supporting religious practices for these patients. This was assisted by all involved including the relatives, the community and the palliative care team with all providing support and encouragement. The importance of religion is further underscored by the observance of religious practices even away from patient interaction.

Palliative care team's spiritual and religious practices

The palliative care team conducted morning meetings for approximately 10 to 15 minutes each day. To begin the meeting, a member of team (different for each meeting) would take the lead beginning with prayers. The group prayer was for a smooth and blessed day as the team went about their work. Following that, the leader would ask everyone in the room to do prayers based on their own religion. The meeting then continued to share updates such as a new policy or meeting notes from upper managerial level. At the end of the morning meeting, the leader did final prayers for activities in the day and for the health and welfare of the patients, relatives and the palliative care team members (Field notes on 24 Feb 2014, P. 89: l. 5-16, 27 Feb 2014, P. 3-16).

Religious/spiritual assistance from the patients/relatives

The patients and their relatives recognised the religious obligations required by the palliative care team. Efforts from the patients and their relatives to assist the palliative care team in meeting these obligations were apparent. The assistance included not only allowing the palliative care team to do religious obligations in their home but also providing facilities to do so.

In the provision of the home visit service, the palliative care team were out in the community between 9 am and 4pm. Most of the palliative care team, but not all, were Muslim. In Islam there is an obligation to do prayers (*Salat*) five time a day, performed at specific times of day, and one of these prayers (*Salat Zuhr* or the noon prayers) has to be performed at midday. On many occasions this would coincide with a home visit. It was observed that the patients and their relatives were happy to be able to assist the staff to undertake their religious obligations.

This also involved providing appropriate facilities. All the Muslims in the palliative care team were female. In doing the five daily prayers it is required that all the body is covered and generally the Indonesian Muslim women wear the *mukena/* the prayers dress (a loose outfit which can be put on over clothes when performing *Salat*). The patient's relatives understood this need and provided *mukena*/the prayers dress and a prayer mat to the palliative care team members (Field notes on 11 March 2014, P. 166: l. 5-6).

Religious acknowledgment and encouragement

Generally, the practice of religion is encouraged in Indonesian daily life, regardless of religious affiliation. Being respectful of other religions is expected and was very apparent during this study. This acknowledgment and encouragement of all religious affiliations existed between all those involved. This was seen in team meetings and during the provision of home-based care. During home visits, when the patients and relatives had a similar religious affiliation with one of the palliative care team, the palliative care team usually asked them to perform prayers together. If one team member had a different religion they might wait in another room. For example, when visiting the Christian or Catholic patients, the doctor who was Catholic performed prayers with them. The nurse who was Muslim waited in the patient's living room because in Islam the way for religious encouragement is by respecting, rather than by participating with other religious rituals. On other occasions, when visiting the Muslim patients, the nurse who was Muslim performed prayers with the patient and relatives (Field notes on 5 Feb 2014, P. 42: l. 11-15, 20 Feb 2014, P.94, L.25).

Dealing with death and dying

> On one evening, the palliative care team went to a funeral home before the patient's funeral ceremony was conducted. About two weeks before, the palliative care doctor told the patient's wife that her husband's condition was deteriorating and the family

> should be prepared for the patient to pass away at any time. The wife cried for a couple of minutes. She then said she still could not accept that her husband's death was imminent and asked if the patient would still be able to celebrate Chinese New Year (five days after the home visit). When the patient's condition deteriorated, he was brought to the hospital and died soon afterwards.
>
> The funeral ceremony was conducted in a funeral home. There were Chinese attributes (e.g. Chinese writing, artefacts in red colour and a Chinese boat), candles, some food, and the patient's photograph in front of the coffin. The patient's wife and children wore white blouses. They stood near the patient's coffin. Several relatives sat on chairs. When the palliative care team arrived, they shook hands with the wife and the children and expressed their condolences.
>
> The palliative care doctor did a prayer for the patient. Afterward, the patient's wife talked with the palliative care team, she talked about the patient's death, explaining that the patient said that he loved her and then died peacefully. The palliative care doctor listened, touched her arm gently, said nothing and looked at the patient's wife attentively. When the patient's wife cried, the doctor gave her a hug. The patient's wife then asked if it was possible that her husband would be alive if another treatment had been given. The doctor said that death was a destiny which had been written by God. The doctor added that the patient was really ready to die. The wife said that her husband looked younger, fresher and like he had no burden. The wife said she did not know what to do now her husband had died. The palliative care doctor suggested she focus on their children.
>
> (Field notes on 19 Feb 2014 p. 78: l.20-34; p.79: l.1-6)

The last cultural domain, 'dealing with death and dying' relates to how this was experienced and managed by the palliative care team and the patient's relatives. There were frequent discussions about prognosis and death between the palliative care team and the patient's relatives that conducted overtly where the palliative care team provided honest information about the patient's condition. In such discussions, however, the patient was almost always excluded.

Preparing and assisting the family caregiver when the patient was dying

From their years of experience, the palliative care team were able to recognise the approaching signs of death. When recognising the patient's condition was deteriorating, the palliative care team would have discussions with the family about the patient's condition to prepare them for their loved one's death and suggest they finalise plans for the patient's funeral. The discussions about death and dying between the palliative care team and the patient's relatives were overt. Although, there was no such overt discussions with the patients themselves, there were occasions where aspects of death and dying were discussed indirectly between the palliative care team and the patients.

The palliative care doctor began talking about the patient's condition and the prognosis to the relatives, then the doctor assessed the relatives' responses. If the relative accepted the situation, the palliative care doctor continued to discuss about the funeral planning such as the burial place and the rites. In a situation where the relatives denied the prognosis, the palliative care team encouraged the relatives saying that they had done their best for the patients and gave comforting touches (e.g. hug, gentle rub on arm). In addition to discussions about funeral planning, it was common for the palliative care team to suggest the family caregivers ask forgiveness from the patients for his/her previous mistakes and that they also forgave the patient's mistakes. The palliative care team also suggested the relative to give thanks for what the patient had done. It seems this request was influenced by the cultural belief that forgiving the patient will smooth his/her way to return to their God.

It was also apparent that the funeral discussions were also held among the family caregivers. For example, when the palliative care doctors asked about funeral planning, the relatives responded that they had already discussed the funeral and reached agreement with each of the involved relatives. The funeral planning usually accommodated the patient's wishes (e.g. place of burial sites, funeral rites).

In preparing and assisting the patient's relatives with death and dying, the palliative care team would encourage families to draw on their religion at this time. In circumstances where the patients were unconscious, the palliative care team would suggest the family guide the patient during their end of life with religion. For example, when a Muslim patient was unconscious they asked the relatives to play a Quran recital near the patient's ear.

(Field notes on 29 Jan 2014, P.9: L.9-14, 19 Feb 2014, P. 82: L. 15-16, 4 Mar 2014, P. 140, L. 31-32)

The family caregivers considered that spiritual support was important for the patients at their end of life. They employed strategies to provide spiritual support such as: reciting the Holy Quran, helping the patients to perform prayers and inviting a chaplain to lead prayers at home. For instance, a patient's wife said that she always recited the Holy Quran near her husband (patient) who was unconscious and had experienced seizures. The patient's son added that after the patient's condition had deteriorated, in addition to the Holy Quran recital, they guided the patient by reciting Islamic words (*Shahadah*/declaration of faith, *istighfar*/asking forgiveness). The family caregivers believed these rituals would ease the patient in his dying and death process (Field notes on 29 Jan 2014, P. 8: L. 33-34, P. 9; L. 1-3, L: 15-17).

There were many issues about the way family caregivers responded to the patient's dying and death. The family caregivers always wanted to do their best for their loved one but when death was approaching they reacted in a variety of ways. Some family caregivers who accepted the dying and death processed it calmly, while others were extremely upset. Many did not want or expect their loved one to die so soon, while others did not want to see prolonged suffering. For some relatives that had previously experienced a family member dying previously it was easier for them to accept what was happening and this brought them some comfort. For example, a patient's wife said that she knew her husband might die any time soon because he had similar signs as when her father passed away (Field notes on 29 Jan 2014, P. 9: l.8-9. P. 13; L. 4-7, 5 Feb 2014, P. 41; L.20-21).

Funeral rites

This section describes how rituals during funerals were practiced encompassing a variety of direct elements (e.g. place and time of funeral mass, type of burial plot, wardrobe worn by the mourning family and supports) and indirect elements (e.g. the patient's wishes).

As illustrated in the previous vignette, the funeral ceremony was conducted in the funeral home employing the patient's ethnic background. The vignette shows that the Chinese ritual was implemented in the Chinese patient's funeral ceremony. It was observed that religion and ethnicity group influenced how elements of a funeral were practiced. For example, in a Muslim family, the funeral mass and burial were conducted immediately. This rite follows the Islamic law (*shariah*) that states the body should be buried as soon as possible after the time of death. In other religions and ethnic groups, the process of funeral and burial could be conducted several days after the death. For example, in a Catholic family with a Chinese background, the funeral mass and burial were conducted several days after the death because the family followed the date determined by the monk.

In Indonesian culture most families turn to their extended families, friends and neighbours for practical and emotional support during the period of grief and bereavement, although the primary support came from their immediate nuclear family. For example, it was observed that extended families some of whom typically travelled great distances, as well as neighbours and friends, attended the funeral ceremony. This was conducted to provide support and comfort the mourning family and show respect to the deceased.

The family caregivers also tried to accommodate the patient’s wishes regarding to the funeral. For example, one patient’s wife said that she did what her husband wished regarding funeral rites and burial site. The wife explained that the patient left messages to be buried in a graveyard near his home and wanted his funeral prayer (*Janazah* prayer/*Salat al janazah*) conducted in the mosque at the residential complex. The wife told that she was happy that she could accommodate her husband’s last wishes (Field notes on 25 Feb 2014, P.115: L. 23-24).

Attending patient’s funeral

Apparently, the palliative care team had a good attitude towards their patient’s death and dying. The term ‘passed away’ was used by the palliative care team instead of saying that a patient had died. This term represents the respect of palliative care team to the patient where in Indonesian culture the use of ‘passed away’ was considered more polite. In addition, it seems that the palliative care team also thought that using the term of ‘passed away’ was softer language so the message made was more palatable.

As illustrated in the above vignette from the field notes, the palliative care team tried where possible to attend the patient’s funeral and considered that attending the patient’s funeral was a feature of the palliative care service. If they could not attend they came before or after the funeral ceremony. In their attendance at the funerals, the palliative care team expressed their condolences to the family and did prayers for the deceased patients. In addition, it was common for the palliative care team to hug the mourning spouses, but care was taken to ensure this was appropriate in terms of gender, and told them to memorise their best moments with the deceased. The palliative care team also offered grief and bereavement services to the family caregivers. The palliative care team considered that this final act of caring was an important part of their practice. They believed that what they did were ways for the palliative care team to respect the patients and their relatives and also gave support and comfort for the relatives (Field notes on 3 Feb 2014, P. 21; L. 1-34, 19 Feb 2014, P. 88: L. 12-18, 25 Feb 2014, P. 115: L. 23-24).

Summary

This chapter has provided detailed explanations of the five cultural domains that were important to understanding the cultural aspect of service provision in the palliative care: *'the provision of care: meeting many challenges*', '*building relationships'*, *'family caregiving*', '*spiritual and religious practices*' and '*dealing with dying and death'*.

'The provision of care: meeting any challenges' was the element that described in general how the palliative care service was provided by the palliative care team even though some challenges existed. The challenges were explored in the beginning of this section which then followed with exploration of other cultural domains. These cultural domains emphasised the complexity of care in the provision of palliative care that related to addressing the many needs of the patients while still maintaining their dignity. Sometimes there were conflicting views about how those needs should be met. In addition, some interventions given to the patients may have been seen as being unnecessary or even aggressive care. This was one of the major challenges in the care provided by the palliative care team.

The cultural domain of 'building relationships' highlighted the importance of building relationships within the palliative care team, and relationships between the palliative care team and the patients/relatives and the palliative care team with the community. The quality care which delivered to the patients and their relatives was resulted from good relationships between the palliative care team. Some strategies from palliative care team were more likely to improve the relationships with the patients/relatives. Observation revealed that the palliative care team tailored their communication style to suit and to respect patients'/relatives' cultural backgrounds. The use of these strategies led to positive outcomes where the patients'/relatives' rapport and trust could be developed. The relationship between the palliative care team and the community was discussed in the last section of the domain 'building relationships'.

The cultural domain of 'family caregiving' was mainly concerned with obligation, burdens and supports. The willingness to provide care for the patients arose due to a sense of obligation because the family caregivers perceived that it was their obligation to look after their loved ones. Being obliged to look after the patients, the family caregivers looked after them by providing basic care, spiritual care and manage their health management. Performing all the aspects of caregiving at home, the family caregivers experienced burdens (e.g. fatigue, needing to resign from job and strained relationships). Fortunately, the palliative care team, extended family and community gave support to these relatives in the process of family caregiving.

'Spiritual/religious practices' emphasised that spirituality/religion was perceived and undertaken as an important aspect for the patients/relatives and palliative care team. It was obvious that they performed religious practices (i.e. worship, prayers) regularly. In addition, the palliative care team integrated spiritual care in their daily care provision. In return, the patients and relatives also provided spiritual assistance to the palliative care team. The final aspects of this domain indicated that religious encouragement existed. Within the palliative care team, they were respected each other in terms of performing religious practices.

The last cultural domain 'dealing with dying and death' focused on how death and dying was perceived, experienced and managed by the patient's relatives and the palliative care team. The family caregivers' perceptions of death and dying affected how they responded. If they accepted the death and dying, they were more likely prepared. Most relatives generally had prepared the patients' funeral based on their wishes. The palliative care team commonly also helped the relatives to deal with the dying and death process. The important point to show a final act of compassionate and comprehensive caring was that the palliative care team managed to attend the patients' funerals. The next chapter will explore the significance of these findings within a broader framework to identify the implications of the study.

Chapter 8: Interpretation

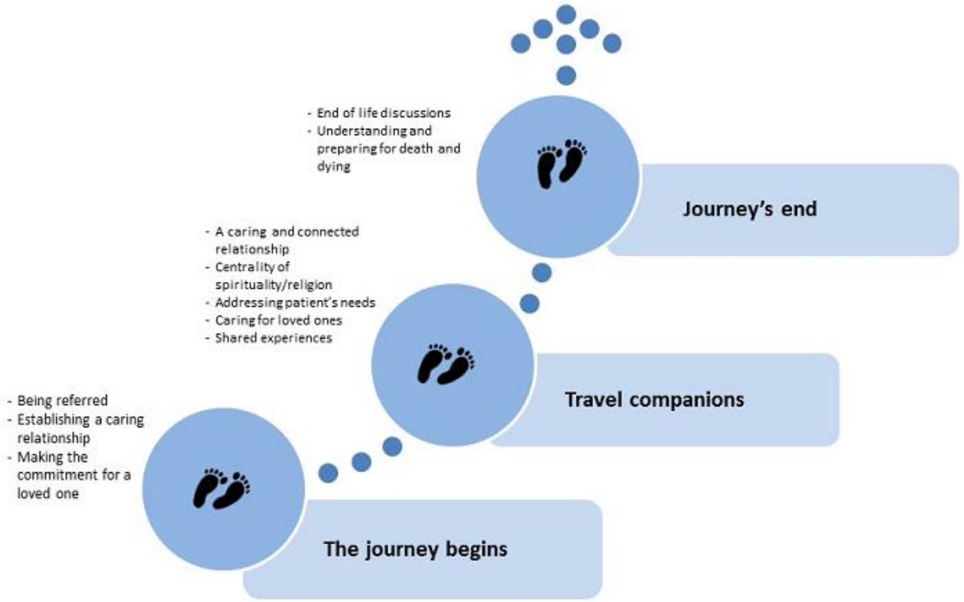
Introduction

The purpose of this study was to explore the provision of palliative care in two Indonesian palliative care facilities and the cultural domains which influence that care. The goals of this study were to gain an understanding of the practice and potentially provide recommendations for care provision that are culturally appropriate. To achieve these goals, this present study adopted an ethnographic approach. Fetterman (2010) has suggested that strategies for quality ethnographic research, include the use of multiple methods, contextualisation and importantly nonjudgmental orientation. Fetterman (2010) further stated that the use of nonjudgmental orientation prevents ethnographers from making inappropriate value judgements of what they observed. Therefore, it is important to understand that the role of the ethnographer is to observe, seek understanding and report rather than to the judge behaviours, values and interactions of cultural groups under study.

This chapter will discuss the findings of the current study and explore their implications and their relationship with the existing literature. The discussion of the findings is presented as a journey (Figure 10) for each traveler (i.e. the patients, the family, and the palliative care team) the destination is inevitable; '*the journey begins*', '*travelling companions*' and '*journey's end*'.

The allegory of the journey is used to focus the discussion about the major cultural themes that have emerged from the study.

Figure 10. The journey



The journey begins

For the patients in this study their final journey begins when they are with their families and are joined by the palliative care team. This journey begins with their referral to the service, but the nature and timing of referral has a strong impact on how things will proceed. Relationships are established and commitments are made. Details of each of these elements will be provided in the following sections.

Being referred to the palliative care service

In this study, the referral to the palliative care facilities was often in the last three months of the patients' life when their active cancer treatment was unsuccessful or ceased. The World Health Organization (2010) has stated that palliative care should be started while patients are receiving active cancer treatments. In Indonesia, the palliative care guidelines issued by the Ministry of Health (2013) also suggest that cancer patients should receive palliative care when having one or more conditions (e.g. uncontrolled pain, severe depression, life expectancy less than 12 months). This indicates that referral for the patients in this study was relatively late. Previous studies of late referral have found an association with negative health outcomes for patients (Humphreys & Harman 2014; Melvin & Oldham 2009), and an increase family caregiver's burden (Higginson et al. 2011).

Witjaksono, Sutandiyo and Suardi (2014) and Effendy et al. (2015) have suggested that referral systems in Indonesia are not yet well-developed and there is a lack of integration between health care providers and settings. In this study, it was observed that the hospital-based palliative care did not have many interconnections with local health care providers. The hospice-based palliative care service, however, did have a more developed referral system. Many health professionals consider palliative care an option only when active treatment is unsuccessful and this view is felt to be a result of lack of education on palliative care (Witjaksono, Sutandiyo & Suardi 2014). The relevant documents in this study showed that the late referral was attributable to oncologists wanting to avoid referring patients to palliative care too early. As a result, most of patients are referred to palliative care in their last few months of life with multiple symptoms, as observed in this study.

Although some patients were receiving palliative care in the hospital following the referral, most patients from both services returned to their homes to receive care. In this study, the patients were generally sent home after their active cancer treatment had ceased. Studies in a number of contexts have shown that the majority of people, including patients with advanced illness, prefer to be cared for at home (Bell, Somogyi-Zalud & Masaki 2009; Gomes et al. 2013; Gomes & Higginson 2013). It was unclear in this study, however, if decisions to be cared for at home included the patients' and their relatives' voice or simply because the treatment had been ceased. In this study patients were cared for by their families with assistance provided by the palliative staff palliative care staff, the extended families and the local community. While being cared for in one’s home has many benefits for the patient, there are also many challenges.

The literature has regularly shown that home-based care is associated with improved symptom control. Gomes et al.’s (2013) systematic review concluded that palliative home-based care reduced symptom burden as compared to usual care (i.e. hospital care, hospice care), particularly for patients with advanced cancer.

For palliative care patients and their families, a feeling of normalcy and comfort, and having a sense of choice and control are associated with being cared for at home (Hudson 2003). This was experienced by the patients and the families in this current study and was seen when the palliative care staff would arrive at a patient’s home. They would not enter unless explicitly invited. Even when the door was left open by the relatives they would still knock before entering.

Several studies have found that home-based palliative care improves patients’ and caregivers’ satisfaction (Brumley et al. 2007; Guerriere, Zagorski & Coyte 2013; Miyashita et al. 2008). Matching findings from previous studies, the majority of the family caregivers in this study stated their satisfaction with the care provision to their loved ones.

Although there were beneficial effects associated with home-based care, gaps were also identified in this study. According to World Health Organization (2014) the involvement of primary care clinicians is important for the home-based and community-based care palliative care service, particularly in limited resource countries. Although one study has described the involvement of a primary care centre with a palliative care service in Indonesia (Saleh, Danantosa & Kusumawardhani 2008), in the current study, such collaboration was not identified for the hospital-based service. As a result, out-of-hours services were also provided by the palliative care staff that potentially increased the burdens on the staff.

In summary, it was found that referral to palliative care was late and there were impacts of this late referral on the patients. A number of possible factors causing the late referral have been identified. This study also found that home-based care was the major model of palliative care delivery in this study. A number of beneficial effects have been discussed. In addition, a number of factors indicate that home-based care might be improved. One suggestion is that the palliative care staff start to collaborate with the primary care clinicians in delivering care for the patients and the families. This will not only reduce burdens for the palliative care staff but also might improve the care.

Establishing a trusted, respectful and caring relationship

The health professional - patient relationship is viewed as a crucial aspect in the delivery of palliative care service. A good relationship can be developed by establishing rapport and trust with the patients and relatives that is influenced by many situational and contextual factors. Situational factors include the communication skills and the attitudes of the staff, and the patient's degree of vulnerability and dependency. The contextual factors are influenced by the setting of the relationships, in this case at the patient's home.

A variety of communication techniques were used by the palliative care staff in this study. When greeting the patient/relatives, their body language and the use of respectful terms such as *Bapak*/*Ibu* (Sir/Mam) demonstrated care and concern. In this study, the palliative care team always addressed the patients/relatives using Bapak/ibu (Sir/Mam) then their first name. This convention is critical due to the cultural expectations in Indonesia. In other contexts, the use of formal terms may be seen as a mechanism of maintaining distance and enforcing a sense of status, but in Indonesia where this study was conducted, such behaviour is expected to show respect without deference to status. Respecting the patients and relatives enabled the palliative care team to feel that they treated the patients and relatives as a person. In addition, it can improve the patient's/relative's comfort and trust during the relationship building. This humanistic approach is important in the health professional - patient/relative relationship. This is supported by findings from a previous study. The palliative care patients in Richardson's (2002) phenomenological study viewed that humanistic interaction could enhance the palliative patient' psychological wellbeing.

Knowing patients and their families plays a fundamental role in building positive relationships (Mok & Chiu 2004). The staff felt it was important to get to know the patients and so much conversation was about the patient's background. Soon after referral the palliative care team would organise a meeting to explain their roles and explore the patient's and family's situation (e.g. number of children, primary family caregiver, the patient's job). These conversations continued throughout the provision of care. Zolnierek (2014) concurred that knowing the patients and the families helps in developing positive relationships which in turn enable health professionals to provide safe and appropriate care.

Tailoring communication based on consideration of the patient's culture and gender is an important aspect in developing relationships and establishing a trusting and caring relationship (Boase et al. 2012). As observed in this study, Indonesia is very multicultural and staff would consider this when addressing patients and their relatives. Chinese patients would be greeted with *Gong Xi Fa Chai* (have a prosperous year) on the lunar new year. The formal Javanese language was always used when addressing elderly Javanese patients and relatives. This was regardless of the cultural background of the staff. Such applications made a valuable contribution towards a more positive outcome in the development of trusting relationship because the patients and their relative may have felt more respected.

The use of touch to convey concern was seen frequently during field observations. Care needed to be taken, however, in using touch to establish and maintain rapport because of various cultural and contextual considerations. For example, comforting measures such as rubbing on arms and hugs were used by the palliative care team to console the patients or the relatives, but only with those of the same gender.

Wiechula et al.'s (2016) review concluded that the environment where care is provided may positively or negatively influence the caring relationships. In this study, the home environment was seen to positively contribute to the caring relationship. This relied on the palliative care staff demonstrating respect for the patients' and the families' privacy and authority. In return, the patients and the relatives welcomed the palliative care team in to their homes, expressing their trust in them and treating them as guests.

Making the commitment to care for a loved one

When the patients were referred to the palliative care service, the family members took responsibility for providing care for them in their homes. For the majority, this process came naturally and was driven by a sense of obligation and responsibility, derived largely from cultural expectations. In this study, the family providing care were mostly the spouses, children and siblings although in some cases the extended family such as in-laws, nephews and nieces provided the care when more immediate family were not available.

The literature has identified that love, obligation, genuine willingness and expectations from the health care system are common reasons for family caregiving (Chaturvedi, Loiselle & Chandra 2009; Linderholm & Friedrichsen 2010; Sand, Olsson & Strang 2010; Stajduhar 2003; Wallerstedt, Andershed & Benzein 2014). In line with these findings, the family members in this study indicated a strong sense of obligation to look after their loved ones. For some family caregivers, taking such a responsibility was due to a lack of alternative options. This occurred when the patient's spouse or children were not available to take care of the patient. This feeling of obligation, in the Indonesian context, is reinforced by cultural expectations (Effendy et al. 2014b; Soebadi & Tejawinata 1996).

The literature has indicated that family caregivers may or may not have any training in providing the care required for palliative care patients (Smith 2004). The majority of the family caregivers in this study had no previous training or experience. Although they did not overtly express concerns about being inadequately prepared they did rely heavily on the palliative care team for advice about providing care. They asked about practical information on managing the patient's symptoms either during the home visit or by phone.

The literature has stressed the importance of educational preparation for family caregivers (Borneman et al. 2015; El Osta & Bruera 2015). Furthermore, El Osta and Bruera (2015) highlight practical strategies to educate family caregivers such as using simple language, using written instructions about administrating medicines, guidance in evaluating symptoms and meeting fundamentals needs and importantly, who to contact to get support. It was noticeable in this current study that the palliative care team facilitated these aspects of family caregivers' experience by providing education and information about patients' conditions and the practical things that needed to be done. During visits there was much discussion about the care that was required with explanations in plain language. In the case of more technical care (e.g. wound care), the palliative care team would always demonstrate the steps slowly to make sure the family were comfortable with procedures. In terms of additional support, the palliative care team from the hospital-based service encouraged family members to contact them at any time. Generally though they did not suggest that local primary care clinicians should be contacted. Consequently, the family caregivers approached only the palliative care team when they needed support which potentially increased the burden on palliative care staff particularly after hours.

Providing this education and support was particularly important for family members in this study. As patients were often referred to the palliative care team late when they were going home they often were very ill with challenging care needs.

Travelling companions

Any journey can be challenging for travelling companions and this journey is no exception. Understanding each other’s needs and working together to reach the destination was extremely important for those in this study. Maintaining a caring and connected relationship between palliative care staff and the patients/family was crucial and a central feature of this was the place of religion. There were many challenges in meeting the care needs of the patients. The palliative care team and the families needed to work together and support each other. The needs of the patients were complex and there were occasions when there were differing opinions about the care being provided. In meeting these challenges it was evident that those providing care, both families and the palliative care team also had needs and mutual support was a theme arising from this study.

A caring, connected and reciprocal relationship

In palliative care, relationship and connection is fundamental and the keystone of care (Offen 2015). As the care provision moves forward, relationships are established and maintained.

Findings from a previous study suggested the use of informal chatting and humour are used to engage with the patients/relatives (Griffiths, Ewing & Rogers 2012). These researchers found these strategies facilitated a full assessment of the patient's needs because it enabled patients to offer information about themselves. Similar to their findings, the palliative care staff in this study used informal chatting and humour. As a result, the patients and the relatives were more comfortable during interactions and willingly gave information about themselves.

The palliative care team in this study actively listened to the patients and the families, demonstrating a willingness to being present and to be readily accessible to the patients/relatives. On this point, de Haes and Teunissen (2005) has identified that such communication strategies and attitudes were the most therapeutic and helpful to the patients/relatives. In addition, El Osta and Bruera (2015) have emphasised the importance of team availability and easy access. The palliative care team were willing to be contacted by mobile phone and emails, even after hours. Patients and families greatly appreciated this level of support. Ciemins et al.'s (2015) study concluded that health professionals' presence was linked to satisfaction with palliative care services. However, this level of team availability and easy access particularly raises concerns of potential burnout among the staff.

Compassionate behaviours are important aspects in maintaining a patient – palliative care team relationship. Shimoinaba et al. (2014) have suggested the importance of compassionate behaviours, demonstrating an understanding of the patients' and relatives' situation, and devoting appropriate time and energy. In this study, the patients and their relatives as expected were quite vulnerable. The patients demonstrated worsening symptoms such as pain, nausea, breathing difficulty, fatigue, and weakness. The palliative care team devoted whatever time and energy was required for the patient and their families. As a result, this level of involvement and connectedness helped to maintain a good relationship between those involved.

The patient/family – palliative care staff relationships in this study are consistent with the literature about the distinctive characteristics of palliative care namely deep (Newton & McVicar 2014), mutual, close (Iranmanesh et al. 2009), and reciprocal (Errasti-Ibarrondo et al. 2015; McGilton & Boscart 2007; Mok & Chiu 2004).

Centrality of spirituality/religion

Religion and spirituality generally are important aspects of everyday life for many people. There has, however, been a growing trend on the separation of the concepts of spirituality and religion (Edwards et al. 2010). In the context of this study, the term religion and spirituality are often used interchangeably and the two are tightly connected.

There are several major religious orientations (e.g. Islam, Christianity, Catholicism, Buddhism and Hinduism) in Indonesia. People in Indonesia generally perceive religion as a fundamental part of their life and this is reflected in the participants of this study. Religious beliefs and practices are the way for the patients, the families and the palliative care staff to express their spirituality. Importantly, in addition to practicing their own religions, it was observed in this study that there was an encouragement to engage in spiritual/religious practices by the participants, regardless of their own religious affiliation.

As expected, the majority of the patients and the families were affiliated with various religions. It was also observed in this study that the palliative care staff were equally willing to demonstrate their religious affiliation. A previous study demonstrated that more than half of physicians in the United States are affiliated with religions and influenced by their religious belief in the medical practice (Curlin et al. 2005). This study suggested an even stronger role of religion.

Patients tried the best they could to maintain their religious practices with support from their families. Other studies have identified the importance of prayer among cancer patients with advanced disease and their relatives (Alcorn et al. 2010; Hexem et al. 2011). Religion was as important to the palliative care staff, who routinely prayed together in the morning meeting before doing their rounds for the day. During home visits it was also observed that the Muslim palliative care staff would perform *Salat* (Muslim prayer) at the appropriate time of the day. These findings parallel with those of previous studies which indicated that Indonesian physicians described themselves as very or moderately religious (Lucchetti et al. 2016; Ramakrishnan et al. 2014).

Hanson's (2008) study identified that families are the main spiritual care providers for seriously ill patients. In this current study the palliative care staff also provided spiritual/religious support to the patients. The palliative care team also often reminded the families to provide such support to the patients. The provision of spiritual/religious care from health care practitioners is likely influenced by several factors; the spirituality/religiosity of clinicians, and the clinician's understanding of spiritual/religious practices of the patients (Curlin et al. 2005; Lucchetti et al. 2016; Ramakrishnan et al. 2014). This religious support by health professionals is contextual. A study of nurses in a secular country found that they saw themselves as non-religious person and providing spiritual/religious care was not something they were likely to do (Kisvetrová, Klugar & Kabelka 2013).

In a number of studies, the use of a spiritual assessment tool to formally assess spiritual needs has been demonstrated (Ahmed et al. 2004; Blaber, Jone & Willis 2015). This was not, however, identified in this current study. Moving from assessment of spiritual needs and supporting the patients to maintain their religious practices to actually joining patients in prayer is somewhat contentious and quite culturally specific. The paper by Poole and Cook (2011) debates this issue within the context of psychiatric practice in the United Kingdom suggesting patient

- practitioner prayer was considered as breaching professional boundaries. Balboni et al. (2011), in contrast, surveyed patients and practitioners in advanced cancer settings in the United States and the majority felt it was dependent on the appropriate circumstance. In this current study the practice of praying together, to some extent, depended on the religion of the palliative care team members. Muslim staff would step out of the room when Christian prayers were conducted, but this was not seen as a lack of support.

An important aspect of the spiritual/religious practices in this study was the reciprocal nature of these practices. The palliative care team provided spiritual/ religious care to the patients and the relatives; in return the relatives facilitated the palliative care team to perform spiritual/religious practice in their home. For example, a family caregiver provided a room, a prayer carpet and clothes so that the palliative care team could perform *Dhuhr Salat* (one of the five compulsory prayings in Islam which must be performed at noon). Such a coexistence has not been identified with any detail within previous studies. To date, there have been no studies indicating how reciprocity in patient/relatives - health professional relationships particularly in spirituality/religion dimension has occurred. This reciprocity may be an important influence in maintaining the relationship between the staff and the patients and relatives as it represents a very tangible sign of mutual respect.

Understanding and addressing care needs

The patients in this study experienced physical, psychological and spiritual symptoms that were challenging for the palliative care team and the families. The following sections address the care provided and raises some questions about the appropriateness of some practices.

The literature has shown that pain, fatigue, lack of energy, weakness, nausea, and appetite loss are common symptoms among patients with palliative care needs

(Abu-Saad Huijer & Abboud 2012; Halawi et al. 2012). Similar to these studies, such symptoms were the most common ones experienced by the patients in this current study. A structured tool to measure a patient's symptoms was identified in this study. The tool was generally used in the first visit, however, while in the later visits it appeared that the tool was less frequently used.

Attention to the patient's symptoms, particularly pain was the main focus of palliative care delivery in this study. It was observed that for the majority of the patient's their pain was reasonably controlled. This finding contrasts with the findings from a previous study conducted in Indonesia which identified that more than half of patients had unmet needs in regards to pain (Effendy et al. 2014a). Pain control is reliant on ready access to opioids for palliative care patients. It has been emphasised in the literature that there remains problems with access to opioids in Indonesia (Soebadi & Tejawinata 1996; Witjaksono, Sutandiyo & Suardi 2014). In this study there were cases where patients had to access opioids from local pharmacies and this did create some difficulties.

Since many patients were referred late, most had multiple symptoms to be managed. Choices had to be made about which interventions would be undertaken to relieve the symptom burden. Although there were attempts to provide individualised care, at times the staff conducted care that could be considered routinised, such as taking vital signs. In addition, some of the interventions might have been seen as being unnecessary or being aggressive in other palliative care settings. Such interventions that were found in this study included blood tests, the use antibiotics, anticancer treatments, and tube feeding. Veerbeek et al. (2008) has suggested that these interventions have been associated with burdensome side effects (e.g. increased source of pain) and minimal palliative effect.

There are a number of potential reasons why the palliative care team in this current study implemented these interventions. Findings from previous studies provide insights and reasons why such situations still occur, these include palliative care developmental issue, scarcity in resources and lack of palliative care education, religion, culture and palliative care team's commitment to patients/relatives (Witjaksono, Sutandiyo & Suardi 2014).

Palliative care in Indonesia is still in its early stage of development where the resources and in particular palliative care education are still lacking (Witjaksono, Sutandiyo & Suardi 2014). The level of palliative care knowledge has been identified by Miller, Lima and Thompson (2015) as associated with the frequent use of feeding tubes, restraints, injections and rehospitalisation at the end of life. In this current study, there was only one certified palliative care clinician among all the health professionals, although other clinicians had at least some informal palliative care training.

Previous studies have shown that religiosity also influences a clinician's decisions particularly in regard to artificial nutrition and hydration. Wolenberg et al. (2013) has found that clinicians with strong religious affiliations are more likely to oppose withdrawal of artificial nutrition and hydration. On a number of occasions artificial feeding and intravenous and subcutaneous hydration were being suggested by the palliative care team, however, this may also show the palliative care team's commitment to the patients and relatives. This aligns with Veerbeek et al.'s (2008) findings on their interventional study where care interventions may be conducted to give the patients and relatives a sense of being supported and to be seen to be doing something.

The literature has identified the many psychological and spiritual/religious needs experienced by palliative care patients. Depression and anxiety are psychosocial symptoms that are frequently experienced by patients with advanced cancer who are receiving palliative care (Solano, Gomes & Higginson 2006). Previous studies have identified that anger at God, loss of faith and despair, and difficulties in accepting the disease are among common symptoms in spiritual/religious dimensions (Byrne 2002; Effendy et al. 2014a; Puchalski et al. 2009). In this study, there have been examples of difficulties in accepting the disease and when death is imminent, as well as depression among patients and their relatives.

The World Health Organization (2002) acknowledge the importance of psychological and spiritual care. In this study, the palliative care team acknowledged that psychological and spiritual/religious issues were important to the patients and families within their care. The palliative care team appeared to have the ability to pick up subtle cues, concerns and to address the issues. Instruments to assess psychological symptoms were available in both of the study settings. However, it appears that the instruments were used in initial interactions but then infrequently used in the later interactions.

Regardless of their discipline, all team members were observed to be comfortable addressing psychological and spiritual/religion issues with the patients and the relatives. Ongoing use of formal mechanisms for assessing psychological and spiritual/religion needs, planning interventions to address the needs, and evaluating the outcomes of the interventions were noted. Although it has been shown that instruments to assess such conditions were available, most of interventions were conducted spontaneously when such issues occurred.

In both palliative care units in this study, there was acknowledgment of the need for social support for patients and their relatives, such as the need for housing and transport. There were no professional staff, however, who were specifically working in the units to address these issues. For example, the palliative care team in the hospital was observed assisting a patient with a housing issue while the team member in the hospice worked with other non-government organisations to address the patients' social needs. Such situations are similar to the previous section where psychological and spiritual/religious issues in the hospital-based palliative care unit were all addressed only by the palliative care team and shows that there was no connection or integration with other services.

The literature indicates the importance of dignity in palliative care (Lee et al. 2013; Pringle, Johnston & Buchanan 2015). It has been shown in this study that the palliative care team recognised the need to maintain and address the patient's dignity. The specific dignity-relevant interventions identified in this study were consistent with Chochinov's (2002) dignity conserving repertoire, where examples of the interventions included: controlling symptoms, preserving autonomy/control, maintaining functional and cognitive capacity, and preserving continuity of self and the patient's role. The palliative care team's efforts can be seen, for example, when dealing with a young mother with bone metastases who refused to use a wheelchair because she did not want to look weak. In this situation the palliative care team offered other options (e.g. using orthotics) to address the patient's dignity while still maintaining her physical function. Therefore, it can be suggested that maintaining the patients' dignity and balancing their needs and wishes is a complex situation.

The palliative care team included doctors and nurses but no allied health staff were involved in home visits. Although there were occupational therapists, social workers and hospital chaplains working within the hospitals they were not involved in home care in either of the palliative care units. As a result, the palliative care team were required to provide all formal care to the patients. Though this is contra to the principles of palliative care from World Health Organization (2002), this situation could be due to limited integration with other available services and referral systems between palliative care and other care settings that are not yet well-developed.

Another finding of concern in this study was the lack of engagement of the hospital-based palliative care with the local primary care centre, primary care doctors and nurses to assist in addressing the patients' needs. The palliative care team had shown their willingness to provide more time during visits and working out of hours. While such strategies were appreciated by the patients and relatives a more collaborative approach with local health professionals would have potential benefits. On this point, the World Health Organization (2014) has emphasised the need to involve primary care clinicians in the community and home-based palliative care, particularly in regions that are not well resourced. Such integration is important to reduce the burden on the palliative care staff and to improve outcomes for the palliative care patients.

In summary, the palliative care provision in this study showed beneficial effects for the patients, however, lack of integration between elements of health services exist because the palliative care in Indonesia is still in its early stage of development. In line with this, Lynch, Connor and Clark (2013) indicate that palliative care services in Indonesia are still isolated and the activities are still patchy in scope. Findings from this study also suggested that in some areas strategies could be implemented to improve the outcomes. In support of this view, the World Health Organization (2014) has stressed the involvement of primary care clinicians in the provision of care, as well as multidisciplinary team, and improvements on palliative care education.

Caring for loved ones

The literature has identified that, generally, in home-based care, the family caregivers provided the majority of care to their loved ones (Stajduhar et al. 2010). Studies have found that the family caregivers perform essential tasks such as helping patients with day-to-day care, coordinating care with health care practitioners, providing physical care (Sand, Olsson & Strang 2010; Williams, Zimmerman & Williams 2012), and spiritual/religious care (Hanson et al. 2008). In this study, it was also observed that the family caregivers spent their time focused on the patients' fundamental physical needs such as helping with eating, drinking and bathing.

The family caregivers were also responsible for numerous tasks such as symptom management (e.g. medication administration, wound care). They were also spending time supporting their loved ones psychologically by motivating them and giving hope and assisting with religious practices. This confirms findings from previous studies related a variety of caregiving ranging from performing tasks related physical care, symptom management, and providing psychological and spiritual support (Funk 2010, Hanson 2008, Sand et al 2010, Tishelman et al 2003).

The heavy load experienced by relatives was, to a degree, counterbalanced by the support given by the palliative care team and with some assistance from those in the community, however, what was missing was input from primary care clinicians who could potentially relieve the burden on families even further by providing additional support. This issue will be addressed further in the following section.

Shared experiences

In this current study the palliative care team and the relatives provided each other with considerable support. This sharing of responsibility had a positive impact on the enduring relationship, but the burden of providing the care that was needed brings many risks.

Most of the family caregivers spent almost all of their time caring for their loved ones and this impacted on their personal life. Providing such care, the relatives experienced physical exhaustion and considerable emotional burden. This is seen in many other studies where family caregiver experience fatigue (Carlsson 2009; Jo et al. 2007), anxiety and emotional burden (Jo et al. 2007; Oechsle et al. 2013a; Osse et al. 2006; Williams et al. 2008). Financial pressures due to unemployment were a noted problem in this study. Strain on interpersonal relationships were also seen as in a previous study (Yoo, Lee & Chang 2008).

In such situations, a connection with the palliative care team and getting the required support is crucial. Accordingly, Guerriere, Zagorski and Coyte (2013) and Epiphaniou et al. (2012) highlight the importance of supporting family caregivers in their efforts. Previous studies have found strategies to prevent adverse effects of caregiving. Grande et al. (2009) and Wallerstedt, Benzein and Andershed (2011) for example, found formal and informal support can increase a sense of security and being valued for family caregivers.

In this study, it has been shown that the palliative care staff provided such supports to the family caregivers by staying longer during home visits, if required. In addition, the palliative care staff also demonstrated their willingness to be contacted after hours. This has positive result in that the family caregivers felt they were being supported, however, more could potentially be done without placing an increased load on the palliative care team. Wallerstedt's, Andershed's and Benzein's (2014) study described a sitting service from community enrolled nurses which eased the load on family caregivers. What this suggests is that the formal support can be provided by local/primary care clinicians, a factor that was not identified in this current study. Consequently, collaboration and integration with the primary care clinicians and other care settings need to be developed and improved.

Informal support in this study was associated with unpaid assistance that could be from the extended family and the local community. Clearly, supports from the extended family during the process of caregiving was identified in this study and this could be due to Indonesian cultural values that expect family members to support each other (Effendy et al. 2014b; Soebadi & Tejawinata 1996). However, a feeling of inadequacy to support the primary family caregivers was also identified. In addition to support from the extended family, the local community also provided supports to the family caregivers. Such a coexistence is congruent with the findings from one study that indicated the availability of local community members providing support to family caregivers. Furthermore, Saleh, Danantosa and Kusumawardhani (2008) have described that the local community had basic palliative care training prior to assisting family caregivers. Such training was not identified in this study.

Various efforts were conducted by the palliative care team in this study to be available and present with the patients and their relatives and addressing their needs Wallerstedt's, Andershed's and Benzein's (2014) study found that these efforts do positively impacted on family caregivers. Nonetheless, it is undeniable that such efforts to be available and be present after hours can increase stress and lead the palliative care team to experience burnout as noted by Kamal et al. (2016). On this point, the predictive signs of stress and burnout were not able to be verified from the data. It was observed that the palliative care team frequently conducted team conferences and retreats and Canning, Rosenberg and Yates (2007) have identified that team conference and debriefing as used by the palliative care nurses, can optimise their self-care and reduce risk of excessive stress.

Journey's end

This journey inevitably moves towards the end point that is the death of the patient. This section addresses a number of issues surrounding this end of life. It considers how the palliative care team prepared and supported all involved for the impending death, what discussions were held and those that did not occur. It then addresses the actions of the team following death, particularly the nature of support given to the relatives.

End of life discussions

The palliative care team informing the patient about their diagnosis, prognosis and discussions about preparing for death were, at best, indirect. These conversations with relatives were, however, far more direct and detailed. Such communications are greatly influenced by country and culture. Disclosure of diagnosis to the patient in some cultures does not occur, although in the last few years both in developed and developing countries it is becoming more common (Mystakidou et al 2003). This is reflected in the current study in which most of the patients and the relatives have understood the patient's diagnosis. The understanding of the patient's diagnosis in this study was likely due to previous diagnosis discussions between the oncology doctors and the patients prior to the referral to the palliative care unit.

Discussions about prognosis and end-of-life were mostly conducted between the practitioners and the patient's relatives, but these discussions with patients were far less overt. This matches with the literature where in some cultures clinicians prefer to disclose such information to the patient's next of kin (Mystakidou et al. 2004). It was observed that the relatives in this present study were willing to participate in the end of life discussions. This finding is in contrast to the situation in Taiwan, in which the relatives were reluctant to have end of life discussions as this was considered a taboo (Cheng et al. 2015). Although end of life discussions were conducted, in this study it was noticeable, however that the overt and detail discussions were only between the practitioners and the patient's relatives as the patient was being largely excluded from such discussion. This matches with other studies which have found physicians are reluctant to discuss prognosis and end of life still with patients in a number of Asian countries (Cheng et al. 2015; Tang et al. 2014; Wen et al. 2013). Such situations are thought to be an effort to protect the patients. Mystakidou et al. (2004) have described that excluding patients from these discussions was meant to protect them from feelings of hopelessness, and despair, which would be detrimental to the patient's wellbeing. In their review, Harrison and Walling (2010) concluded that communicating prognosis was a way to assist patients with life-limiting disease to make informed choices and openly discuss their impending death and wishes related to care at the end of life.

Nonetheless, it is undeniable that special considerations (i.e. culture, belief) need to be considered when conducting discussions about prognosis and about death with patients.

The end of life discussions generally commenced when the palliative care staff understood that the patient's condition was deteriorating. Previous studies from Asian countries have consistently shown a lack of discussion surrounding death due to family's difficulties in accepting impending death and such discussions being taboo (Cheng et al. 2015; Tang et al. 2014; Wen et al. 2013). In this study these discussions varied and were particularly difficult for participants with an ethnic Chinese background.

Hebert et al. (2009) stated that tailoring information is important to prepare family caregivers for death and bereavement. During the discussions about end-of-life, some of the family caregivers preferred to discuss possible treatment to prolong the patient's life. The palliative care team, when presented with this situation, gently brought the discussion back to considering that the death was imminent. They often repeated explanations about the patient's condition in plain language so that the relatives understood the situation. The palliative care team then asked the patient's relatives to fulfil the patient's requests if any, and to provide support in religious belief. Moir et al. (2015) have found that the length of and working in oncology units had significant effects on the nurses' ways of discussing end of life care with a patient's relatives. Such a situation was also demonstrated in this study where the majority of the palliative care staff had experience in oncology and had been working for more than 10 years in this area.

Understanding and preparing for dying and death

Because of their previous experiences, some relatives knew when the patient's time of death was approaching. It has been shown that spirituality/religion are central to the patients, the relatives and the palliative care staff. The patient's relatives in this study often asked a local chaplain or religious person to visit the patients and lead prayers. This is similar to an earlier study that explored common beliefs and practices when death is approaching in East-Asian countries (Cheng et al. 2015).

When the death is imminent, encouragement of religious practices by the palliative care team and the family caregivers occurred; for example, the relatives played religious music and recited the Quran for the patient. In Islam, reciting chapters of the Noble Quran or playing Quranic audiocassettes is considered as a way to ease the patient's dying and death process and facilitating a peaceful death.

As the journey reaches its end point and death is close, in Indonesian culture it is common to seek and provide forgiveness. In this study the palliative care staff, the patients and their relatives were all involved in this process. In most cases there was no specific act for which forgiveness was sought. The purpose is to ensure that all are at peace with each other. van Laarhoven et al. (2012) have concluded that religious characteristics were significantly associated with the notion of forgiveness. A number of studies have also concluded that forgiveness therapy that includes seeking and providing forgiveness could improve patients' quality of life of patients with life-limiting illness (Hansen et al. 2009; Steinhauser et al. 2009). Such a finding could be important because it suggests that forgiveness therapy could be integrated in the provision of palliative care.

When the death is approaching many decisions need to be made and Asian families tended to prefer family-centred decision-making (Kwak & Haley 2005). This was also reflected in this study where the families in general did make decisions about what would happen at the end of life, but if this did not appear to be happening then the staff would encourage the relatives to do so.

When a patient died, religion and ethnicity influenced how elements of a funeral were practiced. Gatrad and Sheikh (2002) stress that a burial should be conducted immediately in Islam, while Taylor and Box (1999) identify that Buddhist families may prefer to have certain time and place for the funeral. In this study, there were examples of this influence of religion and ethnicity in funeral practices.

In this current study, the provision of palliative care still continued after the patient's death. The palliative care team managed to attend the patient's funeral to show respect and provided support to the family caregivers. In addition, the palliative care team provided bereavement follow-up for the family caregivers. The bereavement service was conducted in the form of counselling, either for individuals or as a family. These findings parallel with the guidelines from the World Health Organization (2002) that suggest supports from bereaved family members.

Summary

This study has provided descriptions and an understanding of the cultural aspects of palliative care provision in Indonesia. This ethnographic study was conducted in a setting that would be considered as having limited resources. From the description of the palliative care being provided, it suggests that the provision of palliative care in Indonesia is still in its developmental stage and has many challenges. Such challenges include the lack of integration with local primary care and the appropriateness of particular interventions. Despite this, the study also highlighted some important opportunities for the provision of palliative care in Indonesia. Key to this is the important role family have in palliative care services. Importantly, the spirituality/religion characteristics, the practice and the reciprocal spiritual care among the palliative care team, the patients and the relatives are significant features in this study.

Chapter 9: Conclusions

Introduction

This chapter summarises the findings of the present ethnographic research and considers their significance. The strengths and limitations of this study are also evaluated. Implications are discussed regarding palliative care practice, education and further research.

Major findings of the study and their significance

The main purpose of this study was to explore the provision of palliative care in two Indonesian palliative care services and its cultural aspects. The findings of this study include descriptions of the two palliative care services and how the palliative care was being provided. The study indicated that the provision of palliative care was complex and influenced by the culture of those giving and receiving care.

This study was conducted in two palliative care services located in central Indonesia; a government-owned hospital-based service and the other a hospice-based palliative care service owned by a charitable organisation. The staff in the hospital-based palliative care unit comprised one palliative care specialist doctor, one general doctor, two nurses and two clerks; while the hospice comprised five nurses, and two volunteer doctors. Both the facilities provided outreach programs by having home-based care. During the observation period of this study, most of the services were delivered in the patients' homes.

This study demonstrated that referral to the palliative care service mostly occurred when curative treatment was unsuccessful or had ceased. The late referral appears to be due to the view among health professionals that palliative care is the last option. The referral system demonstrates a lack of integration between acute care services, palliative care services and primary care.

Most of the care were delivered in each patient’s home, and thus the family played a significant role in providing care for the patients. The cultural context also suggests that local community support was an important feature in the palliative care provision. Under such circumstances, the environment has an important role in terms of the patient’s autonomy and privacy, and the development of the patient – health practitioner relationship. The findings showed palliative care staff were concerned about the patient’s autonomy and privacy. The palliative care team were adept at using therapeutic communication skills in their interaction with the patients/relatives. Such strategies have enabled the development of a caring patient – clinician relationship that was characterised as close, deep, and reciprocal. Such relationships improve family caregivers’ satisfaction with the care being provided.

The palliative care team showed an awareness of the patient’s expressed and unvoiced needs through the provision of physical, psychological and spiritual care. In the provision of care, some gaps, however, were identified. It was observed that there was little involvement of primary care clinicians in this home-based care. This study also recognised the palliative care team were conducting interventions that might be considered as unusual or even aggressive in palliative care settings in other countries. Although there may be many reasons why this occurs it is likely due to the stage of palliative care development, scarcity in resources and lack of education, but importantly, also the influence of cultural taboos.

Spirituality/religiosity was so central to daily life of the patients, the family and the palliative care staff in this study that it became a significant cultural domain in the palliative care provision. This study showed that all the cultural actors (the palliative care team, the patients and the relatives) were affiliated with particular religions. The patients and their relatives performed their religious practices (e.g. prayer, worship) in their daily life. It was also observed that the patient’s relatives in this study commonly acknowledged and addressed the patient’s needs for spiritual care. For the palliative care staff, they also provided spiritual care to the patients (e.g. religious/spiritual discussion, conducting prayer together). In return the patients and relatives acknowledged the religious need of the staff.

It has been revealed that when the journey moved toward its end point, there were several issues highlighted, namely discussions about prognosis and end of life, and preparation for dying and death. During the overt discussions about prognosis and the end of life, the patients were mostly excluded as the discussions were only between the palliative care team and the family caregivers. This is not to suggest that this practice is inherently incorrect but it is something that should be considered and debated.

Strengths and limitations of the study

Strengths

This is the first study using an ethnographic approach to explore the cultural aspects of palliative care provision in two Indonesian palliative care facilities to the best knowledge and belief of the researcher. The major strength of this study was the adoption of the ethnographic approach. This approach, which incorporated multiple data collection strategies proved to be particularly valuable in studying the complexity of palliative care provision in Indonesia. In addition, the use of multiple data sources was also able to give an authentic account of palliative care provision and also strengthened the trustworthiness of the data.

This study gives unique insights into the palliative care culture by describing the thoughts, behaviours and practices of those both giving and receiving palliative care. It also confirms several cultural elements (e.g. family and community involvement, shared experiences, centrality of spiritual/religion, being present and reciprocal relationships). The findings of this study can contribute to the knowledge regarding the provision palliative care in Indonesia. Furthermore, it has been identified that there are several gaps in this care provision, an aspect that can provide evidence to assist the policymakers in planning for the improvement of palliative care.

There was a certain degree of 'outsider' in the observations because the researcher did not work in the settings where the data were collected. Being an outsider provided opportunities for the researcher to observe with an open mind and have less bias that may have affected the interpretation of the cultural scene.

Limitations

It should be noted that this study involved only two services in one city in Indonesia. These were the formal services provided within that city and the study was unable to ascertain what informal services were being provided. It has been assumed that the level of resources was limited in terms of the demand for palliative care services, but the study was unable to verify this quantifiably. Of the two services involved, direct observation of patients and families was only possible with the hospital-based service. The researcher requested permission to conduct observations of paediatric patients being cared for by the hospice-based service and although this was initially granted it was later withdrawn. The researcher respected the judgement of those caring for this vulnerable group. It would be logical to assume that palliative care is needed and is being provided by others outside the formal palliative care organisations that were researched. The main limitations of this study relates to this unknown care.

Implications

This study has added to the body of knowledge on this topic by serving as a basis for understanding the provision of palliative care in Indonesia and furthering knowledge of cultural elements in Indonesian palliative care provision.

Implications for practice

In this study, home-based care was the main setting for palliative care delivery where health professionals addressed the patients' needs and comfort. This is very important because home-based care is considered an appropriate setting for palliative care delivery in countries with limited resources such as Indonesia. Indonesian culture supports the expectations of family and community involvement in care delivery. Thus, home-based care should be encouraged; however, relatives should be provided with sufficient support and education so they are not unduly burdened. In this study the palliative care team provided the majority of support to the family caregivers. There was some support from the community, but the involvement of local primary care clinicians was mostly absent. Developing a collaboration with primary care clinicians and primary care centres are thus recommended. This will not only ease the burden for the families but also the palliative care team.

The timing of referral to palliative care should also be considered. The palliative care team could be brought in much earlier, before the patients are to return home. This naturally has resource implications but it would provide time for the families to prepare before having to take on full-time care. This also has the potential for involving patients in discussions about their end of life care before their condition has deteriorated. This is perhaps one of the most difficult areas as different religious and ethnic groups have strongly held beliefs that must be respected.

One very positive aspect of care provision was the role of religion. This was a significant element in the Indonesian palliative care service and many different religions were represented among the participants in this study. Regardless of whether the clinicians' and the patients'/relatives' religious affiliations were aligned, all were encouraged to express and participate in their usual religious practices. This provided the patients with much comfort. It gave them a sense of normality and the mutual respect for religion assisted in developing and maintaining strong relationships between all involved. In some secular jurisdictions this level of religious involvement by practitioners is questioned, but in the Indonesian context it appears culturally most appropriate.

Another strong feature of the palliative care being provided was the strong caring and connected relationship between the palliative care team and the patients and relatives. While this strength of relationship is clearly advantageous to those involved, there is a risk of dependency. Care needs to be taken to avoid overload and burnout for the formal and informal carers. This relationship also should not preclude others, such as primary care clinicians, getting involved. This does have resource implications but integrating care with local services is seen as being a mature approach to palliative care services.

Implications for education

This study indicated that the number of patients obtaining palliative care was still limited due to the limited availability of palliative care trained health professionals. At an early stage, basic palliative care knowledge should be taught in undergraduate medical and nursing schools. But it is also crucial to improve the palliative care knowledge of existing healthcare professionals. For instance, such training could be in the form of compulsory continuing professional development. Regular update and training associated with palliative care for health professionals working in primary care could be useful to achieve this goal.

This investigation implies that the palliative care team commonly provided practical information to the patients/relatives based on their needs. It is therefore important to educate the relatives about basic care at home. By doing this, the relatives may have confidence and be more prepared to provide care to the patient.

Implications for research

This study has raised a number of issues for further research. First, undertaking further ethnographic studies to investigate palliative care services in other sites of Indonesia is one direction for research to gain further understanding about palliative care services in Indonesia.

This study found that the patients were mostly excluded from discussions about prognosis and their end of life. It should not be assumed that these discussions can simply occur. Investigations about the attitude of health care professionals, patients' needs for such information, with due consideration of cultural norms; effective strategies to deliver the discussion; and also the patient's outcomes, including their quality of life, would be useful.

Finally research to determine what palliative care is being conducted outside of the designated formal palliative care services should be conducted.

Summary

This study has provided an in-depth and rich understanding of cultural aspects in the provision of palliative care services in Indonesia. As illustrated in the previous chapters, the use of the ethnographic approach has demonstrated the ability to answer the research question 'What is the current practice of palliative care services in two facilities in Indonesia?'

The provision of palliative care for patients with advanced cancer had strong family involvement. There was a strong respectful relationship between the palliative care team and the patients and their relatives. This relationship was underpinned by a good understanding of the cultural needs of the patients, relatives and also the palliative care team.

Fundamental aspects of palliative care practice including – the importance of addressing the patient's needs and comfort and acknowledgement of physical, psychological and spiritual/religion aspects of care provision – were present in both sites. Religion/spiritual care have been shown to be significant features of palliative care service in this study.

Finally, this study was undertaken with the aim of improving understanding of palliative care provision in Indonesia. The palliative care practices uncovered serve to provide a deeper understanding of the complexities of palliative care.

This study illustrates the stage of development of palliative care services in Indonesia. It provides some insight as to the areas of care provision that should be further considered to move towards further stages of development in a culturally appropriate way.

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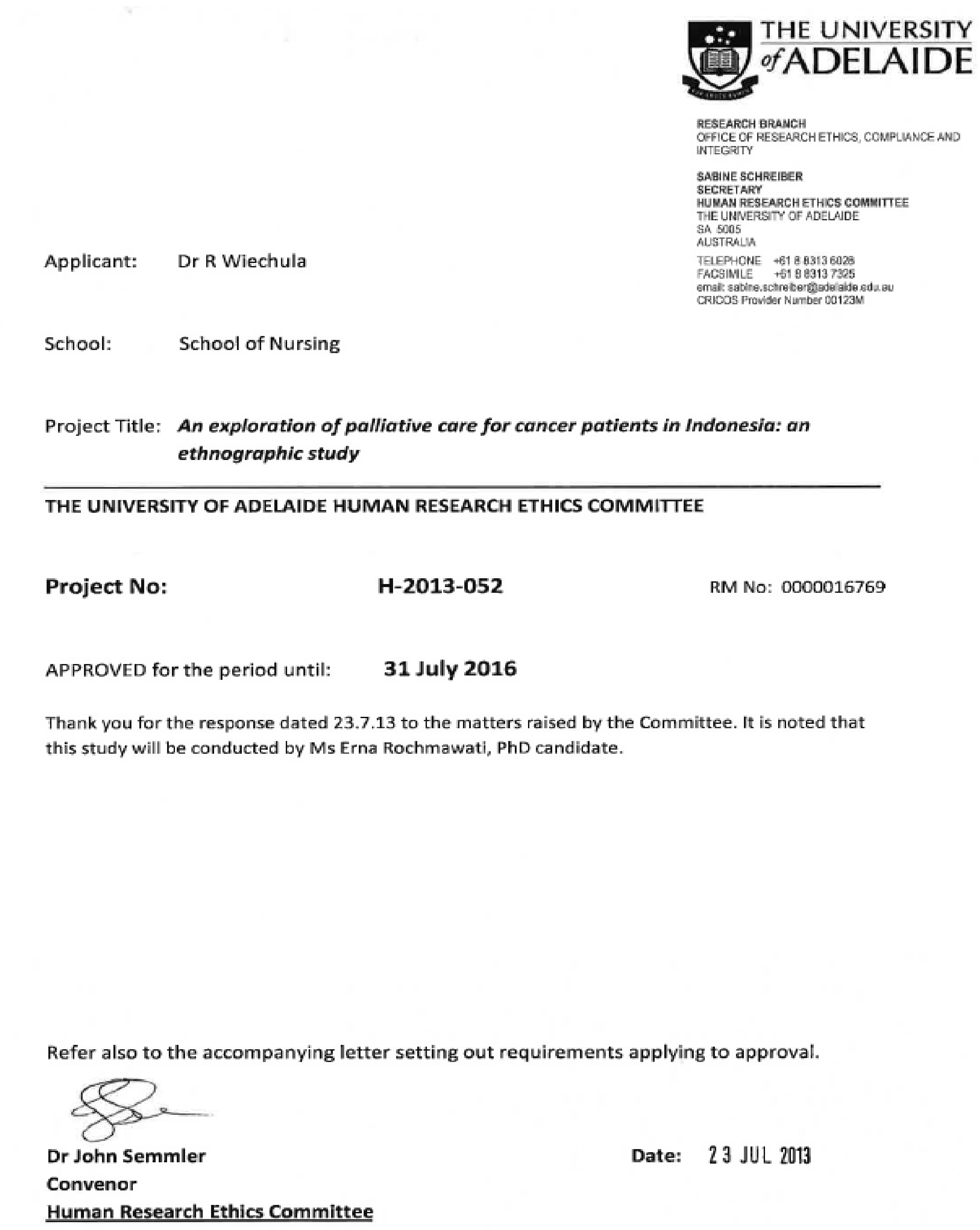
Appendices

Appendix I- HREC Ethical Approval



THE UNIVERSITY of ADELAIDE

RESEARCH BRANCH
OFFICE OF RESEARCH ETHICS, COMPLIANCE AND INTEGRITY

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Applicant: Dr R Wiechula

School: School of Nursing

Project Title: ***An exploration of palliative care for cancer patients in Indonesia: an ethnographic study***

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

Project No: **H-2013-052** RM No: 0000016769

APPROVED for the period until: **31 July 2016**

Thank you for the response dated 23.7.13 to the matters raised by the Committee. It is noted that this study will be conducted by Ms Erna Rochmawati, PhD candidate.

Refer also to the accompanying letter setting out requirements applying to approval.

Dr John Semmler
Convenor
Human Research Ethics Committee

Date: 23 JUL 2013

Appendix II – Information sheets

Information Sheet – Ethnographic Study
Patients

Project title:
An exploration of palliative care for cancer patients in Indonesia: an ethnography study

You are invited to participate in this project, which is described below

Objectives of the study:

This study aims to improve the palliative care services in Indonesia. Specifically, this study will:

- To describe structure, model of care delivery, and policy of palliative care services in Indonesia.
- To explore the provision of palliative care in Indonesia.
- To identify factors which influence the provision of palliative care services in Indonesia.
- To provide knowledge, and recommendations for the provision of palliative care that is culturally appropriate to Indonesia context.

The study involves an ethnographic approach where we observe and ask questions:

Questionnaires – we will ask you several questions about your demographic details (age, gender, level of education), your symptoms, your needs, and your satisfaction to palliative care services. This will be only reported as grouped data.

What you will be asked to do:

We are asking you to agree to fill in the questionnaire.

Confidentiality:

All information that obtained from questionnaires will be treated in a confidential manner. All information will be kept in a locked cabinet in the School of Nursing, University of Adelaide during the study and for a period of 7 years after the completion of the research when it will be shredded. Confidentiality will be maintained at all times.

Consent to participate:

Your participation in the study is entirely voluntary and you have the right to with draw at any time. If you decide not to participate in this study of if you withdraw during the study, you may do this freely without any effect to the treatment of your family member at the hospital.

The possible benefits:

The findings of this study will formulate recommendations that will benefit future patients, nursing and health care provider.

The possible risks:

There are no risks anticipated from taking part of this study. We will be close to you when you fill in the questionnaires. If you find you are exhausted during the process, we can pause the process.

Questions:

If you have any questions or would like to discuss this study, I would be happy to talk with you. Or if you would like to discuss with another member of the research team, I am happy to put you in touch with them.

Contacts:

If you have any queries about any aspect of this study, please, do not hesitate to contact me, my supervisors and the Human Research Ethics Committee (see contact detailed) if further clarification is required.

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Human Research Ethics Committee (HREC)
Research Branch
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Phone: + 61 8 8303 5137
Fax: +61 8 8303 3700

The research team would like to thank you for your participation in this project.

Information Sheet – Ethnographic Study

Patient's relatives

Project title:

An exploration of palliative care for cancer patients in Indonesia: an ethnography study

You are invited to participate in this project, which is described below

Objectives of the study:

This study aims to improve the palliative care services in Indonesia. Specifically, this study will:

- To describe structure, model of care delivery, and policy of palliative care services in Indonesia.
- To explore the provision of palliative care in Indonesia.
- To identify factors which influence the provision of palliative care services in Indonesia.
- To provide knowledge, and recommendations for the provision of palliative care that is culturally appropriate to Indonesia context.

The study involves an ethnographic approach where we observe and ask questions:

1. **Interviews, formal and informal** – we will conduct formal and informal interviews once during the study. Formal interviews will be expected to last 45-60 minutes or less. Informal interviews will be expected about 10 minutes or less. Both formal and informal interviews will be audio-taped and then transcribed. We will ask you about needs, satisfactions, and expectations of the provisions of palliative care.
2. **Questionnaires** – we will ask you several questions about your demographic details (age, gender, level of education), your symptoms, your needs, and your satisfaction to palliative care services. This will be only reported as grouped data.

What you will be asked to do:

We are asking you to agree to fill in the questionnaire and for you to participate in interviews.

During this time we may ask you some questions to clarify findings from questionnaire.

Confidentiality:

All information that obtained from questionnaires and interviews will be treated in a confidential manner. All information will be kept in a locked cabinet in the School of Nursing, University of Adelaide during the study and for a period of 7 years after the completion of the research when it will be shredded. Confidentiality will be maintained at all times.

Consent to participate:

Your participation in the study is entirely voluntary and you have the right to with draw at any time. If you decide not to participate in this study of if you withdraw during the study, you may do this freely without any effect to your treatment at the hospital.

The possible benefits:

There are some potential benefits to you as you may gain advantage to discuss your expectations, and needs from palliative care services. The findings of this study will formulate recommendations that will benefit future patients, nursing and health care provider.

The possible risks:

There are no risks anticipated from taking part of this study. We will be close to you when you fill in the questionnaires. If you find you are exhausted during the process, we can pause the process.

Questions:

If you have any questions or would like to discuss this study, I would be happy to talk with you. Or if you would like to discuss with another member of the research team, I am happy to put you in touch with them.

Contacts:

If you have any queries about any aspect of this study, please, do not hesitate to contact me, my supervisors and the Human Research Ethics Committee (see contact detailed) if further clarification is required.

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The research team would like to thank you for your participation in this project.

THE UNIVERSITY of ADELAIDE

Information Sheet for health professionals–Ethnographic Study

Project title:

An exploration of palliative care for cancer patients in Indonesia: an ethnography study

You are invited to participate in this project, which is described below

Objectives of the study:

This study aims to improve the palliative care services in Indonesia. Specifically, this study will:

- To describe structure, model of care delivery, and policy of palliative care services in Indonesia.
- To explore the provision of palliative care in Indonesia.
- To identify factors which influence the provision of palliative care services in Indonesia.
- To provide knowledge, and recommendations for the provision of palliative care that is culturally appropriate to Indonesia context.

The study involves an ethnographic approach where we observe and ask questions:

1. **Observation** – we will map the process of care delivery in palliative care. You are invited to participate in this study because you work in palliative care unit or on ward that receives patients with cancer. By observing the processes we will better understand the current practice in palliative care service. We will record our observations.
2. **Interviews, formal and informal** – we will conduct formal and informal interviews approximately twice during the study. Formal interviews will be expected to last 45-60 minutes or less. Informal interviews will be expected about 10 minutes or less. Both formal and informal interviews will be audio-taped and then transcribed. We will ask you about models of care, barriers and facilitator of the provisions of palliative care.
3. **Analysis of documents** – we will access current available documents (guidelines, report, procedure manual, patients' files, and policy manual). This will enable us to have a comprehensive description of current practice in palliative care services.

4. **Questionnaires** – we will ask you several questions about your demographic details (age, gender, experience, level of education), and your satisfaction to palliative care services. This will be only reported as grouped data.

What you will be asked to do:

We are asking you to agree to have a member of our research team observe your activities and for you to participate in interviews. We will note the activities that you undertake in relation to care delivery only. During this time we may ask you some questions to clarify your activities. We anticipate undertaking observations and these interviews for one and half month. After we have transcribed the field notes and the interviews, we will present the result and ask your feedback and comments.

Confidentiality:

All information that are gathered from observation, interviews, document analysis and questionnaire will be treated in a confidential manner. All information will be kept in a locked cabinet in the School of Nursing, University of Adelaide during the study and for a period of 7 years after the completion of the research when it will be shredded. Confidentiality will be maintained at all times.

Consent to participate:

Your participation in the study is entirely voluntary and you have the right to with draw at any time. If you decide not to participate in this study of if you withdraw during the study, you may do this freely without any effect to your future employment with the hospital and organisations.

The possible benefits:

There are some potential benefits to you as you may gain advantage to discuss your current role, and possibility of improving your roles as a nurse in the palliative care. You will have the opportunity to be part of the development team that formulates recommendations that will benefit future patients, nursing and health care provider.

The possible risks:

There are no risks anticipated from taking part of this study. The observer is not judging or assessing your practice, but recording the activities. The activities then will be analysed along with information from other participants, and other sources. However, if you find that being observed in your practice is stressful, we will stop the observation.

Questions:

If you have any questions or would like to discuss this study, I would be happy to talk with you. Or if you would like to discuss with another member of the research team, I am happy to put you in touch with them.

Contacts:

If you have any queries about any aspect of this study, please, do not hesitate to contact me, my supervisors and the Human Research Ethics Committee (see contact detailed) if further clarification is required.

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The research team would like to thank you for your participation in this project.

Appendix III – Consent Forms

THE UNIVERSITY *of* ADELAIDE

Human Research Ethics Committee (HREC)

PATIENT CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title	**An exploration of palliative care for cancer patient Indonesia: an ethnography study**
Ethics Approval numbers	**H – 2013- 052 and 004/KEPK/2014**

2. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.
3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.
5. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.
6. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.
7. I agree to the interview being audio/video recorded. Yes ☐ No ☐

   Note; this point is required only for projects involving digital recording (audio or video). Delete part or all as required.
8. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

____

(Name) (Date) (Signature)

Researcher/Witness to complete:

I have described the nature of the research to the participant above and in my opinion she/he understood the explanation.

____

(Signature) (Position) (Date)

THE UNIVERSITY *of* ADELAIDE

Human Research Ethics Committee (HREC)

PATIENT'S RELATIVE CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title	**An exploration of palliative care for cancer patient Indonesia: an ethnography study**
Ethics Approval number	**H – 2013- 052 and 004/KEPK/2014**

2. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.
3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.
5. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.
6. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.
7. I agree to the interview being audio/video recorded. Yes ☐ No ☐
   Note; this point is required only for projects involving digital recording (audio or video). Delete part or all as required.
8. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Researcher/Witness to complete:

____
(Name) (Date) (Signature)

Researcher/Witness to complete:
I have described the nature of the research to the participant above and in my opinion she/he understood the explanation.

____
(Signature) (Position) (Date)

THE UNIVERSITY
of ADELAIDE

Human Research Ethics Committee (HREC)

Health professional CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title	**An exploration of palliative care for cancer patient Indonesia: an ethnography study**
Ethics Approval number	**H – 2013- 052 and 004/KEPK/2014**

2. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

3. Although I understand the purpose of the research project it has also been explained that involvement may not be of any benefit to me.

4. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.

5. I understand that I am free to withdraw from the project at any time.

6. I agree to the interview being audio/video recorded. Yes ☐ No ☐
   Note; this point is required only for projects involving digital recording (audio or video).

   Delete part or all as required.

7. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:
Researcher/Witness to complete:

____
(Name) (Date) (Signature)

Researcher/Witness to complete:
I have described the nature of the research to the participant above and in my opinion she/he understood the explanation.

____
(Signature) (Position) (Date)

Appendix IV – Guide for grand tour observation

Day:
Date:
Start time:
Finish time:
Total number of patients:

No of nursing staff:

Patient/ family member's behaviours
Type of medical interventions____
Pain____
(verbalisation___: Grimaces___: Other/s:___)
Tiredness____
(verbalisation___: Grimaces___: Other/s:___)
Appeared anxious____
Nausea____
(verbalisation___: Other/s___)
Shortness of breath____
(Grimaces___: Other/s___)
Cooperation with nurses and other health care provider___________________

Nurses'
Emphathetic____
Calm and confidence____
Respect____
Type of nursing interventions____
Giving education about presenting symptoms_____________________________
Involving family____

Field note
Time: Events:

Appendix V – CANHELP questionnaires for family caregiver

Instructions:

The following questionnaire includes items that are considered important in terms of quality
of care for people with serious, life threatening illnesses. We are interested in the care you
and your relative received since the last time you completed the CANHELP Lite satisfaction with care survey when you were in hospital.

Please think about the health care that you and your relative has received ***during the past month*** from doctors, nurses and other health care professionals. For each question please fill in the circle beside the answer that indicates how satisfied you are with that particular aspect of care . If you choose "**Not at all Satisfied"**, for example, you will be indicating that this aspect of the care your relative received did not meet any of your expectations of high quality care. At the other end of the scale, your choice of "**Completely Satisfied**" will indicate that this aspect of the care your relative received met or exceeded your expectations of quality care.

The overall goal of this questionnaire is to inform the health care team of things they can do to improve care for patients like your relative. All answers are confidential and will not be shown to doctors or other health care professionals who are responsible for your relative's care. There are no right or wrong answers. **Completely honest answers are most helpful!**

When completed please insert into the stamped, self-addressed envelope provided and mail it back to us.

Start time (Please record): ____________

The following questions concern the care your relative received during the past month. For each one, please fill in the thick (V) to indicate the degree to which you are satisfied.

1 = Not at all
2 = not very
3 = somewhat
4 = very
5 = completely

No	**Questions**	**1**	**2**	**3**	**4**	**5**
A	In general, how satisfied are you with the quality of care your relative received *during the past month*					
B	In general, how satisfied are you with the way you were treated by the doctors, nurses, and other health care professionals looking after your relative *during the past month?*					
Relationship with the doctors						
1	How satisfied are you that the doctor(s) took a personal interest in your relative *during the past month?*					
2	How satisfied are you that the doctor(s) were available when you or your relative needed them (by phone or in person) *during the past month*?					
3	How satisfied are you with the level of trust and confidence you had in the doctor(s) who looked after your relative *during the past month*?					
Characteristic of the doctors and nurses						
4	How satisfied are you that the doctors, nurses, and other health care professionals looking after your relative *during the past month* were compassionate and supportive of him or her?					
5	How satisfied are you that the doctors and nurses looking after your relative *during the past month*					
Illness management						

No	**Questions**	**1**	**2**	**3**	**4**	**5**
6	How satisfied are you with the tests that were done and the treatments that were given *during the past month* for your relative's medical problems?					
7	How satisfied are you that physical symptoms (for example: pain, shortness of breath, nausea) your relative had *during the past month* were adequately controlled?					
8	How satisfied are you that emotional problems (for example: depression, anxiety) your relative had *during the past month* were adequately controlled?					
9	How satisfied are you with the help your relative received with personal care *during the past month* (for example: bathing, toileting, dressing, eating)?					
10	How satisfied are you that, *during the past month*, your relative received good care when you were not able to be with him/ her?					
11	How satisfied are you that health care workers worked together as a team to look after your relative *during the past month*?					
12	How satisfied are you that you were able to manage the financial costs associated with your relative's illness *during the past month*?					
13	How satisfied are you with the environment or the surroundings in which your relative was cared for *during the past month*?					
14	How satisfied are you that the care and treatment your relative received *during the past month* was consistent with his or her wishes?					
Communication and decision making						

No	**Questions**	**1**	**2**	**3**	**4**	**5**
15	How satisfied are you that the doctor(s) explained things relating to your relative's illness in a straightforward, honest manner *during the past month*?					
16	How satisfied are you that you received consistent information about your relative's condition from all the doctors and nurses looking after him or her *during the past month*?					
17	How satisfied are you that the doctor(s) listened to what you had to say *during the past month*?					
18	How satisfied are you with discussions *during the past month* with the doctor(s) about where your relative would be cared for (in hospital, at home, or elsewhere) if he or she were to get worse?					
Your involvement						
19	How satisfied are you with discussions *during the past month* with the doctor(s) about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis)?					
20	How satisfied are you with your role *during the past month* in decision-making regarding your relative's medical care?					
21	How satisfied are you with discussions with your relative *during the past month* about wishes for future care in the event he or she is unable to make those decisions?					

Stop time (Please record): ________________

Thank you so much for completing this survey, as it will help us identify ways to improve care for patients and families like you

Appendix VI- Patient's demographic data

No	Sex	Age	Religion	Diagnose Type of cancer	Level of dependency
1	M	70	Islam	Lung	Moderate
2	F	66	Catholic	Ovarian	High
3	F	51	Islam	Breast	High
4	F	34	Catholic	Pancreatic	High
5	F	35	Christian	Nasopharyngeal	Moderate
6	M	54	Islam	Lung	Moderate
7	F	76	Christian	Thyroid	High
8	F	77	Islam	Breast	High
9	M	73	Islam	Prostate	High
10	F	53	Christian	Breast	High
11	M	60	Catholic	Bladder	High
12	M	NA	Islam	Colon	High
13	M	56	Buddha	Lung	Moderate
14	M	66	Catholic	Renal	High
15	F	NA	Catholic	Cervix	High
16	F	45	Islam	Breast	Moderate
17	F	48	Islam	Breast	High
18	F	87	Islam	Breast	High
19	F	63	Islam	Nasopharyngeal	Moderate
20	F	51	Islam	Breast	Low
21	F	NA	Islam	Breast	Moderate

Appendix VII. Family caregiver's demographic data

No	Age	Sex	Marital Status	Relationship With patients	Education level	Employment	Religion
1	40	M	Single	Children	Bachelor	Self-employed	Islam
2	53	F	Married	Spouse	High school	Self-employed	Catholic
3	61	M	Married	Spouse	Post graduate	Government officer	Islam
4	45	F	Married	Children	Bachelor	Not working	Christian
5	56	M	Married	Spouse	Bachelor	Not working	Christian
6	62	F	Married	Niece	Diploma	Pensioner	Islam
7	40	F	Married	Children	Diploma	Not working	Catholic
8	67	F	Married	Spouse	High school	Pensioner	Islam
9	33	F	Married	Spouse	Bachelor	Self-employed	Islam
10	38	F	Married	Parent	Post graduate	Employee	Catholic

Appendix VIII. Distribution of family caregiver's satisfaction to the palliative care service

Items	**Completely satisfied**	**Very satisfied**	**Somewhat satisfied**
	(in percentage)		
Quality of care	40	60	0
The way the health professionals treated the patient	40	60	0
Relationship with doctors			
- The doctor took personal interest	50	50	0
- Availability	50	50	0
- Level of trust and confidence	50	50	0
Characteristics of doctors and nurses			
- Compassionate and supportive	30	70	0
- Looking after the patients	30	70	0
Illness management			
- Test and treatment for the patient's medical problem	30	60	10
- Control of physical problem	30	50	20
- Control of emotional problem	40	50	10
- Personal care	30	40	30
- Good care when you are not able with the patient	30	40	30
- Health care team work as a team	40	50	10
- Compassionate and supportive	30	60	10
- Financial cost	20	70	10
- Environment of care and treatment	10	60	30
- Consistency of care with the patient's wish	10	70	20
Communication and decision making			
- Straightforward and honest information	50	50	0
- Consistency of information about the patient's condition	40	60	0
- Listening skills	40	60	0
- Discussion when get worse	30	50	20
Your involvement			
- Role in decision making of the patient's medical care	20	70	10
- Discussion with the patient about future treatment	40	50	10