

## Family Caregivers' Preparedness with Death and Dying: An Ethnographic Study

Erna Rochmawati<sup>1\*</sup>, Rick Wiechula<sup>2</sup>

1. School of Nursing, Universitas Muhammadiyah Yogyakarta, Yogyakarta 55183, Indonesia
2. Adelaide Nursing School, University of Adelaide, Adelaide 5005, Australia

\*E-mail: [erna.rochmawati@umy.ac.id](mailto:erna.rochmawati@umy.ac.id)

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### Abstract

Death and dying is a complex process and influenced by belief and culture. Understanding the cultural practice is therefore important to enable providing quality end-of-life care. This paper focus in reporting how family caregivers prepare and deal with death and dying within palliative care context. This study was a contemporary ethnographic study that deriving data from observations and informal interviews. Field observation and informal interviews were conducted over three months with 21 patients' relatives. Data was analyzed using ethnographic data analysis framework. Dealing with death and dying relates to how this was experienced and managed by the patient's relatives. Three subthemes emerged: secret, ritual practices at end-of-life, and respect. Ritual practices at end-of-life demonstrate how religious and cultural influence during the event. The findings of the current research have identified the practice during death and dying of family caregivers that include fulfilment of patient's wishes. An understanding of integral cultural element to death and dying is important to enable providing quality palliative care and end-of life care.

**Keywords:** death and dying, end-of-life, ethnography, family caregiver, ritual practice, religion/spirituality

### Abstrak

**Kesiapan Keluarga dalam Kematian dan Akhir Hayat: Penelitian Etnografi.** Kematian dan akhir kehidupan adalah proses yang kompleks, dan dipengaruhi oleh kepercayaan dan budaya. Oleh karena itu, memahami praktik budaya penting untuk dapat memberikan perawatan akhir kehidupan yang berkualitas. Penelitian ini berfokus dalam melaporkan bagaimana keluarga mempersiapkan dan menangani kematian dan kematian dalam konteks perawatan paliatif. Penelitian ini merupakan penelitian etnografi kontemporer yang mengambil data dari observasi dan wawancara informal. Observasi lapangan dan wawancara informal dilakukan selama tiga bulan dengan 21 kerabat pasien. Analisis data menggunakan kerangka analisis data etnografi. Berurusan dengan kematian dan sekarat berkaitan dengan bagaimana hal ini dialami dan dikelola oleh kerabat pasien. Tiga subtema muncul; rahasia, praktik ritual di akhir kehidupan dan rasa hormat. Praktik ritual di akhir hayat menunjukkan bagaimana pengaruh agama dan budaya selama acara berlangsung. Temuan penelitian saat ini telah mengidentifikasi bagaimana praktik selama kematian dan sekarat pengasuh keluarga. Pemahaman tentang elemen budaya integral kematian dan sekarat penting untuk memungkinkan memberikan perawatan paliatif berkualitas dan perawatan akhir hidup.

**Kata kunci:** agama/spiritualitas, akhir kehidupan, etnografi, keluarga yang merawat, kematian dan akhir hayat, praktik ritual

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## Introduction

Dying and death is a complex process, although it is an inevitable point in the palliative care service and could happen at any time during the care provision. During this period of time, pal-

liative care focuses by providing treatment to relieve the suffering of the patients and the relatives (Rome et al., 2011). Death and dying is influenced by culture (Mah et al., 2019). This includes patients' and relatives' belief and the practice of care during end-of-life. Understand-

ing the cultural practice of death and dying in palliative care service therefore is essential to enable providing quality palliative care and end-of-life care. However, available studies particularly in Asian countries have focused on death and prognosis discussion (Eng et al., 2022; Huang et al., 2018; Sudhakar et al., 2020) and rituals associated with such events (Cheng et al., 2015).

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. A review at palliative care research found that most studies focus on describing the development of palliative care, but none explored the provision of palliative care services or cultural aspects associated with palliative care provision (Rochmawati et al., 2016). However, to date, in relation to belief and practice to death and dying, particularly in the palliative care context, a literature search that was conducted find none related published papers.

Understanding and honouring patients' preference of treatment and wishes at their end-of-life is crucial for quality palliative and end-of-life care. 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 (Sutar et al., 2021). In their study, Sutar et al. (2021) found that prevalence of collusion are still unnoticed in cancer care due to some difficulties. The difficulties in prognostic communication due to lacked training in conducting open conversations with patients, cultural wishes. In addition, the nurses were reluctant to disclose such information due to concerns about possible negative impacts on patients (Newman, 2016). 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, many studies from Asian cultures, show that patients or relatives are more reluctant to have such discussions Tang (Long et al., 2018; Tang et al., 2014).

When recognising that patients are approaching their end of life, health care professionals need to provide appropriate and effective support. Several studies 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 (Renz et al., 2020; Silva et al., 2020). Discussion of life completion which included discussion of patient's values and completions was associated with treatment adherence and better patient's health outcomes at their end-of-life (Huang et al., 2020; Kleijn et al., 2018). 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, asking for forgiveness (Levy et al., 2021; Maungtoug et al., 2021; Okan et al., 2019), and cremation among Hindus and immediate burial and mourning burial in Jews (Gupta, 2011; Silverman, 2021). To date in relation to belief and practice to death and dying, particularly in the palliative care context, a literature search that was conducted find none related published papers. In this paper, the study revealed the findings in relation to the practice of death and dying aspects of palliative care provision. This aspect in one of findings from an ethnographic study that aimed to explore how is the provision of palliative care and cultural elements that influence the provision of care. The study was conducted in two palliative care services in Indonesia over a period of three months.

## Methods

The use of contemporary ethnography for this study enabled the exploration of the cultural elements in the provision of palliative care in Indonesia. Contemporary ethnography is characteristically concerned on settings or culture that close the researcher (Draper, 2015). While the classical ethnography has focused on described culture that is nearer to home. Jones and Smith (2017) highlights the advantage of an ethnographic approach when exploring new and unknown phenomena, in this case, where there is limited knowledge and information in this area. Based on the tenets of contemporary ethnography, the data in this study was gathered from field observations of that include informal discussions, and semi structured interviews.

Fieldwork for non-participant observations was conducted every day on weekdays from 8am to 4pm with the average of 35 hours of fieldwork per week for the periods of three months. The fieldwork was conducted in public hospital that has palliative care unit which service included home visit and outpatient clinic. We observed healthcare professionals and family caregivers. During the observations, we focused on all situations in the daily routines of care provision including communication and interaction within palliative care staff, between staff and patients and their relatives and interventions in care delivery. Field notes were systematically transcribed immediately after each fieldwork episode for analysis. The field notes include details of the researcher's observations together with a reflexive account.

**Participants.** Participant recruitment was opportunistic and purposive due to their involvement in the culture and their specific knowledge or experience related to the cultural setting (Bonisteel et al., 2021). Total participants were 16 including: family caregivers ( $n = 10$ ), while the palliative care team ( $n = 6$ ).

**Trustworthiness of this study.** The trustworthiness and rigor of qualitative study was assessed

using credibility, dependability and confirmability (Korstjens & Moser, 2018). To enhance the rigor, we conducted prolonged observations. We also independently recorded and transcribed data. In addition, reflexivity was implemented to improve the credibility for the study by keeping a reflexive journal that include personal reflection related to the study and all events that happened during the fieldwork. A recursive process of reflexivity on analysis, reviews and validation of methods was also undertaken in this study. To ensure the dependability for the present study immediate recording of date after each observation was conducted. Comparing and contrasting existing data when sorting and coding data into categories was also (Fetterman, 2010), and decision trails were also conducted. Decision trails that included making comprehensive and explicit notes in NVivo were used in data analysis in the present study (Bergin, 2011; Houghton et al., 2012).

**Data analysis.** The analysis was recursive and cyclic using a framework from LeCompte and Schensul (2013). The framework assists the researchers to analysis the data at item, pattern, and structural levels. At item level of analysis, we selected and analysed the data by giving meaning to all the basic items and examine for possible terms for related items. After that, in the pattern-level analysis, we organized the identified terms and searched for any relationship. In this process, we compared, integrated, associated and linked identified and related terms for a higher order of patterns (LeCompte & Schensul, 2013). At the structural level of analysis, items and patterns were repeatedly reviewed to understand how they correlated and addressed to the research questions (Barusch et al., 2011).

**Ethical consideration.** The protocol, information sheets, consent forms, and data collection materials were reviewed and approved by the Ethics Committee of the university and the hospital where the study took place. Ethics approvals were obtained from the Human Research Ethics Committee of the University (No. H2013-

05) and the hospital's Ethic Committee (No.004/KEPK/1).

## Results

There were 16 participants involved in the study (Table 1). Dealing with death and dying relates to how this was experienced and managed by the palliative care team and the patient's relatives. Two themes were emerged: "preparing with death and dying", and "dealing with "death and dying" (Table 2). The sub themes are: 'secret between palliative care team and relatives', 'ritual practices during death and dying', and 'respect'.

**Preparing with death and dying.** The theme preparing with death and dying consists of two sub themes: secret between palliative care teams and relatives, and ritual practices during death and dying. There were frequent discussions about prognosis and death between the palliative care team and the patient's relatives 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. From their years of experience, the palliative care team were able to recognize the approaching signs of death. On recognizing this, 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 finalize plans for the patient's funeral.

The discussions about death and dying between the palliative care team and the patient's relatives were overt. It was demonstrated in an observation below,

*After exiting the patient's room, the palliative care team sit with the patient's wife and sister in the living room while the patient was still in his room. The palliative doctor began talking about the patient's condition and the prognosis to the patient's wife, then the doctor assessed the relatives' responses. The wife looked sad and then cried, blaming the*

*previous doctor of not treating well her husband and not referring to the palliative care unit earlier (field notes, page 11).*

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 religious 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 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).

Findings from reviewing related documents show that the majority of patient's goal of care were for terminal care. 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. The family caregivers also 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. The family caregivers also tried to accommodate the patient's wishes regarding to the funeral. This is evident in some observations:

*A patient's wife said that she always recited the Holy Quran near her husband (patient) who was unconscious and had experienced seizures twice a day. 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 said these rituals would ease the patient in his dying and death process (field notes, page 7).*

Ritual during funerals were practiced encompassed 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). It was observed that religion and ethnicity group influenced how elements of a funeral were practiced. 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. 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 (field notes page. 78: 1.20–34; page 79).*

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 clear family. This is demonstrated in the below field notes:

*The patient's wife said that many of relative from both her side and her husband side travelled from other city to attend the funeral (field notes, page 86).*

Table 1. Participants' Characteristics

Demographic	No (%)
Family caregiver	
Gender	
Female	7 (70%)
Male	3 (30%)
Age (years), range (min-max)	33–67
Relationship with patients	
Spouse	3 (30%)
Children	6 (60%)
Other	1 (10%)
Palliative care team	
Gender	
Female	5 (83.3%)
Male	1 (17.7%)
Profession	2 (33.33%)
Physician	3 (50%)
Nurses	1 (16.67%)
Clerical	

Table 2. Summary of Item, Pattern, and Structural Level of Analysis

Cultural themes emerged during structural level of analysis	Pattern	Item	Exemplar of quotations and fieldnotes
Preparing and dealing with death and dying	Secret between palliative care team and relatives	Overt discussion between relatives and healthcare professionals	In the living room where the patient is absent the palliative doctor began talking about the patient's condition and the prognosis to the patient's wife, then the doctor assessed the relatives' responses (field notes, page 11).
	Rituals practices at end-of-life and death	<ul style="list-style-type: none"> <li>• spiritual support</li> <li>• role of religion and ethnic</li> <li>• support from extended family</li> </ul>	<p>'A patient's wife said that she always recited the Holy Quran near her husband (patient) who was unconscious (family caregiver, field notes page 7).</p> <p>'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 (field notes, page 78: line 20–34; page 79). The patient's wife said that many of relative from both her side and her husband side travelled from other city to attend the funeral (field notes, page 86).</p>
Dealing with death and dying	Respect	<ul style="list-style-type: none"> <li>• the use of term passed away</li> <li>• attending funeral</li> </ul>	<p>The nurse explains that there are two patients passed away this morning (informal discussion, field notes page 38).</p> <p>After visiting other patients, the palliative team went to the patient's home as the funeral ceremony was conducted at the patient's home. It looked that the funeral ceremony was finished as there were only empty chairs. The palliative team came into the patient's and met with the patient's wife and expressed their condolences. The palliative team stayed about thirty minutes talking about the patient and how the wife's response (field notes, page 112; page 113).</p>

*The palliative team arrived at a patient's home to attend the funeral ceremony. There are neighbours and friends visiting the patient's relative (field notes, page 113).*

**Dealing with death and dying.** Apparently, the palliative care team respect their patients that was expressed in using term of passed away and attending the patient's funeral if possible. The term 'passed away' was used by the palliative care team instead of saying that a patient had died. The term 'pass away' is not only used during conversation. The document review (nursing chart and administrative notes, the term is

also used. 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.

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 cere-

mony. At the funerals, the palliative care team expressed their condolences to the family and prayers for the deceased patients. In addition, it was common for the palliative care team to hug offered up 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. For example:

*In the morning, the palliative nurse got a phone call informing that a patient passed away and then the palliative team told the other team member. They plan to attend the funeral. After visiting other patients, the palliative team went to the patient's home as the funeral ceremony was conducted at the patient's home. It looked that the funeral ceremony was finished as there were only empty chairs. The palliative team came into the patient's and met with the patient's wife and expressed their condolences. The palliative team stayed about thirty minutes talking about the patient and how the wife's response (field notes, page 112–113).*

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.

## Discussion

In relation to end-of-life discussion, 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. Communication on patient's diagnoses and prognosis 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 (Abdel-hafeez et al.,

2021). 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 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 (Davis et al., 2012; Fenton et al., 2021). 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 (Tang et al., 2014; Wen et al., 2013). Such situations are thought to be an effort to protect the patients. Fenton et al. (2021) stated that such disclosure was associated with attitude and uncertainty sensitivity. 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 commen-

ced 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. Previous studies stated that tailoring information is important to prepare family caregivers for death and bereavement (Aoun et al., 2017; O'Sullivan et al., 2021) 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 and use direct language so that the relatives understood the situation. These strategies reflected the need of caregivers' during end-of-life discussion needed (Collins et al., 2018). In their study Collins et al. (2018) found that the caregivers of people with advanced in a hospital in Australia wanted the clear information from the health professionals when the patient's death is close. In addition to applying the communication strategies, 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.

Because of their previous experiences, some relatives knew when the patient's time of death was approaching. Knowing what dying looks

like is one of important attributes in death preparedness for family caregivers as this will enable in preparing appropriate care for the dying (Durepos et al., 2019). It has been shown that patient's relatives managed the patients' needs that include organizing patients' affairs and asking 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 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. In this study, it has shown that the majority of the patients' relatives preferred to focus on religious faith and conduct religious practices instead if medical futility. Focusing on this may serve as a coping strategy for them, as reflected in a study that found religious faith as coping strategy among culturally and linguistically diverse patients with cancer and had palliative care needs and their caregivers in two Australian hospitals (Kirby et al., 2018).

As the journey reaches its end point and death is close, in Indonesian culture it is common to seek and provide forgiveness. Such practices were also encouraged by the palliative care team that reflect their awareness and sensitivity to the patients' culture and religiosity. Pentaris and Thomsen (2018) stated that such awareness and sensitivity is an important aspect in providing quality palliative care. 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 in-



clude seek and provide forgiveness could improve patients' quality of life of patients with life-limiting illness (Renz et al., 2020; Silva et al., 2020). Such a finding could be important because it suggests that forgiveness therapy could be integrated in the provision of palliative care. When a patient died, religion and ethnicity influenced how elements of a funeral were practiced. Gatrud and Sheikh (2002) stress that a burial should be conducted immediately in Islam, while Gould et al. (2018) 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.

The provision of palliative care still continued after the patient's death that the palliative care team managed to attend the patient's funeral to show respect and provided support to the family caregivers. In addition to these, participating in the patient's funeral is found as one of strategies to improve of nurses' self-care after caring for dying patients (Huang et al., 2016). The palliative care team also 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 that suggest supports from bereaved family members (Radbruch et al., 2020).

The findings of the current research have identified how is the practice during death and dying. A future study could investigate other factors that influence around death-dying discussion. In addition, as culture appears to strongly influence such discussion, this factor should be taken into account in such related interventions. Our analysis is limited to the views and experiences of patients, family caregivers and small number of professionals cannot be generalized. Because the study was conducted at one hospital-based and a non-profit organization-based palliative care service, the organizational culture could limit the transferability of the results.

## Conclusion

We found discussions about prognosis is between healthcare professionals and family caregivers, where 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. The participants particularly family caregivers generally recognise the signs during end-of-life that leads them to conduct ritual practices. Additionally, the healthcare professional demonstrates the act of caring for patients and their relatives was an important part of their practice by attending funeral ceremony and giving support and comfort for the relatives.

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